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**CHILDREN OF MOTHERS WITH PHYSICAL DISABILITIES:
PERCEPTIONS OF PARENTING, THE MOTHER-ADOLESCENT
RELATIONSHIP, AND THE ADOLESCENT'S ENGAGEMENT IN RISKY
BEHAVIOUR**

FIVE CASE STUDIES

Underé Deglon (HRMUND001)

A thesis submitted in partial fulfilment of the requirements for a Master of Arts
degree in Psychological Research

Department of Psychology
Faculty of the Humanities
University of Cape Town
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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: Date: 25/4/06

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ABSTRACT

This qualitative study investigated the effect of a mother's physical disability on the mother-adolescent relationship, parenting and the adolescent's engagement in risky behaviour. Interviews were conducted with five mothers with visible physical disabilities and with their adolescent children. The adolescents comprised two boys and three girls between the ages of 12 and 15 years. All five mother-adolescent dyads were black, with low maternal educational levels, from low socio-economic backgrounds, and lived in neighbourhoods characterised by unemployment, gangsterism, substance abuse, violence and crime. The multiple case study design was used to compare and contrast evidence from the individual cases. Two separate semi-structured interviews, covering the same topics, were conducted with both the mother and the adolescent in order to triangulate the data. The interviews focused on perceptions of (a) the impact of the mother's disability for mother-adolescent relations; (b) disability-related stigma and the adolescent's awareness of the mother's difference on the mother-adolescent relationship; (c) the ways in which the mother's disability and other contextual factors affect parenting and the adolescent's engagement in risky behaviour. The results illuminated a range of barriers and facilitators to parenting with a physical disability but the variability notwithstanding, the majority of the families reported positive relationships and experiences given the cumulative stressors that they face.

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INTRODUCTION

The well-being of children with disabilities and their families has been the focus of considerable attention amongst researchers, health professionals and policy-makers. However, there seems to be a universal blindness to the existence of a much larger group of children who may or may not be disabled themselves, but who grow up in families where one or both parents have a disability. To date these families continue to be absent from policy formulation and research literature, and are largely invisible to the public eye (Prilleltensky, 2003).

In 2001, national census figures indicated that 5% of South Africa's total population is disabled, and of these 30% report physical disabilities. A large percentage of disabled parents and their children have been identified as living in communities characterised by unemployment and poverty, poor infrastructure and limited access to basic resources (Statistics South Africa, 2005). Similarly, a lack of support structures to deal with the cumulative stressors is associated with a reduction in the ability of both people with disabilities and their families to participate meaningfully in society (Petersen, 1991). Concerning employment, available statistical data indicate that women with disabilities are in a more disadvantaged position than their male counterparts. The employment rate of disabled women is reported as 11% compared to 15% for disabled men. Of the total number of people with disabilities who are unemployed, 80% are women compared to 74% of men (Schneider, 1999). Looking specifically at the impact of race, the figures suggest that 19% of White, compared to 6% of African, 4% of Coloured and 9% of Indian people with disabilities are in full-time employment. Clearly a large number of

black women with disabilities have to negotiate the demands of motherhood in the face of poverty and deprivation.

In the high-risk environments which poor communities often are, children of mothers with disabilities might be at an increased risk of less than optimal development compared to those from more affluent neighbourhoods. As one indication of this, official crime figures issued by the South African Police Service (SAPS, 2006) indicate that in 2002/2003, 142 murders or attempted murders, 62 rapes, 795 assaults, and 139 drug related crimes were committed in one of several neighbourhoods characterised by high levels of poverty. This is in stark contrast to the 4 murders or attempted murders, 7 rapes, 75 assaults, and 14 drug related crimes committed in a comparably wealthier residential area. Internationally, child outcomes have been shown to worsen in proportion to the number of risks to which children are exposed (Dawes & Donald, 1994). Similarly, provincial statistics for the Western Cape indicate murder and public violence rates of 59.9 per 100 000 and 5.7 per 100 000, which is considerably higher than the reported rate of 44.8 per 100 000 and 1.6 per 100 000 for Gauteng province (SAPS, 2006). Much of the literature lends support to the view that structural features of the environment such as exposure to violence has a deleterious effect on childhood development and adjustment (Dawes & Donald, 2000).

Few studies examining the relationship between maternal physical disability and the mother/caregiver-child relationship exist, both locally and internationally. While the issues of disability and parenting have each received their fair share of attention, there is a scarcity of research which examines the intersection of the two. Women with disabilities constitute a particularly marginalised group, and an air of scepticism prevails

amongst the general public and health professionals alike regarding their competency as mothers (Kelley & Sikka, 1997; Prilleltensky, 2003). While the evidence is often clouded by a lack of methodological rigour, most of the available literature contributes to the view that parental disability has a deleterious effect on the family environment, and that children of disabled parents are at an increased risk for adjustment problems when compared to children of non-disabled parents (Buck & Hohmann, 1981; 1982; Kelley & Sikka, 1997). This concurs with findings from an extensive literature review conducted in 1995 aimed at establishing the extent to which parental physical illness impacts on child functioning (Armistead, Klein & Forehand, 1995). However, this finding was not confirmed by a meta-analysis, drawing on 56 reports of qualitative studies conducted with HIV-positive mothers. Sandelowski and Barroso (2003) capture the complexity of mothering in contexts of physical vulnerability. The authors report on the women's resistance against factors threatening mother-child relations while engaging in distal caregiving practices, particularly during times when they are physically unable to care as a result of health problems. With the growing focus on disability rights and the increasing likelihood of disabled people becoming parents, the issue of child outcomes is of considerable relevance (Thurmann, Whaley, & Weinraub, 1985).

It should be noted that empirical research on parenting and disability, specifically in contexts of poverty, is virtually non-existent. Furthermore, the available literature commonly draws on samples of North American families and therefore offers perspectives that may be specific to that society. While useful as a starting point, childhood and parenting philosophies and practices rooted in the developed world do not address the realities of most South African children's lives. A large number of South African children have to deal with the multiple stressors associated with poverty and

deprivation. Nevertheless, research findings from different contexts remain relevant provided that they are applied in a thoughtful and critical manner (Dawes & Donald, 2000).

There are at least four key ways in which the present study departs from previous work in the area of parenting/mothering/caregiving and disability. Firstly, the current study approaches the issue of mothering with a disability from the perspective of adolescent children, in addition to the use of maternal reports. Secondly, most other research studies do not take into account the interaction between health condition, personal and environmental factors (Arnaud, 1959; LeClere & Kowlewski, 1994). Thirdly, the importance of the dimensions of the disability (including severity, chronicity and stability) is commonly overlooked (Cohen, 1998). Finally, the particular methodology used in this study will enable the investigation of contextual factors related to maternal-adolescent relations. While other studies are valuable in their contributions to the topic, they frequently fail to contextualise the parent-child relationship within the community and broader society, and do not account for neighbourhood characteristics and influences (Blackford, 1999; Prilleltensky, 2004). It is believed that achieving a better understanding of the cumulative effects of these variables on parenting and child well-being will lead to improved policy formulation and service delivery to this sector of the South African population.

Whilst the voices of women with disabilities are largely ignored in the general literature on parenting, there appears to be a small but growing body of literature on pregnancy and parenting arising from disabled theorists themselves (Blackford, 1999; Finger, 1990; Prilleltensky, 1999; 2003; 2004). My own experience as a black mother with a physical

disability has provided the impetus for this research which draws, firstly, on the faithful representations of experience as shared by the participants, and relates to the narratives through experience as lived. As such, the present study does not seek to pathologise mothers with disabilities but rather to illuminate the problems and issues faced as a result of health condition, personal and societal factors.

Consequently, the primary objective of this thesis is to investigate the effect of a primary caregiver's physical disability on perceptions of the mother-child relationship, parenting and the child's engagement in risky behaviour for black, adolescent children from low socio-economic backgrounds. As the caregiver-adolescent relationship is dependent on the transaction between caregiver, child, familial and contextual factors, the thesis aims to provide a means to deepen our understanding of:

1. The implications of the nature and features of the mother/caregiver's disability, in combination with other demographic variables, for mother-adolescent relations;
2. The effect of disability-related stigma and the adolescent's awareness of the mother's difference on the mother-adolescent relationship;
3. The ways in which the mother's disability, as well as low socio-economic conditions and high-risk neighborhood characteristics affect parental involvement in the adolescent's school and other activities, monitoring and supervision and lastly, the adolescent's engagement in risky behaviour.

CHAPTER 1: LITERATURE REVIEW

The key objective of this chapter is to integrate, summarise and evaluate literature on parenting, the impact of parental disability on parenting and child outcomes in the context of maternal disability. As a first step towards understanding the effect of physical disability on parenting and child outcomes, the review begins with critical theories on disability in Section 1.1, and then presents empirical studies which investigate the impact of authoritative parenting on child and adolescent outcomes in Section 1.2. Results from studies on the impact of parental chronic illness and disability on children are presented in Section 1.3, followed by a discussion on the mediating and moderating factors in the impact of parental disability on parenting and child well-being in Sections 1.4. Figure 1 presents the conceptual model which guides the study and finally, the scope and objectives of the thesis, as informed by the literature, are stated in Section 1.5.

1.1. Models of disability

1.1.1. The Medical model

Theories of disability have become increasingly diverse, as they have shifted away from the traditional medical or individual model with its unitary, essentialist focus on disability as chronic illness needing rehabilitation. Under this model, disability was viewed as an inherent feature of the person and disabled people were perceived as tragic victims and dependent recipients of care, often resulting in their systematic

oppression (Darling, 2003; Marks, 1999; Prilleltensky, 2003). As an indication of this, cross-culturally, the construct of “motherhood” is often viewed as an experience exclusive to healthy, fertile women, while disability is something which resides within damaged bodies (Watermeyer, 2000).

1.1.2. The Social model

Largely motivated by the participation of disabled people themselves, the Medical Model has largely been replaced by the British Social Model of Disability, and the Minority Group Model in the United States, both of which incorporate the view that disability is separate from the individual. In addition, disability is viewed as a socially constructed disadvantage, inextricably linked to “issues of power, oppression and civil rights and share the premise that many of the barriers associated with disability are socially constructed and thus preventable” (Prilleltensky, 2004, p.209).

1.1.3. The International Classification of Functioning, Disability and Health

For the purpose of this paper, my use of the term disability is consistent with The International Classification of Functioning, Disability and Health (ICF) as developed by the World Health Organization (Schneider & Swartz, 2004; WHO, 2001) which reframes disability as a complex phenomenon consisting of multiple components or aspects that make up the experience. According to the ICF, disability is an outcome of the dynamic interaction between health condition, personal, and environmental factors that determine the extent of disablement in any given situation. The outcome is described at three levels – body (body functions and structures and impairments),

person (activity and activity limitations) and societal (participation and participation restrictions). The ICF further distinguishes between impairment, as a problem in bodily function, and disability as inclusive of a range of factors serving as either barriers or facilitators. Further, the ICF views participation in important life areas, such as education and employment as the ability to perform tasks associated with either education and employment, incorporating the impact of environmental factors (including physical, social, attitudinal).

1. 2. What do we know about good parenting?

In order to examine the effect of physical disability on parenting and child outcomes, it is first necessary to review the literature on what constitutes “good enough parenting”. Research into parenting has focused on identifying variables of benefit to the parent-child relationship, the role of such variables in child- and adolescent development and an understanding of the fundamental mechanisms underlying the relationship between the two.

1.2.1. Authoritative parenting

Nearly 40 years ago, Diana Baumrind (1967; 1977; 1991 as cited in Sigelman & Rider, 2003) proposed the use of two dimensions of acceptance/responsiveness and demandingness/control to classify parenting styles as either authoritarian, authoritative or permissive. Parents who are accepting of their children, responsive to their needs and who demand consistent high standards while exerting some control over their children’s behaviour are considered authoritative. Baumrind documented the findings from a longitudinal study which suggested that children of authoritative

parents scored high on measures of cheerfulness and social responsibility and were more likely to be self reliant, co-operative and motivated (Sigelman & Rider, 2003).

Building on our understanding of authoritative parenting, Darling and Steinberg (1993, p. 487) identify authoritative parenting as parental attributes that include “emotional support, high standards, appropriate autonomy granting and clear bidirectional communication”, and argue that such attributes have been “shown to help children and adolescents develop an instrumental competence characterised by the balancing of societal and individual needs and responsibilities”. In an attempt to operationalise authoritative parenting, the authors proffer that a conceptual distinction be made between parenting practices as day to day behaviours (such as visits to the museum or attending school events) and parenting style as a combination of attitudes communicated to the child, creating an emotional context in which the practices are expressed.

A considerable amount of professional literature regarding the positive association between authoritative parenting and child and adolescent adjustment has been amassed (Darling and Steinberg, 1993; Gray and Steinberg, 1999; Rutter, 2000; Steinberg, 2001). Drawing on a sample of 10 000 socio-economically and ethnically diverse high school students, Steinberg, Mounts, Lamborn and Dornbusch (1991) examined the impact of authoritative parenting style on four domains of child adjustment. The results point to the broad conclusion that the positive impact of accepting, firm and democratic styles of parenting transcends ethnicity, socio-economic conditions and family structure. Moreover, this study adds to the evidence that children of authoritative parents, fare better educationally, report lower scores of

anxiety and depression, and are more self-reliant and less likely to engage in juvenile delinquency (Steinberg et al, 1991).

It is postulated that parenting practices directly impact on the development of specific child behaviours and characteristics: from table manners to academic performance, while parenting style transforms the nature of the parent-child interaction and moderates the association between parenting practices and child outcome (Darling & Steinberg, 1993).

Bronfenbrenner (2001) documented the results of a longitudinal study investigating the impact of the quality of the mother-child relationship on developmental difficulties experienced by 4-year-olds as a joint function of birth weight and social class. The findings indicated that the effect of a proximal process, particularly the mother-child relationship, was the most salient predictor of children's functioning and further served as a protective factor against other potential risk factors such as social class. McBride et al. (2005) conducted a quantitative study, using the Youth Risk Behaviour Survey (YRBS) to examine the effect of the perceived quality of the parent-child relationship on sexual and substance use risk behaviours among a sample of 1,078 students between the ages 14 and 18 years. It was found that students who rated their relationship with both parents as "great" were significantly less likely to engage in sexual and substance use risk behaviours than those who rated the parent-child relationships as "not good". Rutter, Giller and Hagell (1998) argue that children of responsive parents, who set clear rules, used creative methods to circumvent arguments, promoted prosocial behaviours and fostered the development of internal controls assisted their children in developing healthy social functioning.

Building on our understanding of parenting, Patterson, DeBaryshe and Ramsey (1989) identified three sequential steps which might lead to engagement in delinquent behaviour. The authors suggest that ineffective parenting practices combined with other contextual factors which impact on child and parent interaction patterns are important determinants for conduct disorders. The deviant behaviour may lead to educational failure and peer rejection which results in depressed mood and involvement in antisocial peer groups during later childhood and early adolescent developmental stage. The authors argue that these processes are important predictors of delinquency over the course of early childhood and adolescence. With regard to child management strategies used by parents, several studies draw attention to the broader spectrum of communication and interaction styles between parent and child. Poor supervision and monitoring of child activities and inadequate limit-setting (permissive or lax parenting), particularly over extended periods of time, have repeatedly been associated with antisocial and violent behaviours in children and adolescents (Jones, Forehand, Brody & Armistead, 2003; Patterson et al, 1997; Rutter et al., 1998). Furthermore, inconsistent, critical, coercive, excessively harsh and abusive ways of disciplining may lead to later delinquency (Rutter et al, 1998). A study conducted by Farrington (1989a, as cited in Hawkins et al, 1998) reported a significant relationship between an authoritarian style of parenting, a cruel/passive/neglecting parenting attitude and parental disputes about child rearing techniques and later problem behaviour. Loeber and Stouthamer-Loeber (1986), drawing primarily on male-only samples, found that low levels of parental emotional support, love, care and involvement combined with lack of parental supervision were shown to be the strongest predictors of juvenile behavioural problems and even delinquency. Similarly, Jones et al. (2003) argue that parental monitoring is positively

associated with child and adolescent adjustment across sex, age and ethnic contexts. Moreover, the authors suggest that adequate monitoring might lead to improved self-esteem and enhanced academic performance in children.

Research conducted by Brown, Mounts, Lamborn and Steinberg (1993) using data from a sample of 3,782 high school students between the ages of 15 and 19, examined parenting practices and peer group affiliations. More specifically, the authors focused on the impact of several family processes including parental monitoring, encouragement of achievement and joint decision making on adolescent behaviours such as academic achievement, drug use and self-reliance. The findings contribute to the evidence that parents, in addition to other contextual features associated with the broader system in which the child is embedded, continue to exert substantial influence on their children's behaviour during adolescence. In addition, other factors such as ethnicity and family structure, rather than socio-economic status, were shown to be an important factor in peer group affiliations. More specifically, Brown et al. (1993) noted that parents who focus on academic achievement, monitoring and joint decision-making are more likely to steer the child towards a peer group with similar values.

Another cross-sectional analysis conducted by Gray and Steinberg (1999), drew on a sample of 8,700 adolescents in order to examine the relationship between adolescent adjustment and three dimensions of authoritative parenting (including acceptance-involvement, strictness-supervision, and granting of psychological autonomy). The findings suggest that behavioural problems are significantly associated with low behavioural control, psychosocial development with both parental acceptance-

involvement and granting of psychological autonomy. Internal distress was also associated with low granting of autonomy. An important finding was that all three dimensions of authoritative parenting were significantly associated with academic competence in 14-18 year old adolescents. The findings contribute to the evidence that authoritative parenting is associated with positive psychological, behavioural and educational outcomes of adolescents.

1.2.2. Family structure

Research on the relationship between family structure and delinquency has shown that the risk of delinquency is almost double for children who live with single mothers as compared to children raised by their biological, intact two parent families, particularly in the presence of other social disadvantages (Rutter et al., 1998). In a sample of 1,891 school children from Ontario, Canada, Kierkus and Baer (2002) found that parental attachment substantially reduced the significance of parental structure as a predictor of delinquent behaviour. This finding concurs with an earlier study conducted by McCord (1982, as cited in Rutter, et al., 1998), which found that boys raised in conflictual two-parent homes had higher rates of antisocial behaviour when compared to those from single-parent homes where the mother was affectionate. With regards to single parenthood, Demuth and Brown (2004) examined antisocial behaviour among adolescents from biological, intact two-parent families, single-mother families, single father families, mother-stepfather families and father-stepmother families. Using data from the USA 1995 National Longitudinal Survey of Adolescent Health, the authors focused on measures of family processes (including parental involvement, supervision, monitoring and parental attachment). The findings suggest that rates of delinquency were highest among adolescents from single-father families and lowest

among biological, intact two-parent families with adolescents from single mothers and stepfamilies falling in-between. Further analysis of the data showed the gender of the parent held no importance once parental controls and family processes were accounted for. They concluded that parental absence was significantly related to the development of delinquency, while family processes mediate family structure. The findings clearly showed that in single-parent families, family processes rather than family structure per se affects children's developmental outcomes

Thus, the findings contribute to the evidence that single-parenthood might impact on children but that family processes mediates this impact rather than family structure.

1.3. The impact of parental disability on parenting and the adolescent's engagement in risky behaviour

Several authors have argued that the nature of the disability/illness appears less important than the degree to which it impacts on the quality of the parent-child relationship (Newman, 2003; Coates, Vietze, & Gray, 1985; Cogan, 2004). As such, it has been suggested that the main risk factors threatening child well-being appear to be the degradation of the parent-child relationship and other social and economic features of the household and broader environment in which the child is embedded, rather than the disability itself (Newman, 2003; Glass, 1985).

1.3.1. Child outcomes

Most research generated since the 1970's regarding the impact of parental disability on child outcomes has been speculative in nature (Buck & Hohmann, 1983). A comprehensive literature review conducted in 1993 with a view toward examining the impact of parental disability on parenting and the well-being of children, revealed a total sample of 93 references including 20 on general disabilities, 46 on mental disabilities and only 27 on specific physical disabilities (Smith, Bland & Grey, 1993). The small amount of professional literature published since 1975 emphasises negative outcomes, with nearly every domain of child development hypothesised to be at risk, including personality functioning, body image, sex role identity, interpersonal relationships, physical health patterns, recreational activities and parent-child relations (Buck & Hohmann, 1983; Glass, 1985). For example, one study investigating the psychological characteristics of children of parents with Multiple Sclerosis (MS) concluded that such children displayed increased levels of body concern, dysphoric feelings, hostility, constraint in interpersonal relations, dependency longings and an increased incidence of false maturity as compared to those children of healthy parents (Arnaud, 1958). In another study, LeClere & Kowlewski (1994) found that children with more than one disabled relative were at increased risk for severe behavioural problems and for experiencing an accident, injury or poisoning requiring medical attention. One possible explanation for this finding might be that the increased risk of an accident, injury and poisoning might be related to the parent's physical inability to monitor the child sufficiently closely.

These findings, however, have been discredited by Buck & Hohmann (1983, p. 205) who, after an extensive review of the available literature condemned it as consisting mainly of “unsystematic observation (and) anecdotal material”. Citing lack of methodological rigour, limited scope and lack of internal validity, the authors argued that the existing research provided insufficient evidence on which to draw any conclusions on parenting and disability. In 1981, the same authors embarked on possibly the most controlled and systematic research on parental disability of that time and examined the relationship between parental disability, (specifically Spinal Cord Injury (SCI)) in fathers and the adjustment patterns of their children (Buck & Hohmann, 1983). Participants completed tests chosen to test the major speculations found in the literature regarding the impact of parental disability on childhood development. Buck and Hohmann (1981) found that physical disability was not associated with psychological maladjustment in children. Moreover, the findings suggest no significant difference on measures of personality, behaviour, attitudes, body image, sex role orientation or physical health patterns. Based on analysis of the data, the authors concluded that the relationship between disability and child adjustment is largely mediated by quality of parenting.

One argument regarding differences in research findings is that previous research ignored the conceptual difference between physical disability and disability associated with chronic, progressive illness. Buck & Hohmann (1983) proffer that the experience of disability and that of illness has differential effects on individuals and their families and therefore should be treated as conceptually different.

1.4. Mediating and moderating factors in the impact of parental disability on parenting and child well-being

Research on the effects of many family stressors on children has moved from “first generation” research which simply examines group differences between those exposed to the stressor compared to those not exposed to the stressor, to “second generation” research which focuses on factors that mediate (account for) or moderate (influence the strength of) the relationship between the stressor and child outcomes.

1.4.1. Individual factors

Several studies have demonstrated the relevance of individual factors including age and gender of the child and parent, dimensions of the parent’s disability and the child’s appraisal of the illness or disability (Armistead et al., 1995; Coates et al., 1985; Irvin, 1988; Newman, 2003), as well as other social and environmental factors which either mediate or moderate the impact of the stressor (Cohen, 1998; Green, Davis, Karshmer, Marsh & Straight, 2005, Irvin, 1988).

1.4.1.1. Age and gender of the child

Research conducted by Coates et al. (1985) highlights the importance of the child’s age and gender in determining developmental outcomes in contexts of parental disability. Newman (2003) reports on findings from a Welsh school survey which suggests that, for children between the ages of 8 and 11, girls are more likely to be negatively affected when faced with the cumulative stressors of poverty and parental

disability or illness. Within this group, girls reported worrying about others, looking after an ill adult and engaging in housework with more frequency than did boys of the same group. In the older group of children (aged 14-15 years), the proportion of boys who reported looking after siblings and/or sick adults was similar to the proportion of girls reporting such activities. Looking specifically at children's contribution to household tasks and responsibilities, gender was the most important predictor with both older and younger girls reporting significant more responsibilities than boys (Newman, 2003).

1.4.1.2. Nature and severity of the disability

Irvin (1988) asserts that children are likely to be affected by the severity of parental disability as it relates to the ability for independent personal care, the utilisation of emotional and financial resources and the nature, frequency and quality of caring that the parent is able to provide to the child. Using data from a sample of 11,997 children between the ages of 2 and 5 years collected as part of the 1994 and 1995 United States National Health Interview Surveys, Hyatt and Allen (2005) examined the impact of parental disability on indicators of children's preventative healthcare and health status at the age of 24 months. The findings suggest that children living with one or more parents who are unable to provide for their own personal care as a result of the severity of parental disability were 65% less likely to be immunized than children living with parents who are not disabled. However, an important finding was that children of parents who were only partially limited in their ability to provide for their own personal care had a higher probability of being immunized. One possible explanation might be that parents with partial limitations have frequent contact with

health care providers or health centres, making immunizations possible (Hyatt & Allen, 2005).

1.4.1.3. Age at onset of the disability

The onset of parental disability is thought to be as important as the type of impairment affecting the parent (Newman, 2003; Coates et al., 1985), and it may be possible different factors may impact on children according to whether the parental disability is adventitious or congenital (Newman, 2003). Irvin (1988) argues that over time, persons with congenital disabilities integrate the reality of the disability into aspects of their selves, and this seamlessly pervades the social roles of the individual. However, in the case of precipitous onset, the disability is often appraised as a threat or loss which also extends to other family members, and must be met with a coping and adaptive response. Thus suddenness of onset may be a partial explanation for outcome variation (Coates et al., 1985; Irvin, 1988). Emotional distress experienced in response to the adventitious onset of a disability is suggested to be a temporary phenomenon, lasting only until the family is able to restore itself with the parental disability as part of its reality; it is not necessarily an indicator of long term maladjustment (Buck & Hohmann, 1983; Irvin, 1988).

1.4.1.4. Stability

In addition to the above mentioned factors, the stability of the disability is thought to be of critical importance. Irvin (1988, p. 99) notes that the unpredictability associated with progressive disability, particularly if accompanied by periodic bouts of illness,

might provide situations in which the child experiences many “little deaths” during the trajectory of the disability. Drawing on a sample of American mothers with various types of physical disabilities, Cohen (1998) examined the relationship between maternal disability and developmental tasks of children. An important finding was that some of the mothers expressed concerns about their children’s difficulty in dealing with the uncertainty of sporadic health problems and separations during hospitalisation, the disruptions in daily routines and their fears about the possibility of their mothers’ premature deaths.

1.4.1.5. Chronicity

Drawing attention to the chronicity of the disability and its implications for access to familial and social support, Irvin (1988) suggests that parents with “acute” disabilities may find it easier to access emergency support than those with “chronic” disabilities who might require sustained long term support.

1.4.1.6. Psychological functioning

Research has documented the impact of mothers’ poor psychological functioning, and in particular maternal depression, on children’s physical, emotional and psychological well-being. Children of parents whose physical disabilities are accompanied by mental limitations which negatively impact on the emotional environment of the child, might be more at risk of negative developmental outcomes than those whose parents’ mental processes remain unaffected (Irvin, 1988).

1.4.1.7. The difference between disability and illness

While many of the general research findings on parental disability offer useful insights into children's experiences, it is most important to investigate the implications of the nature of the disability itself (Coates et al., 1985). Children may be affected in different ways by different parental impairments, for example parental alcohol dependency, degenerative illness, adventitious disability or chronic mental disorder (Newman, 2003; Buck & Hohmann, 1983). Each impairment type may hold different implications for patterns of interaction occurring within the household, the roles of family members and the associated emotional and physical impacts (Newman, 2003; Romano, 1976). Furthermore there is a distinction between disability that is stable, does not require medical attention but causes significant limitations and disadvantage, and disability which causes limitations but requires ongoing medical attention. A third type of disability is that which is intermittent, and possibly progressive, in nature and which has other effects on the process of caregiving to children. Another important aspect is chronicity, which characterises both disability and illness. Moreover, chronic illness as a health condition may or may not lead to a long-term disability.

1.4.1.8. The differential effects of paternal and maternal disability

Perhaps one of the more important considerations addressed by the general developmental literature, but largely ignored by early disability research, is the way in which mothers and fathers impact on their children's development through different pathways (Thurmann et al., 1985; Coates et al., 1985). Mothers and fathers have been

shown to influence different aspects of their children's behaviour, thus, according to Lynn (1974; 1979 in Coates et al., 1985) it should be presumed that the gender of the disabled parent is likely to determine how the child is affected. Indeed, while Olgas (1974) found no evidence of greater body image distortion occurring amongst children of parents with MS than children of healthy parents, body image distortion was found to be significantly higher in girls with MS mothers than in girls with MS fathers. Moreover, measures of body image distortion were also significantly higher in girls with MS mothers than in boys with MS mothers. However, research that has directly addressed the differential effects of maternal versus paternal disability suggests that maternal disability might be more problematic for body image than for the quality of the parent-child relationship (Crist, 1993).

1.4.1.9. Inappropriate caring

Since the late 1980's a substantial body of literature highlighting the situation of children and young people who provide physical or emotional care in response to a family member's disability has emerged. This interest in "young carers" and their circumstances is informed by a children's rights perspective, and is the motivation for a number of "Young Carers" research programmes currently operating in Australia and the UK. Such research aims to identify the number, characteristics and needs of such children with the intention of providing support in order to facilitate them in their role and their participation in society (Noble-Carr, 2002). Young carers are generally defined as those "up to (18) years of age who provide care and support for a parent, partner, child, relative or friend who has a disability, is frail aged or who has a chronic mental or physical illness" (Noble-Carr, 2002, p. 6). International and local

data collected by the Young Carers Research Project in Australia revealed that, of an estimated 18,800 young carers in Australia, over half are caring for a parent (Noble-Carr, 2002). Where children are caring for a parent, that parent is most likely to be the mother of a single parent household. In a national survey of 6,178 young carers in the UK, it was found that more than fifty percent of young carers were living in single parent families (Dearden & Becker, 2004). Consistent with the findings from Australia, the majority of people needing care were mothers. This was especially true in single-parent homes, where mothers accounted for 70% of people needing care. Of young carers, nearly half were found to provide general and nursing type care, intimate personal care and childcare. In addition, the overwhelming majority of young carers were found to provide emotional support and supervision. An important finding was that more than 20% of young carers reported missing school and/or experiencing educational difficulties.

The young carers' paradigm differs from previous literature in its treatment of children as social agents, able to influence and negotiate transactions occurring between themselves and their environment (Coates et al., 1985; Aldridge & Becker, 1993b). By placing emphasis on examining "the quality of life of these children - examining, in-depth, their conditions, experiences and needs" (Aldridge & Becker, 1993a, p.376) caring by children is embedded within a wider social and economic context.

While some potential benefits of caring have been acknowledged, the negative impacts are thought to "easily outweigh" any positive effects (Noble-Carr, 2002, p. 9). Because such children assume levels of responsibility inappropriate to their

developmental stages the suggestion that caring by young people has an adverse effect on their well-being is implicit (Barnett & Parker, 1998). Young carers are known to commonly assist disabled relatives in a number of tasks related to mobility, the provision of medication, housework and intimate personal care (Noble-Carr, 2002). Numerous studies have reported that the negative effects of caring by children include negative physical, emotional, psychosocial and educational outcomes (Noble-Carr, 2002; Aldridge & Becker, 1993b).

In South Africa, literature pertaining to parental disability is virtually nonexistent. Petersen (1991) examined the extent and appropriateness of care given by children caring for physically disabled persons. Using data collected from 65 children from across the Western Cape, the author found that almost 60% of respondents were involved in inappropriate caring, with 5% of the 60% having dropped out of school to care for their disabled family member. Consistent with findings from both Australia and the UK, the majority of family members requiring care were mothers (47%). The authors concluded that caring is generally provided by members of the community or family as a result of restricted access to schools, transport, hospitals and other support structures.

1.4.2. Social and environmental factors

1.4.2.1. Stigma

It is well recognised that disability is often stigmatised; discrimination against persons with disabilities holds serious consequences both for that person and their family (Cohen, 1998; Goffman, 1963; Green et al., 2005; Irvin, 1988; Perkins, 2000; Taub,

McLorg & Fanflick, 2004). A stigmatised person has been defined as someone whose social status as a full human being is questioned, and who is thus perceived as “marginal, secondary (at best), flawed and impaired” (Ratele & Duncan, 2003, p. 349). If this devalued image is internalised, the individual is vulnerable to negative psychological, emotional and behavioural consequences such as low self worth, depression, self-blame, self-hatred, impaired motivation, retarded behaviour and pathological compensatory activities (Irvin, 1988; Green et al., 2005). The child’s perception of his or her mother/primary caregiver as stigmatised may lead to a situation where the child starts to devalue the parent, thus creating a range of difficulties in their relationship, particularly during the sensitive developmental stage of adolescence.

In addition, the other members of the family may also come to be viewed as stigmatised by virtue of their relation with the affected individual, a phenomenon referred to as “courtesy stigma” (Goffman, 1963). Detrimental consequences of courtesy stigma for the child of a parent with a disability might include increased risk of attracting negative experiences such as teasing, rejection, discrimination, social isolation and violence (Kirshenbaum & Nevid, 2002). Compound stigma, sometimes referred to as multiple stigma, occurs when a person accumulates stigma on top of pre-existing stigmas as in the case of black, disabled women from disadvantaged backgrounds who have to contend with the cumulative effects of gender, race disability and socio-economic status (Kalichman and Simbayi, 2004).

1.4.2.2. Societal acceptance

Irvin (1988) notes that certain disabilities are regarded more favourably and worthy of understanding than others on the basis of their aetiology. Several explanations have been offered for the differential view. For example, the individual with a congenital disability such as polio might be offered more understanding than the person with HIV/AIDS. Thus the child's experience of the parental disability is a function of numerous other variables related to the emotional sequelae of the disability.

1.4.2.3. Poverty

It has been shown that poverty constitutes a particularly salient obstacle for those belonging to the disabled community (Abberley, 1987; Kirshbaum, 2000). Disabled people are more likely to attain lower levels of education and consequently are more likely to be unemployed than their non-disabled counterparts (Olsen & Clarke, 2003; Randolph, 2004). The experience of disability thus constitutes an additional factor intersecting with the various issues associated with parenting in general (Newman, 2003).

Building on our understanding of the impact of poverty on caregiving, McLoyd (1990) finds that economic hardship affects parental psychological functioning in a range of ways. It appears that parents/caregivers experiencing economic difficulties are more likely to be depressed, irritable, explosive and are at increased risk of experiencing marital conflict when compared to parents from economically secure circumstances. The degree of psychological distress experienced by the

parent/caregiver in response to economic hardship was found to render them more or less vulnerable to negative life events. Furthermore, poor parents were less likely to be consistent and responsive and more likely to use excessively harsh methods of discipline. Moreover, they were unaffectionate and unlikely to clarify their commands. Research studies point to the disempowering implications of poverty in limiting a) the individual's access to opportunities and services, b) personal choices and decision-making, and c) prestige, power and status (McLoyd, 1990).

Richter (1994) argues that there is sufficient evidence to suggest that the poor environmental conditions associated with poverty and deprivation have the most powerful and pervasive impact on a broad range of negative child outcomes. Although the contention that poverty uni-directionally leads to health and developmental problems has been disputed, there is general agreement about the role of poverty in exacerbating less than optimal development in children: "There is much to suggest that poor parents do not raise their children the way they do because they believe in, or value the correctness of their behaviour; but rather because their circumstances frequently leave them few options, economically or personally" (Richter, 1994, p.36).

1.4.2.4. The cumulative effect of poverty and disability

Several studies have demonstrated the importance of socio-economic status in influencing developmental outcomes (Coates et al., 1985; Thurmann et al., 1985). Buck & Hohmann (1982) investigated the impact of paternal disability on children's well-being, particularly the relationships between children's adjustment patterns, the severity of disability, paternal employment and family financial status. The authors

found that neither the severity of the disability nor unemployment amongst fathers was associated with psychological maladjustment amongst their children. Interestingly, the family's financial resources appeared to be more important for family functioning than either of the above two mentioned variables (Buck & Hohmann, 1983).

There are multiple pathways through which poverty appears to impact on children's circumstances (Newman, 2003). A Welsh school survey was conducted to investigate the impact of parental impairment on child health and well-being. Comparisons between children were made using the proportion of free meals provided by schools as a proxy measurement of poverty (free meals were given to those children whose parents/guardians qualify for income support) (Newman, 2003). Free meals were provided to more than 60% of pupils from one school, while only 12% in the comparison school received such meals. The findings suggest that, in addition to needing free meals, the children from the first school also reported having more responsibilities towards both sick adults and siblings, worrying more about sick people and engaging in more household tasks than the children from the second school. These findings are consistent with the hypothesised effects of poverty as an additional stressor, increasing the salience of illness in a child's environment and the likelihood that children will assume responsibility for household tasks.

1.4.2.5. The cumulative effect of poverty, disability and single parenthood

Randolph (2004), utilizing data from 23,143 people across nine American states, found that persons who were female, disabled, less educated, single, and not

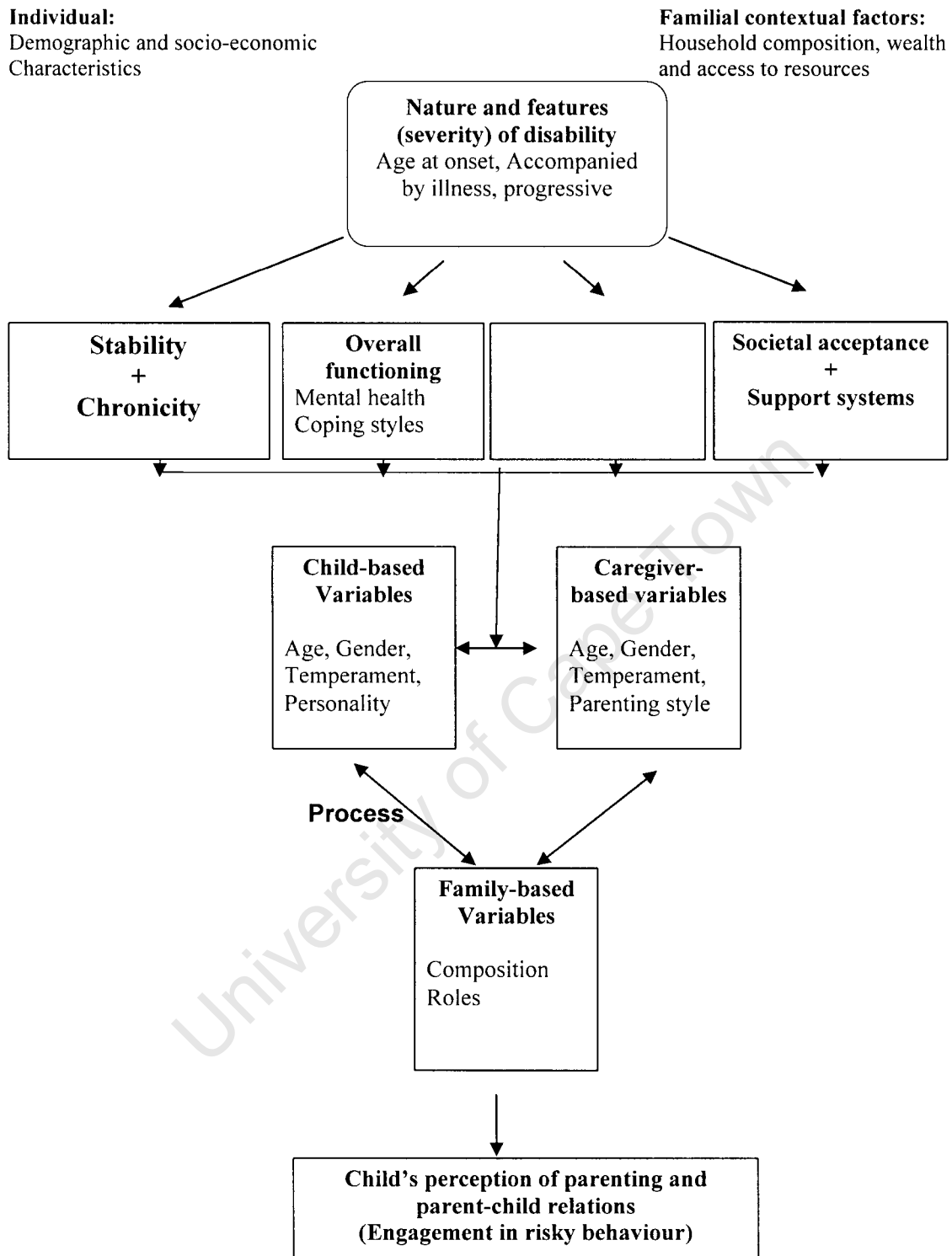
Caucasian were least likely to be employed and, if employed, were more likely to receive lower incomes. These findings hold important implications for parenting with a disability as their influence impacts on the situation of young carers. Research into the characteristics of children who care for disabled or ill relatives in both Australia and the UK, suggests that, where children are caring for a parent, that parent is most likely to be the mother of a single parent household (Dearden & Becker, 2004; Noble-Carr, 2002). One of the most robust findings in the literature about parenting in general is the association between single parenthood and the less than optimal development of children (Olsen & Clarke, 2003; Newman, 2003). Family structure is thus also a variable hypothesised to influence the relationship between parental disability and developmental outcomes (Coates et al., 1985). Psychological distress has been proposed to explain the relationship between single parenthood and child functioning. Hetherington (1979, in Coates et al., 1985) suggests that the child may experience difficulty adjusting to the stress of having only one parent, and that if that parent is disabled, the psychological resources available to the family may be severely reduced. As of yet there appears to have been no attempt made to test this specific hypothesis.

Findings from a school survey conducted amongst 729 students to investigate the relationship between parental impairment and poor child health and well-being contradict those of Hetherington (1979 in Coates et al., 1985). Newman (2003) compared responses of children from both single and two parent families and found no statistically significant differences: children from single-parent homes reported no greater frequency of household tasks, looking after siblings or helping sick adults. The

findings support the argument that poverty appears to have a bigger impact on children than does family structure.

From the reviews presented in Sections 1.1 to 1.4 it should be clear that extensive research has been conducted into authoritative parenting in various ethnic, cultural and socio-economic contexts but that comparatively little research has been conducted into authoritative parenting in contexts of maternal disability. The research presented in this thesis is relevant to the areas of child development and disability research, and aims to gain a greater understanding of the impact of maternal disability on adolescent development by delineating variables identified as impacting on this relationship.

Figure 1 is a schematic overview of the conceptual model which underpins the present thesis. The study will focus on important dimensions related to the nature and features of maternal disability as identified by Irvin (1988). The emphasis in this review is placed on how these factors combine to influence the relationship that mothers and women caregivers with physical disabilities have with their children. Since parenting cannot be removed from the broad context in which it occurs, attention is paid to the structural features of the family, household or characteristics of the neighbourhood and surrounding environment including levels of poverty, unemployment, gangsterism, substance abuse and crime and violence. The scope and objectives of the thesis are outlined in Section 1.5 and are motivated by the literature review presented in Sections 1.1 to 1.4.



Neighbourhood characteristics: poverty, violence, gangsterism, substance abuse

Figure 1. Conceptual model of the impact of maternal physical disability on parenting/parent-child relationship and child well-being

1.5. Scope and objectives of thesis

This thesis was initiated to investigate the effect of the mother's physical disability on perceptions of the mother-child relationship, parenting and the child's engagement in risky behaviour for black, adolescent children from low socio-economic backgrounds.

Specifically, it aimed to examine:

1. The implications of the nature and features of the mother's disability, in combination with other demographic variables for mother-adolescent relations;
2. The effect of disability-related stigma and the adolescent's awareness of the mother's difference on the mother-adolescent relationship;
3. The ways in which the mother's disability, as well as vulnerable low socio-economic conditions and high-risk neighborhood characteristics affect parental involvement in the adolescent's school and other activities, monitoring and supervision and lastly, the adolescent's engagement in risky behaviour.

The key contribution of this thesis is to achieve a better understanding of points 2 and 3 above, which to date, has received very little attention in the literature.

CHAPTER 2: METHODOLOGY

This chapter outlines the procedures employed to conduct the research, including the selection of the participants, the instruments used and the design of the instruments. In order to achieve the objectives outlined in Section 1.5, it was necessary to select and develop tools most suitable to determine the impact of maternal disability in combination with other child and mother related demographic variables, as well as low socio-economic conditions and other contextual factors impacting on parenting, the parent-child relationship and ultimately the child's engagement in risky behaviour. Conducting the study within a qualitative paradigm, using the case study method appeared to be most suitable. Padgett (1998) suggests that qualitative methodology is useful when attempting to illuminate processes from the perspectives of the role players who live and construct meaning from their experiences. Further, qualitative methods are best utilized when the researcher seeks understanding, marking them as "emic (the respondent's point of view) rather than etic (from the perspective of an objective outsider)" (Padgett, 1998, p. 8).

The principles of the case study method are described in Section 2.1 and the suitability of the case study method for this thesis is discussed in Section 2.2. This is followed by the study description in Section 2.3, then the selection of participants and data-collection methods in Sections 2.4. and 2.5 respectively. Schedules for the interviews held with the mothers are presented in Appendices A, B and C while schedules for the interviews held with the adolescents are to be found in Appendices D and E. The information sheets for the mothers and adolescents are presented in Appendices H and F, followed by the

assent and consent forms in G and I respectively. Finally, results from the case studies are discussed in detail in Chapter 3.

2.1. The principles of the case study research method

Yin (2003) proposes that the case study method is the preferred method of empirical inquiry when 1) the research questions are “how” and “why”; 2) the researcher has minimal control over behavioural events and 3) the issue at hand is contemporary, within some real-life context. Furthermore, an essential feature of the case study is that it describes the object of investigation as it exists, particularly when contextual factors are deemed highly relevant to the phenomenon of study (Yin, 2003). Moreover, the case study is deemed useful for understanding “the individual, a broad range of variables pertaining to the individual, his or her interpersonal relationships, and indeed the larger social matrix” (Kazdin, 1992, p. 152).

2.2. The suitability of the case study method for this thesis

Armistead et al. (1995) suggest that when a field of study is truly in its infancy, case stories serve as a sound foundation for generating hypotheses. They argue that case histories have proved most useful in examining the effect of chronic physical illness on the lives of individuals and their families by highlighting the complexity of emotions which range from despair and depression to acceptance and coping. Based on a review of the available material, the case study method was chosen as the most appropriate

method to advance our knowledge on parenting and child well-being in the context of maternal physical disability, due to “its ability to deal with a full variety of evidence” (Yin, 2003, p. 8). The fundamental premise underlying the researcher’s decision to utilise the case study was to test theoretical propositions regarding the effects of maternal disability and to relate the findings to the existing body of theory on some aspects of parenting and child well-being (Burton, 2000). One of the most significant outcomes of the case study method is that it allows for common and contrasting experiences to emerge from the individual cases, thereby increasing the utility thereof.

Multiple cases were carefully selected based on a range of similar cluster characteristics with the purpose of predicting fairly similar results in each case (Yin, 2003). Such characteristics included race, educational levels, socio-economic status, urban residence, and visible physical disability. This approach allowed for the collection of subjective data from a variety of sources in order to confirm insights and search for contradictory evidence arising over a period of time (Burton, 2000; Yin, 2003).

Although each case was studied individually, evidence from the multiple cases was compared and contrasted, thereby increasing the robustness of findings due to the logic of replication (Burton, 2000; Kazdin, 1992; Yin, 2003). Furthermore the conclusions drawn from several cases minimised the “possibility of idiosyncratic findings characteristic of one single case” (Kazdin, 1992, p. 157). The reliance on multiple cases therefore provided a much better basis for drawing some tentative generalisations (Burton, 2000; Kazdin, 1992; Yin, 2003).

2.3. Study description

This thesis reports on the analysis of data from five case studies conducted with black mother-child dyads where the mother has a physical disability. These case studies were conducted as part of a larger study focusing on women with physical disabilities and their experiences of motherhood. The primary objective of this thesis was to explore the impact of maternal disability on parenting, parent-child relationships and perceived child outcomes, incorporating the views of the children themselves.

2.4. The selection of participants

Sampling: Snowball sampling was used to recruit participants using the following inclusion criteria:

- 1) The woman was the primary caregiver and must have lived with her child since birth or adoption.
- 2) The mother had a visible mobility impairment.
- 3) The children were between the ages of 12 and 18.
- 4) The child had no known disability.
- 5) The mother-child pairs were black and from low socio-economic backgrounds.
- 6) The families were proficient in either English or Afrikaans.

The minimum age of the child was set at 12 years due to the fact that older children are more likely to be able to articulate their feelings and experiences through language minimizing the process of interpretation by the researcher.

The first two women were recruited through a disabled people's organization. Each woman was asked to identify possible research participants and obtain verbal consent for their contact details to be given to the researcher. Following this, the researcher made telephonic contact with the mother in order to discuss the nature and purpose of the project, as well as what would be expected of each of the family members should they be willing to participate. Prior to the interviews, the researcher discussed the study with the mother and child and gave each person an information sheet (see Appendix H and F) outlining the project, before securing written consent from the adults (see Appendix I) and assent from the children (see Appendix G). One of the mothers was illiterate and marked the form with an x. It was explained to the participants that they did not have to answer any questions with which they were not comfortable, and could stop the interview at any time. The mother and child took part in two separate, confidential interviews with seven to ten days between each session. Meeting with each participant on two occasions over a period of time was useful for building rapport, and facilitated a trusting relationship where the mothers and children were able to speak freely and openly about their experiences. In order to maintain confidentiality and ensure anonymity, the names of the women and children have been changed.

2.5. Data collection

Semi-structured interviews: Two separate semi-structured interviews, each lasting approximately 40 minutes, were conducted with the mother and the adolescent. Key questions generated through a review of the literature informed the design of the interview schedules for both the mother and the child. The primary objective of the interview schedule was to gain an understanding of the components of the conceptual model for the study detailed in Figure 1 of Chapter 1. More specifically, the questions were intended to explore family background information, relevant contextual factors, the dimensions of the disability and the perceived impact on 1) parental involvement in activities, 2) parenting practices and style, 3) perceptions of monitoring and supervision, 4) emphasis on educational performance, and 5) perceptions of the child's engagement in risky behaviour.

The interview style was non-directive allowing the conversation to evolve as participants introduced topics of particular relevance to their own experiences (Kvale, 1996). Particularly in the child interviews, questions were often rephrased and simplified according to the child's individual cognitive processes. In order to provide a "thick description" of the childrens' experiences of their lived worlds, they were encouraged to provide examples to illustrate and clarify their particular points. Thus the interview schedule served merely as a trigger to the non-standardised nuances and differences between people's "contextuality of meaning" (Kvale, 1996, p. 168).

2.5.1. Interviews with the mothers

For the purpose of triangulation, two separate semi-structured interviews lasting approximately forty minutes each were conducted with each woman covering the same topics as the child's interview. The interviews were conducted separately and confidentially with each family member in their home.

2.5.1.1. Interview one

The first interview schedule contained two sections.

Part one: The first (see Appendix A) consisted of a range of questions designed to capture background demographic information, including the caregiver and partner's disability and overall health status, the family's financial resources including other types of available support, household composition, the roles and responsibilities of each family member and the division of labour within the family.

Part two: This part of the schedule (see Appendix B) included twenty six questions on the mother's perception of the child's knowledge, understanding and feelings about her disability, family coherence and the mother's involvement in activities, perceptions of the child's relationships with others, stigma and courtesy stigma, educational outcomes and positive and negative effects associated with maternal disability.

2.5.1.2. Interview two

The second interview (see Appendix C) consisted of twenty-nine questions designed to assess the key elements of the maternal-adolescent relationship. This was separated into parental practices and parenting style (Gray and Steinberg, 1993). The schedule included questions on love, warmth and acceptance; support, encouragement and praise; granting of psychological autonomy; high and consistent expectations about educational performance; conflict situations; monitoring and supervision; inappropriate caring and the child's engagement in risky behaviour.

2.5.2. Interviews with the adolescents

For the purpose of triangulation, two separate semi-structured interviews lasting approximately forty minutes each were conducted with each child covering the same topics as the maternal interview.

2.5.2.1. Interview one

The first interview (see Appendix D) with the adolescent contained the same questions as the maternal interview.

2.5.2.2. Interview Two

The second interview (see Appendix E) consisted of the same questions as those in the maternal interview.

2.6. Translation of instruments

All instruments employed during the study were translated from English into Afrikaans for one of the families. After the questions had been translated, a back translation was conducted in order to validate the quality of the original translation. The researcher is multilingual and together with other researchers attempted to retain the essence of the questions, taking into account the local ways of expression.

2.7. Data analysis

The same transcriber was used and typing procedures were standardised across the different case studies to allow comparisons between the various responses. During the initial transcription process, the audio material was transcribed verbatim or near verbatim. Later, speech mannerisms such as “uhhhhs” and “mmms” were removed from the direct quotes in the main section of the report, but retained in the original interviews. Repetitions and comments that had no relevance to the topic have been omitted to preserve the main thought. Grammatical errors made by participants have not been corrected and the dialect of the interviewee has been retained. The interviews are

presented as unbiased descriptions of the mother and adolescent's accounts with direct quotes extracted to illuminate similar or in certain cases contrasting experiences.

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CHAPTER 3: RESULTS

The goal of this chapter is to present the results of case histories derived from the mother-adolescent dyads as outlined in Section 2.3 of Chapter 2. Tables 1 and 2, overleaf, display the demographic information of the five case studies. In order to maintain confidentiality and ensure anonymity, the names of the women and children have been changed. The families who participated in the study were black, the mothers between 40 and 50 years old with differing health conditions such as cerebral palsy, spinal cord injuries and polio. One of the mothers also had panic disorder and osteoarthritis. Two of the five women were married to partners with mental disabilities, one lived with a partner and the other was divorced. Two of the mothers have more than one child and the rest have only one. The three girls and two boys interviewed were between 12 and 15 years old and did not have any disabilities. Table 3 shows the educational and socio-economic profile of the families including household composition and their monthly expenses. One of the mothers had a primary school education, two had completed one year of secondary schooling and the remaining two had matriculated.

Table 1: Demographic profile of adolescents (names have been changed)

Name	Age	Gender	Race	Grade	Family Structure	Details of Siblings
1. Angus (C1)	15	Male	Black	9	Step-parent family	1 Sister, 8 years old
2. Jeremy (C2)	12	Male	Black	6	Intact family	1 Sister, 8 years old
3. Radia (C3)	13	Female	Black	7	Step-parent family	None
4. Sophie (C4)	13	Female	Black	7	Single-parent family	None
5. Eileen (C3)	15	Female	Black	Dropped out	Step-parent family	None

Table 2: Demographic profile of mothers (names have been changed)

Name	Age	Home Language	Highest Grade Passed	Race	Disability	Time of Onset	Relationship Status	Partner's Disability Status	Employment Status
1. Aimee (M1)	40	English	7	Black	Paraplegic	Polio at age of 9 months	Single, lives with partner	No disability	Unemployed
2. Debbie (M2)	40	English	12	Black	Diaplegic + Panic disorder + Osteo- arthritis	C P at birth + panic disorder at 34yrs +OA (gradual onset)	Married	No disability	Unemployed
3. Fairuz (M3)	40	English	8	Black	Quadraplegic	Cerebral Palsy at birth	Married	Psychiatric disability	Employed
4. Pearl (M4)	50	English	12	Black	Paraplegic+ Hip injury	Polio at age of 16 months	Divorced	N/A	Employed (Protective Workshop)
5. Magdalene (M5)	40	Afrikaans	8	Black	Paralysis+ Brain injury	Car accident at age of 17	Married	Mental disability	Employed (Protective Workshop)

Table 3: Socio-economic characteristics of families

Name	Occupation	Partner's Occupation	Family Composition	Residence	Income	Household Expenses
1. Aimee (M1)	Unemployed	Builder	2 Adults + 2 Children	Two bedroom house	R2 240	Water and electricity, car maintenance, food and clothing, school and medical expenses
2. Debbie (M2)	Mailhandler	Cleaner	2 Adults + 2 Children	Two bedroom house	R1 300	Rates and taxes, water and electricity, food and clothing, school and medical expenses
3. Fairuz (M3)	Licensing Official	Unemployed	2 Adults + 1 Child	Rented room	R2 740	Rent, water and electricity, car maintenance, food and clothing, school and medical expenses
4. Pearl (M4)	Telephonist	N/A	1 Adults + 1 Child	Residential care centre	R2 000	Accommodation, transport, clothes, school and medical expenses
5. Magdalene (M5)	Unskilled contract worker	Semi-skilled contract worker	2 Adults + 1 Child	Rented wooden house	R2 200	Rent, water and electricity, food and clothing, school and medical expenses.

3.1. CASE ONE: Aimee (M1) and Angus (C1)

3.1.1. Demographic, socio-economic and residential information

Aimee is a 40-year-old, black woman who contracted polio at the age of nine months. The medical diagnosis of her disability is spastic paraplegia, meaning that both her legs are affected. She has used a wheelchair since she was about three years old. Aimee lives with her partner, Hein (52 years) who is not disabled, her son Angus (15) and her daughter Catherine (8) in a two- bedroom house in an informal settlement on the Cape Flats. Their home is one of just a few brick houses in the area, which is notorious for high levels of unemployment, gangsterism, substance abuse, violence and crime. Official crime figures issued by the South African Police Service (SAPS, 2006) indicate that in 2002/2003, 142 murders or attempted murders, 62 rapes, 795 assaults, and 139 drug related crimes were reported in this area.

Aimee dropped out of school after completing grade seven at a mainstream school. She has had a number of jobs but is presently unemployed and receives a disability grant of R740 per month. Although her partner works as a builder, his income is inconsistent due to the unpredictable nature of the building industry. When he does have work, he earns a monthly salary of R1 500, bringing their total monthly income to R2 240. This income supports two adults and two children and is used to pay water and electricity, car maintenance, food and clothing, school and medical expenses. Aimee was never married to the father of her children and neither Aimee nor Angus has any contact with him; he provides no financial support for the children.

Angus, a 15-year-old boy, attends high school in a nearby area. He is currently in grade 9 and has never repeated a school year. Each school class contains between 40 and 50 learners, all from surrounding neighborhoods. According to Angus, most of the older boys in his school are gang members.

3.1.1.1. Family roles and responsibilities

Aimee performs the majority of household tasks and responsibilities. She is a very good housekeeper and prepares all the family meals, does the cleaning and the laundry, with occasional assistance from neighbours. She has always been the primary caretaker of both her children and receives minimal support from her sister, who lives in the area. Hein and the children use public transport to get to the nearest shopping mall to do the shopping at the end of each week. Aimee is responsible for managing their finances, thus she makes most of the decisions about the running of the household.

3.1.1.2. Nature and features (severity) of disability

3.1.1.2.1. Age at onset of disability

Aimee acquired a physical disability during infancy when she contracted polio at the age of nine months. She experiences limitations with the following activities: getting in and out of bed, getting in and out of the bath, dressing, gaining access to buildings, moving in and around the house, getting clothes from cupboards, reaching kitchen cupboards, using kitchen utensils and cooking. She uses a wheelchair to get around.

3.1.1.2.2. Stability and chronicity

Aimee describes her disability as stable, chronic and as impacting on her mobility. Her mental processes are unaffected.

3.1.1.2.3. Overall psychological functioning

Aimee's overall psychological functioning is excellent. She appears to be a cheerful, positive and outgoing person, as well as a warm, patient and attentive parent.

3.1.1.3. The implications of the disability for maternal-adolescent relations

Aimee was asked about her perception of her relationship with her son. She described Angus as understanding and accepting of her disability. She feels that she has a very good relationship with the boy, and reported that he often asks her to accompany him to the library to find good books. Aimee says: *"I must tell you I'm very proud of Angus. The way he handles his mother's disability to put it like that. I regard him as brave"*.

Over the years, Angus has shown an interest in understanding the reasons for his mother's disability, and he appeared to be informed about the implications thereof. Angus appears to make sense of his mother's disability in a spiritual way, saying, *"It's the way God sent her to me."* Angus admits to occasionally feeling anxious and stressed about his mother's vulnerability. When asked how his mother's disability impacts on him he responded: *"But sometimes, it makes me sad and I ask myself why the Lord gave a mother like that to me"*. Angus was asked about his relationship with his mother. He

feels that they are “*quite close*”, and mentioned that they sometimes clean the house and watch TV together. He estimated engaging in these activities about three or four times a week. Angus also reported that he was not shy to walk in the road with his mother. He further explained that, unlike his friends, “*If she asks me to go to a place with her I’ll say yes*”.

3.1.1.3.1. Perceived positive effects associated with maternal disability

Aimee feels that growing up with a disabled mother has taught her son to be more sensitive, attentive and emotionally supportive. Angus reported that having a mother with a disability has taught him to appreciate her. He explained that she is more responsible than some of his friends’ mothers: “*She’s not like other mothers. Like some mothers they fight with their children some mothers drink and they lay with any man and such stuff. I know my mommy’s not like that*”.

3.1.1.3.2. Perceived negative effects associated with maternal disability

Aimee does not think that being raised by a mom with a disability has impacted negatively on Angus. Angus explained that when he was younger, he used to feel ashamed of having a mother with a disability and of being seen with her: “*we were shy to walk in the road with her sometimes. But not now, I’m over it now*”. Angus said that he occasionally feels sad about taking his mother for granted and not listening to what she says.

3.1.1.4. Disability-related stigma and the impact of the adolescent's awareness of the mother's difference on mother-adolescent relations

3.1.1.4.1. Stigma and courtesy stigma

Aimee was asked whether she has experienced any incidences of stigma and she reported occasional incidences of verbal abuse due to her disability: *“they swear at him or me, then he want to fight all the time”*. Angus explained that he has seen his father's family treating his mother differently by talking about her. He said that: *“Some of them treat her different. Not my mother's family. My father's family treat her different. I don't really know. They talk about her”*. He also has the impression that his teachers react differently to his mother. On the other hand, he did not recall any experiences of courtesy stigma because of his mother's disability.

3.1.1.4.2. Relationships with others

Aimee feels that her disability does not impact on the manner in which Angus relates to other people. Similarly, Angus reported that his mother's disability does not affect his relationships with other people. He said that: *“I talk to other people just like normal and if I talk about my mother I just talk like she is a normal person”*.

3.1.1.5. The cumulative effect of the mother's disability, low socio-economic conditions and high-risk neighborhood characteristics on parenting, parent-adolescent relations and engagement in risky behaviour.

3.1.1.5.1. Parental involvement in adolescent's activities

Aimee explained that she is not as involved in Angus' activities as she was when he was younger. She expressed concern about the fact that he is not as open and honest as he used to be. The researcher asked whether she knew about his extra-mural activities at school and she said: *"At the moment, I don't know what's going on there, so I must go to the school again on Friday when I have money for the taxi to go look"*. Angus reported that his mother phones and visits the school in order to keep track of his school performance. He mentioned that she tries to help him see right from wrong, but she does not give reasons when she disagrees with him. He said that his mother knows all his friends and that she allows them to come to their home when they collect him. Angus explained that his mother encouraged him to take up boxing because he *"can get far with it."* He says that he listens when his parents talk to him and that he does not talk back. Angus asks his mother for advice when it comes to domestic chores and seeks help from his stepfather on technical tasks.

3.1.1.5.2. Quality of interaction

Aimee feels that they respect and trust each other. She said: *"We got a good relationship"*. Aimee reported that she allows Angus to make decisions and expects him to follow through on them: *"He must deliver because I give him like a privilege to make his own choices so I would like him to make a success"*. Angus said that the people whom he trusts the most are his mother and stepfather and that he listens when they talk to him. He said that: *"Mostly I trust my mother. Like when I tell her something she doesn't speak to other people about it"*. Angus explained that his mother allows him to

make major decisions about matters affecting him and that she supports his decisions. He said that: *“she let me choose if I want to go to this school or the one in Lavender Hill”*.

3.1.1.5.3. Parenting practices

Aimee expects Angus to do well and helping him to succeed in school is very important to her. She is determined to give him the opportunity to study because she did not have the opportunity to further her education: *“I motivate and expect him to do good because I didn't have the privilege to do it”*. Aimee feels that her expectations of Angus remain consistent and she makes sure that he knows exactly what is expected from him: *“I don't change my mind. I tell him always he must do it. He also can't change his mind”*. Aimee was asked whether she keeps track of his school performance and she said: *“Yes. I do keep track. I go look in his schoolbooks and talk to his teachers. I also ask him did you do this and do that”*.

Angus reported that his mother expects him to do very well at school and he agrees that this is a reasonable expectation. He also reported that she used to assist him with his homework while he was in primary school, but that now that he is in high school she expects him to be able to do it independently. Angus said that her expectations of him are not always consistent and that she does change her mind. He feels that Aimee shows concern and interest in his school performance by phoning the teachers and occasionally visiting the school. He explained that she tries to ensure that he meets her expectations about his school performance by threatening not to buy gifts for him.

3.1.1.5.4. Parenting style

Aimee reported that Angus is very special to her and that she is determined to help him succeed in life. Her biggest fear is that he will fall prey to gangsterism which is rife in the area. She tries to be a friend to him so that he does not seek acceptance from antisocial friends: *“I try to make him feel loved so he does not go outside to the wrong company to look for it”*.

Angus reported feeling supported by his mother. He said that she stops his stepfather when he wants to hit them. He also felt that she praises him when he does well. He reported feeling affection for his mother, stepfather and his sister. He explained that he mostly asks his mother for advice and that she encourages him to do things: *“Like when I took up boxing I didn’t want to go she said I must go I can get far with it”*.

3.1.1.5.5. Monitoring and supervision

The researcher asked Aimee how she tries to find out where Angus is and or what he is doing. She replied: *“Most of the time I know where he is. He’s by his friends in the street and when I don’t know I send his sister sometimes. Sometimes I give him a call back and ask where he is”*. Aimee tries to find out about his friends and their families and elicits information about them from Angus: *“I ask him to tell me about his friends. If I don’t like a friend I tell him I don’t like that friend. Sometimes he gets cross, but I don’t care”*. Aimee reported that Angus does not stick to his curfew. She has requested that he be home by a certain time, but: *“Yes, but he don’t listen. He always comes in his time”*. She explained that he does not have a curfew over the weekend. Aimee was asked

about the consequences of not obeying his curfew and she explained: *“I scowl him or whatever when he comes in. I said: “you must come in. You must be here in this time and that time. I told you.”*

Angus feels that his mother does keep track of his whereabouts by phoning him to find out where he is. He said that she knows his friends and she knows where they are. On weekdays his curfew is nine o'clock and on the weekend he needs to be home by ten o'clock. If he is not on time, his mother or stepfather reprimands him.

Both Aimee and Angus reported difficulties with setting rules and managing conflict in an effective manner. They both agree that they yell or shout at each other when they have a serious disagreement. Angus felt that his mother does not provide reasons when she disapproves of his behaviour. Aimee was asked how she deals with reprimanding Angus and resolving conflicts. She said that they either talk about the problem or the problem goes away by itself. If the problem does not go away they would try to solve it. She replied: *“We talk about it and resolve it or the problem go away by itself or sometimes it doesn't, but we try to make it happen”*. Aimee was asked whether she clarifies and gives reasons to Angus about why she disagrees with him on certain things and she said: *“No. I tell him not to do it. You must stay away from that”*. Angus was asked how he and his mother resolve conflicts and he reported that: *“Either we argue or I walk out. That's the only way or if I hit my sister she will hit me”*. He explained that she does not provide reasons when she disapproves of his behavior.

3.1.1.5.6. Inappropriate caring

According to Aimee, Angus does not have to assist with caring tasks: “*No. I do everything myself*”. Besides pushing his mother’s wheelchair and helping her into the bus or taxi, Angus confirmed that he does not have to assist with caring for his mother. He reported that they enjoy going to the public library which is some distance from their home, and that this is one of the few occasions on which he assists his mother.

3.1.1.5.7. Engagement in risky behaviour

Aimee is confident that Angus neither smokes, drinks nor use other substances. Similarly, Angus reports not smoking, drinking alcohol or using drugs but he said: “*My cousins and my uncle drink and I think they use drugs*”.

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3.2. CASE TWO: Debbie (M2) and Jeremy (C2)

3.2.1. Demographic, socio-economic and residential information

Debbie is a 40-year-old black woman, who was born with cerebral palsy. She has spastic hemiplegia and speech impairment and has gradually developed arthritis in her joints. Since being hit by a car five years ago, Debbie has been diagnosed with a panic disorder for which she takes medication. Debbie and her husband, Jack, have been married for 14 years and live with their two children, Jeremy (12 years old) and Cheryl (8 years old). Debbie completed matric at a school catering for learners with special educational needs. Four years ago, the factory in which she held a permanent job closed down and she has since struggled to find suitable employment. At one stage she completed a subsidised training course hoping it would lead to employment but the prospective employer did not provide reasonable accommodation for her disability. She explained: *“I think I was not recruited because one had to work on a production line. Because we were working on letters and books and you had to be able to put like 5000 letters into envelopes in order to get R50 for the day and I could not make it. My disability is on my left hand side and it involves my hand, so I get tired and I have got arthritis also, so you know you must work like very hard to make 5000 books a day or put 5000 letters into envelopes and seal it with a water sealer, so I could not. And then I phoned the company and explained to them that the work makes me too tired and then at the end of the month I come home with R300”*

Debbie’s husband Jack is 45 years old, not disabled and works as a cleaner at a school for learners with disabilities. Jack earns a monthly salary of R900, while Debbie receives

a disability grant of R400 per month, thus bringing their total monthly income to R1300. The income supports two adults and two children and is used to pay rates and taxes, water and electricity, food and clothing, school and medical expenses and transport. Jack's sister and a neighbour sometimes supply food when the family do not have any. Debbie expressed concern about their financial situation and feels that it limits the type of experiences the children are able to enjoy. She explained: *"And I think when you are financially strong then it doesn't matter. That's why when I'm working then its fine. I sometimes phone my cousin and ask for clothes from his wife's family and ask if they can bring me some. The financial part of things is the difficult part for me. Because especially when you don't have then you need to worry about it. Now the children come from school, mommy I need this and mommy I need that. Now on a Friday, its casual day, and like children are, they ask mommy do you have the money for me, and you don't want to say no but sometimes you just don't have. Sometimes when I don't have then I just say to them I'm sorry I don't have any at the moment but when I do have then I will give to you. I have never had the opportunity to take them out to go eat somewhere else and then the small one ask mommy when we are going out. When are we going to Spur cause she's got friends who go to the spur and who go to Kentucky. Now Jeremy is not one that will come and ask now mommy when are we going out? He wouldn't".*

The family owns a two-bedroom council house in a neighbourhood on the Cape Flats. This area is characterised by high levels of unemployment, substance abuse, gangsterism, crime and violence. Official crime figures issued by the South African Police Service (SAPS, 2006) indicate that in 2002/2003, 506 murders or attempted murders, 230 rapes, 3, 819 assaults, and 557 drug related crimes were committed in this

area. This is much higher than the 2 murders or attempted murders, 4 rapes, 57 assaults, and 13 drug related crimes committed in a comparably wealthier residential area.

A few months earlier Jeremy narrowly escaped being caught in the crossfire between two rival gangs. The street in which they live is reportedly flanked on either side by drug lords selling drugs to schoolchildren in broad daylight. The family is religious and draws on their church for support. They occasionally receive financial assistance from Jack's family who lives down the street from them.

Jeremy is currently in grade six. He attends a high school within walking distance from his home and has never had to repeat a school year. Both his mother and father describe him as a shy, sensitive and helpful boy. Jeremy is doing well in all his school subjects except for mathematics. He has a keen interest in music and is learning to play the organ at church.

3.2.1.1. Family roles and responsibilities

Debbie expects her children to help with household tasks. Jeremy's responsibilities include cleaning the yard and caring for the dogs. Debbie prepares most of the family meals and does the laundry. Her husband assists with the cooking, cleaning windows and the shopping. Working at a school, he receives long periods of vacation leave four times a year. On weekends, Debbie receives instrumental help from her 17-year-old niece and her sister's twin daughters. She explained that: *"If it is not holiday I can sweep, I can tidy up myself. I don't worry with windows and stuff until somebody comes here to help with it. Because I don't stand on chairs and things. I'm scared of heights"*. Because

she is mostly at home, both her sister and her brother's six children stay with her during the school holidays. Debbie has explained to her mother that she is unable to care for the children over the holiday period because it is difficult for her to feed six children when she is unemployed. She said: *"Even being disabled does not matter because most of the family's children want to come to me for the holiday. I called my mom last night and I told her, please keep my two brother's children. Because there are about six children who want to come to me. So I asked my mom to tell them not to send their children because I don't have any money now and bread is R5 each and I don't have that. The children just want to come from their houses and they just want to be here"*.

3.2.1.2. Nature and features (severity) of disability

3.2.1.2.1. Age at onset of disability

Debbie was diagnosed with cerebral palsy at birth. She believes that her mother was severely stressed during her pregnancy which might have caused the health condition.

3.2.1.2.2. Stability and chronicity

The medical diagnosis of her disability is spastic hemiplegia which affects both limbs on the left side of her body. She uses a crutch to aid her in walking. Over the years she has gradually acquired osteoarthritis which is accompanied by pain in her arms and knees. She experiences limitations with the following activities: getting in and out of bed, getting in and out of the bath, dressing, gaining access to buildings, negotiating stairs, mobility in and around the house, using kitchen utensils and cooking. Five years ago, she

was run over by a car and has since had a panic disorder which is managed with chronic medication, namely Rivetral and Edronax. Debbie feels that her condition has steadily deteriorated over the years: *“I wasn’t bad like this. I’m getting worse like before I did not need to walk with a crutch and I could go to the shopping centre on my own. I could take public transport on my own. I could cross roads on my own, but after Jeremy was born I started getting worse. Jeremy was about three years old when I started getting panic disorder and anxiety. I’m still a patient at the clinic. I still get medication. I was on Rivetral and Edronax but it was quite expensive so I could not get the medicine”*. She has undergone two operations, the first when she was 12 years old and the second when her children were aged five and one respectively. In addition, she explained that: *“When Jeremy was a baby I could pick him up and I could carry him. I put him in a pram and I would take him to the clinic. But now I don’t even think about picking up a baby. That’s why I’m saying my health has become weaker”*. Her general practitioner has advised her to use a wheelchair and not to walk anymore: *“But my GP also say that I should think of buying a wheelchair and using a wheelchair. He doesn’t want to walk anymore. I’ve got burning feet and things and he is scared that it will get worse. I can’t walk near the road without someone with me. It’s like I’m scared. I walk with the stick and I hold my husband or my sister. That’s why the doctor said that I should buy the wheelchair and then they can push me”*.

3.2.1.2.3. Overall psychological functioning

Debbie feels that her overall physical and psychological functioning has deteriorated over the years. She is falling down more frequently and is attempting to get a wheelchair which she feels will help her to move around better. Debbie suffers from panic disorder

due to an injury she sustained when she was hit by a car. She did not receive immediate treatment and gradually developed panic and anxiety at the thought of crossing roads independently: *“Since that time I’m suffering from anxiety and panic disorder and the cause of it the doctor says was when I was hit by a car here in the road. I just felt the knock and the car drove off. I did not bother to go to the doctor. Then after a year it started like I was almost scared from the road. I could not cross the road I was scared of the road and up till today I can’t do it. The doctor said it’s because I did not go to the doctor on that day. They had to give me an injection for the shock. Up till today I try to cross the road without being scared”*. Debbie’s anxiety and depression are exacerbated by the worry she feels about not earning an income at the moment.

3.2.1.3. The implications of the disability for maternal-adolescent relations

Debbie has explained to Jeremy what cerebral palsy is and its effects on the body. When asked whether she thought that her disability had an effect on the relationship she has with her adolescent son, she said that: *“At night he will make sure that everything is closed even if his father is here. He will see that the door is locked and if I ask for water he will put it there. He will clean the room and when I woke up yesterday, he was changed. He was different. I don’t know what was going through his mind. I got up yesterday and came to sit here and when I heard again the vacuum was on and he was vacuuming my room. He was making up my bed. They are very conscious when I am around. They don’t want me to fall or their daddy can’t talk too loud to me. If we argue Jeremy and his sister will come and say daddy why are you shouting or yelling? They are very sensitive about that. When I walk and he is around he will always like say I must keep his hand. He wants to take me there safe where I must be. He wants me to*

cross the road safely. Jeremy confirms that his mother has explained to him that her disability is a result of cerebral palsy and that she has been disabled since birth. He feels that the disability does not impact upon their relationship and explained that “*she does all the things other moms do and...she is a good mom*”. He further explained that she helps him with his school subjects: “*My mom. She’s very clever. My mom helps me with my maths and my Afrikaans and my life orientation*”.

3.2.1.3.1. Perceived positive effects associated with maternal disability

Debbie places great emphasis on educational progress and tries to instill this in her child. She would like to buy a printer for Jeremy to make his schoolwork interesting and motivate him to learn computer skills. Debbie has made several attempts to find a class photograph of the year when she matriculated as she feels that this might motivate her son to work towards completing matric: “*I want him also to love learning and love his school. I don’t want him to feel that school is not important. I told him now the other day that I don’t have a printer now but I want him to do certain things of his schoolwork on the computer so that he can get familiar with certain things and different programs. So my aim is to get a printer. I want to make school interesting for him. So you know if school is interesting for him then I’m sure that I don’t have to worry about him running away from school. Okay his friends are both now in grade 8, standard six and I want him to learn. I just want to make school interesting for him. I want him to look out for the next day and look forward to going to school the next day. For him it must be something new everyday. He must learn something everyday*”. When asked about his perception of positive effects associated with maternal disability, Jeremy explained: “*I can help her; help her go to where she wants to. I can help do the stuff that she want me to do.*”

3.2.1.3.2. Perceived negative effects associated with maternal disability

Debbie is concerned that her son is secretive and non-communicative. She said that he does not communicate openly and freely with her and this might be an indication that he does not feel loved and supported enough. Furthermore, she worries that he lacks opportunities for interesting experiences, which might contribute to substance abuse later on. She said that: *“The only thing that I would like to improve on is like to make life for him interesting. Because if life is interesting for him then he wouldn’t look to, why do children go to drugs? Because they don’t feel loved. I want him to feel all the love and all the support. So that they don’t have to go to their friends and drugs because they feel that they can’t speak to their mom. I want to improve on that”*.

The researcher asked Jeremy whether he could think of negative effects associated with maternal disability, and he replied: *“She can’t go opposite the street because when she’s in the street she’s nervous. When she’s inside now then she can’t also listen to loud music”*.

3.2.1.4. Disability-related stigma and the impact of the adolescent’s awareness of the mother’s difference on mother-adolescent relations

3.2.1.4.1. Stigma and courtesy stigma

Debbie mentioned numerous experiences of stigma, especially in the workplace. She feels that people treat her differently but reports that she has learnt to cope by ignoring

these incidents. Debbie's main supports are her sister-in-law and a female friend who lives nearby. She describes the community as helpful and caring and said that: *"I fell once here outside and then Jack struggled to pick me up and my neighbor jumped over his wall and he came to help me. And the time when I had the operation, Jack had to go to work and then Dial-a-Ride is here for me to pick me up to take me to the hospital and then the woman here opposite she used to come and help me because the wheelchair can't go out here at the door. So I used to fold it up and put it up outside the door and the woman used to come and help me"*.

Debbie feels that Jeremy has not experienced courtesy stigma and that his peers, family members or other people do not treat him differently because of her disability. She reported that he is popular with the other children. She said that: *"His relationship with others is very good, they like to come here. I think he mostly attracts them. Like you see his friends who come here to visit him. He's quite popular; I think he is open-minded with his friends. He can make very quick friends with these boys in the road here and nobody holds my disability against him"*.

She did, however, mention that Jeremy might withhold this type of information, as he does not always tell her what happens to him. She said that: *"Now Jeremy is someone like when someone fights with him in the road he wouldn't come and tell me. He will never ever come and tell me about it. I'll find out from somebody else and I'll deal with it"*.

With the exception of his aunt, Jeremy felt that the majority of his relatives do not treat his mother differently to how they treat the other family members. On the other hand, he

has noticed that other members of the community, particularly church-members, gossip about his mother's physical appearance. He expressed disappointment and anger that people would say things like: *"Like look how she look and stuff, stuff like that"*. Jeremy reported no personal experiences of courtesy stigma and feels that his friends, family members and other people do not treat him differently because of his mother's disability.

3.2.1.4.2. Relationships with others

The researcher asked whether maternal disability affected the kinds of relationships that Jeremy has with his peers, family members and other people. Debbie felt that Jeremy is popular with the boys in the neighbourhood and that her disability does not seem to affect his relationships with other people. When the researcher asked Jeremy whether his mother's disability affected his relationships with his peers, family members and other people, he said: *"The people who stay in this community here, almost all of them are my friends. Mostly the children come and sit here by me because my parents don't want me to go out in the street."*

3.2.1.5. The cumulative effect of the mother's disability, low socio-economic conditions and high-risk neighborhood characteristics on parenting, parent-adolescent relations and engagement in risky behaviour.

3.2.1.5.1. Parental involvement in the adolescent's activities

Debbie reported not participating in most of the children's school-related activities due to her activity limitations. She said that Jack attends the school functions and he

accompanies the children to fairs and other extramural activities. She explained that the family does not own a car and is reliant on public transport. Jeremy recognises that his mother is unable to be involved in his school activities as a result of the inaccessibility of the buildings: *“I think she would like to go there but there are too many stairs and stones to bump into”*.

3.2.1.5.2. *Quality of interaction*

Debbie feels that Jeremy trusts and respects her. On the other hand, one of her main concerns is that he is not completely honest with her and that he keeps secrets from her. The researcher asked Jeremy about the quality of their interaction and he said: *“I still respect her and love her for the person that she is and not for how she is and she, she still loves me. She’s still my mother and ja, that’s all”*.

3.2.1.5.3. Parenting practices

Debbie values education and tries to motivate Jeremy to do well in all his school subjects: *“I want him also to love learning and love his school. I want to make school interesting for him. So you know if school is interesting for him then I’m sure that I don’t have to worry about him running away from school”*. Jeremy acknowledges that his mother is concerned about his school performance. He mentioned that she keeps track of his work and tries to help with his homework: *“She always ask if I have school work and she always like tell me do you need help with something. Stuff like that. She will always encourage me to do something”*.

3.2.1.5.4. Parenting style

Debbie reported that she and her husband are Jeremy's main sources of support, advice, encouragement, praise and affection. Jeremy agreed that his parents are his most important source of support, advice, encouragement and praise. He said that he felt the most affection for his mother and that he would fight with his friends if they insulted his mother: *"I will fight with people, like my friends if they had to tell him that my mother is disabled. I am very for my mommy, and will always support my mommy. Like sometimes when there is a disagreement I will tell my father to stop because it is my mother"*.

Debbie explained that Jeremy is allowed to make his own decisions about most things. Jeremy, too feels that he is allowed to make decisions but that his mother also likes to give him advice. He said that: *"I decide about lots of stuff. Like clothes. Sometimes when I am dressing myself my mom says no not that clothes rather this clothes. She will say no, put that on because that suits you better"*. According to him, he listens to her when she gives him advice.

3.2.1.5.5. Monitoring and supervision

Debbie explained that Jeremy does not participate in many extra mural activities because the neighbourhood is too dangerous and they have to be more vigilant: *"This community don't let their children go play very far, because here is sometimes dangerous. There is gangsterism in the community and last year the gangs were shooting at each other in broad daylight. In the daytime there used to be shooting, gangsters at each other. But the police did come here. And nowadays it's fine. The police said that they have made peace now, but there are still drug houses and things here. People are selling drugs from their*

houses and things. Last year was really bad people were shooting and we had to close our doors and people were running away. It was terrible but this year it is still fine." She has also asked Jeremy not to play football since the football damages his shoes which is quite costly. She explained that: *"He comes home and he plays on the computer. He's actually mostly working on games on the computer. When the boys in the road come and ask him to go play football, then he will go with them. But I don't like him to go because they kick the ball and that breaks his shoes. That's why I rather say Jeremy stay here don't go play with the ball because the football is very hard. It's just two or three months then we will have to buy new shoes and you know how they say: money doesn't grow on our backs. We have to work very hard for it and then he understands. You must be open with your child; you must tell them the truth."* Jeremy is allowed to attend afternoon functions and is expected to be home by 7pm on weekdays and 8pm on Saturdays. He needs to request permission from his mother to attend school functions.

Debbie explained that she tries to deal with conflict situations by explaining to Jeremy why she disapproves about things: *"I speak a lot to my children. I tell them that they will get far if they are obedient. I tell them if they do their own thing they can turn out to be in big trouble. But so far I am happy with them. We always sort it out"*. The researcher asked Jeremy how he and his mother deal with conflict situations and he explained: *"Often, she sits down and discuss things with me. She does it a lot to me. First she like gets cross with me but after she has cooled down she will speak nicely to me and tell me this is wrong and then she explain why"*.

3.2.1.5.6. Inappropriate caring

Debbie reported struggling with life because of financial stress and the fact that her mother is not available to provide assistance. She mentioned that when she had to go to work, Jeremy was responsible for looking after himself and his younger sister: *“My mom stays very far. My other sister works now so she’s not at home. What I do seeing that Jeremy is now big enough is I leave them alone. They know that they mustn’t open the door for anybody. They know what to do when the phone ring”*. In most instances, Jeremy feels proud about assisting his mother but he also reports feeling sad about having to look after his younger sister. He said that: *“Sometimes I feel sad when she tells me that I must go look for Cheryl because she is opposite and then I must always go look for her”*.

3.2.1.5.7. Engagement in risky behaviour

The researcher asked Debbie whether she knows if Jeremy or his friends smoke tobacco, drink alcohol or use substances and she said no. She explained that she knows his friends and their parents because they belong to the same church group. She said that: *“There are two of them that come here. I don’t let him associate with anybody because you know this is a dangerous area and here the young children use drugs and so on. Jeremy likes music especially gospel music. Both of them are going to music lessons on Saturdays”*. Jeremy reported that neither his friends nor himself smokes tobacco, drinks alcohol or use other substances.

3.3. CASE THREE: Fairuz (M3) and Radia (C3)

3.3.1. Demographic, socio-economic and residential information

Fairuz is a 40-year-old, black woman who was born with cerebral palsy. She has spastic quadriplegia and speech impairment. Fairuz completed grade eight at a school catering for learners with special educational needs. Nine years ago, her first husband was killed in a drive-by shooting, just a short distance from their home. After four years she remarried and currently lives with her second husband, Faizel (45 years) and her 13-year-old daughter, Radia. Radia was four years old when she lost her father. Both mother and daughter were severely traumatised at the time. This tragedy plunged the family into severe financial difficulties for several years as Fairuz had no means of income besides a disability grant. After a long spell of unemployment, she managed to obtain a part-time job as a licence controller for the department of transport. The job is of a temporary nature and without benefits such as pension, sick leave and medical aid. She is currently the primary breadwinner of the family. Her husband has a psychiatric disability and is unemployed. He receives a disability grant of R740 per month, which contributes to the running of the household. Fairuz receives a monthly salary of R2 000, bringing their total monthly income to R 2 740. The income supports two adults and one child and is used to pay rent, water and electricity, car maintenance, food and clothing and school and medical expenses.

The family lives in a rented room containing a kitchen and small cubicle bathroom. The neighbourhood on the Cape Flats in which they live is characterised by high levels of unemployment, violence, crime and gangsterism. Official crime figures issued by the

South African Police Service (SAPS, 2006) indicate that in 2002/2003, 161 murders including attempted murders, 94 rapes, 978 assaults, and 202 drug related crimes were committed in this area.

Radia is a 13-year-old girl, who attends a Muslim college for girls. She is currently in grade seven and has never had to repeat a school year. Radia participates in drama at school and she plays volleyball. She also likes going on camps with her school-friends.

3.3.1.1. Family roles and responsibilities

At one stage Fairuz was receiving assistance from Mary, a 60-year-old, single mother who, at one stage along with her two daughters, shared the home of Fairuz, Faizel and Radia. According to Fairuz, Mary assisted her around the house and later became her trusted friend, making her confident that she could *“put her life in (Mary’s) hands.”* Eventually it became too difficult for the six people to live together in the one room: *“eventually you could notice the atmosphere wasn’t the same, and we were very sad when the carer and her family had to leave”*.

After Mary left, Fairuz’s partner, Faizel took on responsibility for the majority of household tasks. He does the cooking and cleaning with occasional assistance from Radia and provides personal care to Fairuz on a daily basis. The couple pays somebody to clean the windows and do the laundry twice a week.

3.3.1.2. Nature and features (severity) of disability

3.3.1.2.1. Age at onset of disability

Fairuz was diagnosed with cerebral palsy at birth. She believes that the cerebral palsy was caused by an injury occurring during the birthing process as opposed to genetic factors. The medical diagnosis of her disability is spastic quadriplegia which means that mobility in all four of her limbs is severely restricted. She uses a motorized wheelchair to move around and experiences limitations in the following activities: getting in and out of bed, getting in and out of the bath, bathing, dressing, gaining access to buildings, mobility in and around the house, getting clothes from cupboards, using kitchen utensils and cooking and eating independently. Fairuz needs a full-time carer to assist with all aspects of care. She reported feeling extreme anger, hurt and helplessness when people withhold assistance when she most needs it: *“like for instance somebody tells me if you don't give me that or do that then I won't take you out of the chair and put you into bed. Don't think it's going to break me. Then I just say you don't have to put me into bed, I can get into bed. Don't ask me how because when I'm angry I do much more than what I'm capable of doing. I go blank and then I don't care what happens. Whether I am going to sleep on the floor or whether I am able to get into bed on my own.”*

During her childhood, Fairuz attempted walking with various types of crutches, but eventually understood the severity of her disability and gradually accepted the need for a motorized wheelchair: *“at a very late stage in my life I actually started accepting the wheelchair. Although it was cerebral palsy and of course, in most cases in my understanding depending on the, the severity of your disability I think, especially being a quad one would require a chair. When I was much younger I didn't think with my*

understanding then that a wheelchair is meant for me. Do you know that at school? They tried all types of crutches, one hand, two hands all types”.

Fairuz feels that she is aging much faster as a result of her disability. Her condition is not accompanied by pain and she requires no medication except in the case of the occasional migraine. Her mental processes are unaffected.

3.3.1.2.2. Stability and chronicity

Despite having undergone numerous operations since infancy aimed at improving her movement, Fairuz feels that her disability has been degenerative. She explained that: *“after each operation I had I could do less. My pattern, the way it looks now, the way you see me now and if you had seen me then I looked pelvis up, pulled up but I could do anything. I remember staying with my granny. You now, in the old days stay in one big house and I remember. I remember that I would sweep the whole house for her and wash dishes, and would I get up to a chair, fall in a chair with no support. I could get in and out of the bath. I could sit by myself but after each operation I could do less.”*

3.3.1.2.3. Overall psychological functioning

Fairuz feels that her psychological functioning has deteriorated over the years. She expresses anger and disappointment about the fact that she is unable to do certain things for her child or partner due to her functional limitations. She explained that: *“what upsets me the most is I cannot enjoy the independence, to be independent as a mother and as how can I say, as a mother to do, to cook, or to do certain things for my child and for my partner because it’s limited.”*

3.3.1.3. The implications of the disability for maternal-adolescent relations

Fairuz described Radia as an intelligent child, who is understanding of her disability. She feels that Radia loves her very much and has mentioned that she would never swap her mother for another. When asked how she thinks maternal disability might affect Radia's relationship with her, she responded: *"I think it's as normal as a relationship between a normal woman and a normal child can be"*.

Radia is aware that her mother has cerebral palsy and has been disabled since birth. She said that the disability does not impact upon their relationship and explained that she accepts it as *"not like a big thing"*. While she acknowledges that her mother is unable to do a range of physical tasks for her, she feels that she is more equipped to do others: *"okay like she can't do some physical things but she can do other things that other people can't do for their children. It doesn't affect me."* The researcher asked about the effect of maternal disability on their relationship and she said that: *"I don't mind at all because like she's still a person and it's not, it's not like a big thing. It's my mommy and we are quite close to each other."*

3.3.1.3.1. Perceived positive effects associated with maternal disability

Fairuz was asked about Radia's perception of positive outcomes related to growing up with her mother's disability and she replied that it *"taught her to be independent, to make decisions for herself and never to take anything for granted"*. Asked about her perception of positive outcomes related to maternal disability, Radia said that: *"It opened my eyes to see how they work and they are also people like everybody else and (she's*

still), she's still a person. It's made me more supportive of disabled people. Like she raised me and I don't, it's, (I don't) hold her disability against her".

3.3.1.3.2. Perceived negative effects associated with maternal disability

Fairuz was asked about her perceptions of negative outcomes related to maternal disability and she said that: *"Negative criticism from people from the outside, the children at school. Okay, especially in the primary school. They really made life very tough for (Radia) and (ah), but I think that was more, more of about ignorance. People don't take the time or have the knowledge to know what it's all about. Let me think about something else. Ja, teasing"*. The researcher asked Radia about her perception of negative outcomes related to maternal disability and she said: *She couldn't do anything for me physically, but at least, ja but I knew that she loved me and she could raise me and she always found a way"*.

3.3.1.4. Disability-related stigma and the impact of the adolescent's awareness of the mother's difference on mother-adolescent relations.

3.3.1.4.1. Stigma and courtesy stigma

Fairuz mentioned numerous experiences of stigma, particularly from her immediate siblings. She explained that in the past, she had provided her brother with financial assistance and that *"he stabbed me in the back because he does not respect me because I am disabled"*. She also reported that her sister does not allow her to travel in her car

because she is afraid that the wheelchair might scratch the car. Other than those mentioned, Fairuz feels that the rest of the family treats her “*quite normally*”.

Fairuz felt that Radia is not the victim of courtesy stigma and that friends, family members and other people do not treat Radia differently to how they treat other children of the same age. Radia explained that her friends and other family members do not seem to treat her mother differently to how they treat mothers without disabilities. On the other hand, she does remember times when strangers have stared at or have treated her mother differently to how they treat people without disabilities. Radia feels that she does not experience courtesy stigma and that her friends, family members and other people do not treat her differently because of her mother’s disability.

3.3.1.4.2. Relationships with others

Fairuz expressed concern about Radia’s ability to relate to other people: “*When she (Radia) started High School, I was worried. She was the kind of child that was in a world of her own. She feared meeting people and new surroundings. Her life only revolved around me and school, and maybe my mother and my sisters. And then she always feared moving out of that circle. I was very worried, but it appears to me now that as she’s getting older it’s changing a lot*”. Radia herself does not feel that her mother’s disability affects the kinds of relationships that she is able to build with other people.

3.3.1.5. The cumulative effect of the mother's disability, low socio-economic conditions and high-risk neighbourhood characteristics on parenting, parent-adolescent relations and engagement in risky behaviour.

3.3.1.5.1. Parental involvement in adolescent's activities

Fairuz commented on how inaccessible transport systems have affected her ability to participate in activities with Radia. She said that: *"You won't believe. You don't how nice it is to have a car now, we can basically go anywhere. If we didn't have a car, I probably would go mad. The one time in the train I was getting out of the train and the train pulled away with the wheelchair clamped between the doors and we reported it to, what is this, Metrorail or whatever. We are still waiting to hear from them. It is about 2 years ago, 3 years ago. They don't even bother to, to return our calls which, I was nearly killed and I told Faizel if I can help it we'll never travel on public transport again. We now go with the car wherever we need to go otherwise we'll walk"*. Radia said that either her mother or Faizel ensures that she gets to school even on days when her mother is unwell. She explained that they encourage and assist her to attend camps and extra-curricular activities as and when organized by the school. She reported difficulties with using the public transport system when they need to attend events. Three years ago, after Fairuz started working, they were able to buy a car and their situation has consequently improved. She said that: *"We got a car about 6 months after she start working. That was about 3 year ago and since then we, we can do basically everything we want. We can go here, we can go there. Before that we had to travel on transport, taxis and buses it was terrible"*.

3.3.1.5.2. *Quality of interaction*

Fairuz thinks that Radia trusts and respects her: *“all I can say is that I know that she loves me dearly and I know she understands that I am special because she does say it, and she would often say to me, I wouldn't change mommy for any other mother”*. Radia says that she makes a distinction between the secrets she shares with her friends and those that she shares with her mother.

3.3.1.5.3. *Parenting practices*

Fairuz explained that she expects Radia to do very well at school. When asked how she ensures that Radia meets her expectations about her school performance she said that she does not withhold privileges as a behaviour management strategy: *“There's so little privileges that Radia has compared to many others in her surroundings, be it at school or in the family. Why I saying that is because all my life and even hers we've always had a limited space around us. For example, I don't have the money to say look here's pocket money and today, tomorrow or this week I'm taking away your pocket money if you don't do your work or don't study. There's not much I can take away from her because in the environment that we have at the moment it's only, the only pleasure we have is the T.V. and the computer and with the 3 of us being so limited and on top of each other”*.

Radia explained that her mother keeps track of her school performance in various ways: *“She always checks up what I am doing and she asks me if I have done my homework and sometimes she asks me about things at school”*. The researcher asked about her

mother's involvement in school-related tasks and she reported that: *"We always have time to spend with each other and she always asks when I have a project and she always encourages me and supports me and when I need help, she always helps me with my projects and assignments"*. Radia mentioned that her mother articulates her expectations regarding her academic performance and motivates her to try and do well. She explained that: *"Like the past years I've always been first, second, third, like that but not this year because there are more classes, more people and the competition is stronger"*. Radia feels that Fairuz's expectations about her school performance are reasonable *"in certain respects"* and says: *"She always tells me: You have done very well"*.

3.3.1.5.4. Parenting style

Fairuz reported that they have had a number of traumatic experiences over the years, but she feels that through communicating and supporting each other, they have managed to cope. She reported that she is Radia's main source of support, advice, encouragement, praise and affection: *"Between the two of us we spoke a lot, also about her father's death. We have always had to be there for each other. I think the way she accepted her father's death, to come to terms with it and the fact that she handles my disability is because the two of us have a very good communication line and always support each other"*. Radia agreed that her mother is her most important source of warmth, support, advice and encouragement. She said that she and her mother spend quality time together: *"We often sit down and talk about things"*. Radia compared their relationship to the relationship other children have with their mothers: *"me and my mother, we are closer, very close. She always tries to tell me it's not material things that spending quality time and, and being there and, and stuff is more important. So she always spend quality time*

with me and go somewhere and do stuff whatever". According to Fairuz, she allows Radia to make independent decisions and she tries to understand her choices: *"I believe that a mother should have a lot of love and you need to understand a child's behaviour or why a child reacts the way he does"*. Radia feels that her mother allows her to make her own decisions while at the same time guiding her through the decision-making process.

3.3.1.5.5. Monitoring and supervision

Fairuz explained that she knows most of Radia's friends and she always knows where she is and whom she is with. Radia is allowed to attend school functions and her stepfather collects her afterwards. She is not allowed to go out with people unknown to Fairuz. Radia is allowed to go out during the week and has a curfew of five o'clock on weekdays and eight o'clock on weekends. She is allowed to sleep over at friends' homes provided that her mother knows them. Fairuz feels that they do not deal with conflict situations very well and that she would like to improve on this: *"If she really doesn't want to do something then she will just ignore me. I can moan or turn blue, speak all the 11 languages that come to me. Radia is not a very difficult child. I think she's an easy child with discipline, but because of my physical circumstances, the environment and the cramped space we have got, it has a lot to do with it. It could improve"*. Fairuz feels that one of the key issues about disciplining Radia is her physical superiority: *"Maybe it's a problem because she can easily sort of take advantage or maybe I'm too weak to stop her. I don't know, and she can, she can get away with murder because she knows there's certain things that I cannot do that under normal circumstances she would not have gotten away with"*. Radia reported on how they deal

with conflict situations: *“Then she will explain why it is wrong, why is it helping me. It’s wrong or right and ask: how do you feel about it? and I will say oh now it makes more sense.”* She also mentioned times when their disagreements are not amicably resolved: *“Or I will just try more and more to have an argument with her and like debate the topic the whole time”*. She also reflected on those times when they have major disagreements. *“Sometimes she does scream at me about things that I have done wrong and when I get into trouble and just basically when I’m naughty, sometimes she’s reasonable, but sometimes it’s right what she does, but sometimes she shouts, but she doesn’t know the story properly so she shouts. But only afterwards then she will apologise afterwards if she was wrong”*. She explained how she feels about her mother’s behaviour: *“It makes me sad but sometimes she has just to listen like to my side of the story like what, like what happened really, what really happened rather than what she thought happened”*.

3.3.1.5.6. Inappropriate caring

Fairuz was asked whether Radia is expected to assist with caring tasks and she said that: *“She does not have to do any unless Faizel is away”*. Radia explained her ambivalence about not always being able to do things that she chooses to do. She said that: *“sometimes I mind if like I couldn’t, I can’t go somewhere because she’s either alone at home and she has to go somewhere. I can’t do something because she needs help”*. She also reported that she did not need to assist her mother as much when there was a carer: *“The situation was different when Mary used to live with us. It wasn’t so much to do taking care of mommy and there wasn’t really much to do like now”*.

3.3.1.5.7. Engagement in risky behaviour

The researcher asked Fairuz whether she knows if Radia or her friends smoke tobacco, drink alcohol or use substances and she said that they do not. She explained that she knows her friends and their parents because they live in the same area. Radia said that neither her nor her friends smoke tobacco, drink alcohol or use substances.

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3.4. CASE FOUR: Pearl (M4) and Sophie (C4)

3.4.1. Demographic, socio-economic and residential information

Pearl is a 50-year-old black woman who contracted polio at the age of 16 months. The medical diagnosis of her disability is paraplegia, and since she fractured her hand a few years ago she has used a wheelchair to move around. She is divorced from her first husband and lives with her 13-year-old daughter, Sophie. Pearl completed grade eight at a school catering for learners with special educational needs. She has worked as a telephonist for a non-governmental organisation which provides services to disabled people for ten years. She receives a monthly salary of R 2 000 but no benefits such as pension, sick leave and medical aid. Pearl and Sophie used to live with Pearl's brother in their parents' home. In 1980, when her father died, her brother bought the house. For a while, the two families shared the house but eventually the mother and child moved out after the brother's wife developed a drinking problem. Sophie explained that: *"there can be no other term for it because every weekend she was drunk so, you know, that was the only thorn in my side there"*. In 2000, the family moved into a residential care centre for people with disabilities who have nowhere else to live. The centre accommodates twenty other individuals and families where either one or both parents have disabilities. Meals are prepared by fulltime staff-members, and their laundry gets done once a week. They pay R1000 per month for their accommodation. The rest of the income is used for transport expenses, clothes, school and medical expenses. Neither Pearl nor Sophie has any contact with Sophie's father and he provides no maintenance or emotional support to them. The residential centre is in an area characterised by high levels of unemployment, drug abuse, violence and crime. Official crime figures issued by the South African

Police Service (SAPS, 2006) indicate that in 2002/2003, 82 murders including attempted murders, 49 rapes, 694 assaults, and 235 drug related crimes were committed in this area. On the other hand, this is much higher than the 2 murders including attempted murders, 4 rapes, 57 assaults, and 13 drug related crimes committed in a nearby wealthier residential area.

Sophie is 13 years old and attends a high school for girls. She is currently in grade six and has never had to repeat a school year. When she was eight years old, Sophie's family was asked to leave their home and to move into a residential care facility for people with disabilities. At the time of the interviews, Sophie and her mother shared a bedroom in the centre. Sophie participates in extra-curricular activities such as concerts and plays. Sophie's parents were divorced when she was a baby and she has never met her father.

3.4.1.1. Family roles and responsibilities

Neither Pearl nor Sophie has to perform any household tasks as the centre's staff do the cooking, laundry, cleaning and shopping. Because she likes children, Sophie cares for one of the other resident's two-year-old son after school and on weekends. Pearl explained that her mother was instrumental in caring for Sophie for the first two and a half years of her life: *"I was a single mom with crutches so my mom helped me. She was just there for 2½ years. Then she passed away. At first, for the first 6 months, my mommy helped me. She used to wet her for me, then I'd take her and soap her, and she would rinse her, then I would dry her and dress her on the bed, 'cause I can't stand. I can't balance, you see, so I can't stand and so she helped me"*. As Sophie became more

independent Pearl gradually started doing more of the caring: *“Ja, but when she was 6 months old, she could sit fine. I took over from there. I did everything”*. When Sophie was about 2 and a half years old her grandmother passed away and Pearl did all the caring: *“When my mom wasn’t there, I saw to her. I saw to her myself up till today”*. When Sophie was a toddler, a family friend was her main source of support in caring for Sophie. Pearl explained how the inaccessibility of the primary school restricted her participation in Sophie’s education: *“Well, the school isn’t, but I just about managed the steps. There are a lot of steps there. Even to her class. I couldn’t go to her classroom because of the steps you know”*.

3.4.1.2. Nature and features (severity) of disability

3.4.1.2.1. Age at onset of disability

Pearl experiences limitations with the following activities: getting in and out of bed, getting in and out of the bath, dressing, gaining access to buildings, mobility in and around the house, getting clothes from cupboards, reaching kitchen cupboards, using kitchen utensils and cooking. The nature of her disability changed after an accident: *“I had crutches. I had a slight fracture in 1988, so since then I’ve been using the wheelchair. I fell and fractured my left hand. So I had to struggle along for 6 weeks without, you know, managing like that, so then I started with the wheelchair”*.

3.4.1.2.2. *Stability and chronicity*

Pearl describes her disability as stable and chronic and as affecting her movement; her mental processes are unaffected.

3.4.1.2.3. *Overall psychological functioning*

Pearl's overall psychological functioning is excellent. She presented as a mature, articulate person who seemed to be a loving, responsive mother. It was clear that she spends considerable time thinking about her daughter's future.

3.4.1.3. *The implications of the disability for maternal-adolescent relations*

Pearl reported that she has always had a very close relationship with her daughter: *"I married her father shortly after I fell pregnant but the marriage did not work out. Ever since it's just the two of us. We laugh and joke and try to enjoy life despite everything"*.

When asked how she thought Sophie feels about her disability, she explained that: *"There were times when she was still younger and she used to ask why don't you wear other shoes? I then explained to her about polio and she seemed satisfied"*. Sophie explained that she does not have any knowledge about the cause of her mothers' disability since her teacher has not explained it: *"My teacher never told us about polio, so I don't really know."* When asked how she feels about her mother having a disability, Sophie replied: *"I feel alright with it"*. The researcher also asked how she felt her mother's disability affected her, and Sophie responded: *"It doesn't, I feel good about myself"*.

3.4.1.3.1. Perceived positive effects associated with maternal disability

Pearl feels that having grown up with a disabled mother has taught her daughter to be more independent and caring. Sophie feels that her mother is better than other mothers: *“My mommy is very kind and she’s loving. Not like some women that abuse their children. When I went to my friend’s house and so her mommy, her mommy grabbed her and took her and hit her with a broomstick”*.

3.4.1.3.2. Perceived negative effects associated with maternal disability

Pearl does not think that being raised by a mother with a disability has impacted negatively on Sophie: *“No. I don’t think so”*. She explained the difficulties of single parenthood: *“Because I tell you one thing it’s not easy. It’s not easy being a disabled parent. Being a parent is hard enough, but a disabled parent and especially when you’ve got to be mother and father I mean, it’s no joke at all. But anyway I hope we can overcome that and move forward”*. Sophie feels that one of the negative things about having a mother with a disability is that they cannot go out as often as they would like to: *“The one thing is that because of the wheelchair we don’t go out a lot, you see because it’s quite a distance from here”*. She is hopeful that this will change soon, however: *“Do you see that mall they are building? My mommy said that when that is finished then she say we must make time to go there because we hardly ever do it because my mommy’s wheelchair is heavy and I can’t, I can hardly push her”*.

3.4.1.4. Disability-related stigma and the impact of the adolescent’s awareness of the mother’s difference on mother-adolescent relations

3.4.1.4.1. Stigma and courtesy stigma

Pearl was asked whether she has experienced incidences of stigma and she reflected that both her siblings and later on her employer have treated her differently to how they treat other people without disabilities: *“Sometimes they speak to me as if I am retarded. Like I can’t understand them or like I’m stupid or whatever”*. Pearl did not think that people treated Sophie differently to how they treat other children of the same age. Asked whether she felt that her friends treated her mother differently to how they treat other mothers, Sophie said: *“They won’t. My friends aren’t like that, you see. I don’t choose friends that, that make fun or something. I know which friends to choose, you see. Like good manners, kind, and that help disabled people”*. Sophie felt that her mother has been the victim of stigma and she reported that one of her mother’s brother’s had treated her mother very badly because of the disability. She said: *“Only my uncle. He used to swear at my mommy. So he was the only one that did that”*.

3.4.1.4.2. Relationships with others

Pearl reported that her disability does not affect Sophie’s relationship with other people: *“She doesn’t really have lot of friends at home because we are just basically inside. She has a friend down the road who used to come sometimes and she used to go to her. She’s got a lot of friends at school”*. Sophie explained that her mother’s disability does not affect her relationships with other people: *“I told my friends already but we still play together and chat so I’m still good friends with people”*.

3.4.1.5. The cumulative effect of the mother's disability, low socio-economic conditions and neighbourhood characteristics on parenting, parent-adolescent relations and engagement in risky behaviour.

3.4.1.5.1. Parental involvement in adolescent's activities

Pearl explained that Sophie remains after school to participate in extra-mural activities and after that, she takes the bus home: *"I used to go to watch her but not since we moved in here. She started traveling alone actually since last year. April, she started travelling on her own. She used to go with me on the Dial-A-Ride in the afternoons, but it was a bit too much actually, finance wise. But, you know, for the two of us it's R8 there and R8 back at a time. So now she goes alone. If we had a system in place to give the necessary assistance and a mother with a disability or anybody for that matter with a disability or have dreams and wishes in life and there was a system that you could go to and assist your children to achieve whatever you dream for them"*. Sophie reports that she and her mother enjoyed a number of activities together. She said that: *"When we used to live in the other area we used to bake cakes and biscuits and only once we cooked some chips"*.

3.4.1.5.2. Quality of interaction

Pearl feels that Sophie respects, trusts and shares secrets with her: *"Yes, I think she trusts me. I always tell her, confide in me. I'm your mother. Come tell me if you see something that doesn't make you happy and I'll see what I can do. Then she will tell me, she doesn't have anybody else. We've only got each other"*. Sophie believes that she and

her mother respect each other since they share secrets with each other. She expressed reluctance to hide information from her mother. She said that: *“I tell her everything that happens because I must tell her. I don’t like not telling her”*. Sophie feels that she has an open and honest relationship with her mother and that they are able to communicate openly about everything. Both mother and daughter agreed that Sophie is allowed to make her own decisions about most things.

3.4.1.5.3. Parenting practices

Pearl does not attend school events due to transport difficulties: *“No, I don’t attend any of the functions at the school. There is no access to the school. There are stairs and I can’t manage that. When there is a problem, I usually call the teachers. Then my brother gives me a lift because his daughter is at the same school. I sometimes phone the vice-principal. They also got my number and they know that it’s difficult for me to come to school, so they phone me otherwise”*. Pearl assists Sophie with her schoolwork and is concerned about her daughter’s progress. Despite the inaccessibility of the school building, Pearl attempts to keep track of Sophie’s educational performance by phoning the relevant teachers to make enquiries.

3.4.1.5.4. Parenting style

Pearl reported that she is Sophie’s main source of support, advice, encouragement, praise and affection. She feels that they get on extremely well. She said that: *“You know we get on so well. We sit in front of the television and chat and watch and laugh at things and so on”*. Sophie described her relationship with her mother as being *“much stronger than*

the other peoples' relationships". She attributes this to being honest; taking care of each other; being open with each other; being positive and not negative and speaking to each other properly. Asked how she thought her mother's disability affected their relationship, Sophie stated that: "Even though she has a disability I still love her very much."

3.4.1.5.5. Monitoring and supervision

Pearl tries to keep track of Sophie's social life: *"She has a few friends. I know her friends by name. When she comes back, I usually ask her by what friend were you? What's her name and what were you doing?"* Sophie reported that her mother generally prefers to know where she goes and who accompanies her. With the exception of friends at school, Pearl knows the friends who live near to the centre. Sophie has a curfew of 10 pm on Fridays and Saturdays. Her mother reprimands her when she arrives home later than this.

Pearl explained that she talks to her daughter about disagreements and she does not believe in physical punishment: *"That's why I don't believe in hitting Sophie because I might just overstep the mark and that will be abuse, you see. Okay, verbal abuse is bad enough but once you start using your fist for hitting. No, it just doesn't work. So that is why I practice that. From a early age I've spoken to her. We had our talks. If I'm upset about something then I will tell her. I don't think you should, you should have done that and then it's fine. Just get it off our chest".* Sophie explained that during disagreements, Pearl raises her voice and that she feels hurt by this behaviour. She also said that her mother gives reasons why she disapproves of certain things and normally tells her when

she does something wrong so that she will “*know for next time*”. Sophie explained that she feels understood by her mother.

3.4.1.5.6. Inappropriate caring

Pearl reported that Sophie is not responsible for caring for her. She mentioned that Sophie does make the bed and also assists with getting clothes out of the cupboard, but said: “*I don't think she has an unreasonable workload. She must have some chores. She does much less chores than any of my brother's children*”. Sophie assists her mother with dressing and making the bed. She voluntarily assists with some of the housework and the laundry.

3.4.1.5.7. Engagement in risky behaviour

The researcher asked Pearl whether she knew if Sophie or her friends smoke tobacco, drink alcohol or use substances and she said no. She believes that Sophie is a pro-social adolescent who likes to achieve at school. The researcher asked Sophie whether she or her friends smoke tobacco, drink alcohol or use substances and she said no.

3.5. CASE FIVE: Magdalene (M5) and Eileen (C5)

3.5.1. Demographic, socio-economic and residential information

Magdalene is a 40-year-old black woman who is disabled as the result of a serious car accident which occurred when she was 30 years old. Two other passengers were killed in the accident. Magdalene has right hemiplegia and speech impairment. She uses crutches to aid her mobility. Magdalene lives with her husband, Elliot (52 years) and her daughter Eileen (15 years), who was 5 years old at the time that her mother became disabled. Magdalene completed grade eight in a mainstream school. She has battled to find employment and presently holds a contract position at a protective workshop. She earns a monthly salary of R500 and a disability grant of R500. Magdalene and Elliot met five years ago while working at the workshop and married shortly afterward. Elliot has a mild intellectual disability, but after some training has moved on to employment in the open labour market. He earns a monthly salary of R1 200 bringing their total income to R2 200 per month. This income supports two adults and one child and is used to pay rent, water and electricity, food and clothing, school and medical expenses.

Magdalene was not married to the father of her daughter. Neither Magdalene nor Eileen has any contact with Eileen's father and he provides no financial support. According to Magdalene, Elliot's family live in the same neighbourhood but do not provide support to her family. The couple live with their daughter in a rented wooden wendy-house in a backyard. Their neighbourhood is characterised by high levels of unemployment, violence, crime, gangsterism and substance abuse. Official crime figures issued by the South African Police Service (SAPS, 2006) indicate that in 2002/2003, 34 murders

including attempted murders, 27 rapes, 499 assaults, and 25 drug related crimes were committed in this area. This is in stark contrast to the 4 murders including attempted murders, 7 rapes, 75 assaults, and 14 drug related crimes committed in a comparably wealthier residential area .

Eileen is a 15-year-old girl who is currently not attending school. She plans to try to find some money in order to enroll in a secretarial course at a private college. As a young child, she was very ill and still has asthma. Eileen said that she never enjoyed school because the teachers were too strict. At the moment, she performs the majority of the household tasks and responsibilities when her parents are both at work during the day.

3.5.1.1. Family roles and responsibilities

While in grade 7, Eileen decided to drop out of school. She is responsible for most of the household tasks like cleaning, cooking and doing the laundry while both her parents are at work. At the end of each month, Eileen assists her father with the shopping.

3.5.1.2. Nature and features (severity) of disability

3.5.1.2.1. Age at onset of disability

Magdalene wears a calliper and uses crutches to aid her in walking. Her disability is accompanied by pain in her arms and knees. She experiences limitations with the following activities: communicating with people, being understood by others,

participating in employment, mobility in and around the place of employment, getting in and out of bed, getting in and out of the bath, dressing, gaining access to buildings, negotiating stairs, moving in and around the house, safety in the kitchen, using kitchen utensils and cooking.

3.5.1.2.2. Stability and chronicity

After the accident, Magdalene underwent a long period of rehabilitation which helped her to regain a certain sense of independence. She describes her disability as stable and chronic, and as affecting her movement and her speech. Her mental processes are unaffected.

3.5.1.2.3. Overall psychological functioning

Magdalene feels that with age, her overall psychological functioning has deteriorated. She feels that she is slower and that people have more difficulty understanding her speech. Magdalene presents as quiet and soft-spoken.

3.5.1.3. The implications of the disability for maternal-adolescent relations

Magdalene was asked about her perception of the relationship with her daughter. She described Eileen as understanding and accepting of her disability. She feels, however, that their relationship is conflictual and describes Eileen as a stubborn adolescent: “*She will spend most of her time with her buddies but she does not speak to me. Eileen does not share things with me. Whenever she gets the chance then it's to her friends. She will*

never ask me about things but only her friends". Magdalene explained that despite her warnings, Eileen became friends with the wrong group of girls, then started smoking and drinking and eventually dropped out of school.

Eileen knows and understands that her mother has a physical disability. The researcher asked her about her feelings about her mother's disability and she said: *"What do I know? My mother is a normal person just like me. She only has impairment. There is nothing wrong with her. She is just like everybody else. I do not see anything wrong with that."*

3.5.1.3.1. Perceived positive effects associated with maternal disability

Magdalene explained that Eileen has been around people with disabilities since she was small, and that this has taught her to be comfortable with disability. She said that: *"You know, for me since she was little I educated her regarding my disability. What she shouldn't worry about, what he shouldn't take notice of and all those type of things. I think she was 4 or 5 when I started working here, so ever since that time when we had functions or stuff she comes too. So she mix with different types of persons with disabilities. It's not that she doesn't know anybody besides her mother that has got a disability. I mean she got along with the people and stuff like that"*. Eileen explained that growing up with a mother with a disability has made her different to her friends. She said that she thinks more about things than her friends and she feels more mature. She explained: *"A lot of times when we are sitting then they will say something and then I don't agree. Then I think I don't think the same as them. Then I am just quiet and they ask me what's wrong"*.

3.5.1.3.2. Perceived negative effects associated with maternal disability

Magdalene does not feel that being raised by a disabled mother has impacted negatively on Eileen. Similarly, Eileen does not feel that being raised by a mom with a disability has impacted negatively on her.

3.5.1.4. Disability-related stigma and the impact of the adolescent's awareness on mother-adolescent relations

3.5.1.4.1. Stigma and courtesy stigma

Magdalene was asked whether she has experienced incidences of stigma. She feels that her husband's sisters try to tell her what she needs to do as if she has a mental disability: *"Then they come into my house and tell me this and that. But I tell them that this is my place and I will decide"*. Magdalene explained that there were times when Eileen told her that other people were mocking her (Magdalene). She reported explaining to Eileen that despite her disability she still tries to provide for her: *"There was occasions when she was small and she came to me and say, Mommy they are making fun of you. Then I needed to inspire her and motivate her where I'm concerned. I said you've got a mother whether she's disabled or not, but she can do this for herself, she can do that for herself, and there is lazy people that can use every limb of their body but they, they just don't want to do it. So why worry what other people say about your mother basically"*. Magdalene has not seen people treat Eileen differently to how they treat other children of the same age. When asked whether she thinks Eileen might be the victim of courtesy stigma, she explained: *"No, not that I have seen. With the friends that I've seen her*

interacting with she's always like the top one". Eileen reports having seen other people mock her mother. She said: "Me, What could I have against her? She's just the same as us. There are a few people, who make jokes about my mom, and then I stress and I get angry. And then I say: I don't know why you take my mom for a joke, because she's a person just like we are". On the other hand, Eileen did not recall any experiences of courtesy stigma because of her mother's disability.

3.5.1.4.2. Relationships with others

Magdalene explained that her disability might impact on the relationships that Eileen has with others, but that Eileen does not tell her about it. She said that: *"It could have with some children because I mean really as grown ups if somebody says something to you, you don't tend to forget easily so what about kids, you know. Do they ever forget that that child said something about the parent? In our area, especially they have this thing that they swear at each other but she would not tell me about it".* Eileen reported that her mother's disability has not impacted on her relationships with other people.

3.5.1.5. The cumulative effect of the mother's disability, low socio-economic conditions and high-risk neighborhood characteristics on parenting, parent-adolescent relations and engagement in risky behaviour.

3.5.1.5.1. Parental involvement in adolescent's activities

Magdalene explained that since Eileen has dropped out of school, it is very difficult to know what she is getting involved with. She said that: *"I think the cause is that she is not*

attending school. So last Thursday and Friday last week, she slept at her friends and the Friday morning her father went down to them to find out what is this child's problem. But like I said I don't know". Eileen was asked about her perception of their relationship and she responded: "My relationship with my mother? Many times, I don't feel the same. Then it looks to me as if my mother prefers other people above me. If I ask her for something then she does not want to give it. If other people ask her then she gives it to them. Many times then I don't tell them that I'm sleeping out, then I sleep out and I only come home the next day".

3.5.1.5.2. Quality of interaction

Magdalene was asked who Eileen most respects and trusts: *"I cannot really say. But her friends do care about her. Sometimes she goes to her friends for social events. And sometimes then she comes back home and then I can see that she has changed quite a lot and so on".* Magdalene was asked who Eileen shares secrets with and she said: *"She will tell her friends but not me".* Magdalene explained that she has always allowed Eileen to make her own decisions. Eileen said that she respects both her parents and she feels that she can trust and share secrets with her mother. She feels that she can ask her mother for guidance and that she helps her to make decisions. She explained: *"My mother. Like is this right or is this not right or what must I wear?"*.

3.5.1.5.3. Parenting practices

Eileen explained that her parents are her most important source of acceptance. She said that she and her mother do spend quality time together: *"We often sit down and talk*

about things". When she was asked about the people who support her, Eileen said: *"My mother and my father. They support me when I ask them for something. When we used to go out to school concerts and things, they used to come with me"*.

3.5.1.5.4. Parenting style

Magdalene explained that Eileen has always been quite independent and does not get close to people. Magdalene feels that people do not encourage or praise Eileen because she is a loner. When asked who does encourage and/or praise Eileen, she said: *"There is no people who encourage her. I do not know which people praise or say something nice to her"*. Eileen explained that she prefers to ask her father for advice because she feels that her mother does not listen to her: *"My father. Because when I ask my mother, then she does not want to listen to me"*. On the other hand, she does feel that her mother encourages her to do things: *"My mother, she tells me how to do things and if I don't do it, then I feel bad about not doing it"*.

3.5.1.5.5. Monitoring and supervision

Magdalene does not know all her daughter's friends and does not always know where she is. She tries to find out about Eileen's friends and their families: *"I tell her everyday, I mean every where you go, you get gangsters every where but especially in this area. I grew up in this area. I was born here, not in a hospital. And I mean because they are targeting her now because she comes out of a gangster area. But she hasn't come to that point where she listens to me about where she is going and who she is with. So I don't have an idea"*. Magdalene reported that Eileen does not obey the curfew which has been

CHAPTER 4: DISCUSSION AND CONCLUSION

The primary objective of this exploratory study was to investigate the impact of maternal physical disability on perceptions of the mother-adolescent relationship, parenting and the well-being of black adolescents from low socio-economic backgrounds. The present study has contributed to the field of disability studies, generally an under-researched field both internationally and locally, as well as to developmental psychology in two ways. Firstly, it assisted in conceptualizing an area of increased importance due to the marked increase in women with disabilities becoming mothers and with this the impact of disability on children. Secondly, it incorporated the views of the adolescents themselves as they reflected on their perceptions of the effect of maternal disability on parenting and the mother-adolescent relationship. The use of the case study method allowed for full consideration of all the variables related to the various processes considered relevant to the parenting of adolescents.

The thesis does have several limitations, however, and the results should be evaluated in the light of these. The small sample size and the fact that the sample of mother-adolescent dyads was not randomly selected means that the study findings cannot be generalised to all children of mothers with physical disabilities in other communities, and elsewhere in South Africa. As the participating children were all between the ages of 12 and 15, this study could not investigate age-related changes in children's

set for her. Eileen explained that her parents do know her friends and that she always introduces them to her mother when they come to fetch her from home. She reported that her parents expect her to be home at 12 pm on weekends and 10 pm during the week. When asked whether they are consistent about her curfew she said that they understand when she gets home at 11pm on weekdays. However, on an earlier occasion, she said that they reprimand her when she does not adhere to her curfew.

Magdalene was asked how she deals with reprimanding Eileen and how she resolves conflicts; she said that Eileen always believes that her mother is wrong: *"When I disagree with her then she says why are you like this. Mommy is always so wrong. Then she raises her voice or she says something that I do not like"*. She also explained that they sometimes shout at each other when they have a disagreement about something. Magdalene said that she mostly shouts at Eileen who in return laughs at her, further infuriating her: *"Then I say, Eileen why are you laughing at me, I am your mother. Then she calls me on my name and she says you are very wrong"*. Magdalene explained that she knows that this is not the best way to deal with Eileen but she does not know what else to do. Eileen reported that sometimes her mother calls her to one side and explains why she disagrees with certain decisions: *"she will say you shouldn't have done this now. If you didn't do this then things would not be like this."* She also said that her mother often yells at her when they disagree. According to her, they always sort it out and *"after then we are fine, and we talk just like we did before"*.

3.5.1.5.6. *Inappropriate caring*

Eileen reported that she assists her mother with certain caring tasks: “*I enjoy helping her with certain things that she can't do for herself*”.

3.5.1.5.7. *Engagement in risky behaviour*

Magdalene was asked whether she knew if Eileen smoked, drank alcohol or used other substances and she said that she did not know. Similarly, Eileen was asked whether she or her friends smoked, drank alcohol or used other substances and she said: “*we only smoke cigarettes and drink one or two beers, but only on weekends. Some of the other girls but not my friends drink during the week also*”.

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perceptions of, and responses to maternal disability. Also, some of the methodological limitations of the study included the fact that the researcher is a black woman with a physical disability. This could have impacted on the primary data collection process in both positive and negative ways. For instance, the adolescents might have withheld important information in an attempt to present their mothers in a positive light. On the other hand, had the researcher not been a black woman with a physical disability, some of the crucial issues that bear on the parenting situation of women with physical disabilities may not have been openly discussed and much less rich material would have been generated.

However, despite the limitations mentioned earlier, the study serves to illustrate a set of dynamics and experiences, which can be explored in future research. The data highlighted the complex way in which maternal disability intersects with parenting, specifically within high-risk contexts. For the families in this study, longstanding difficulties such as parental divorce, absent fathers, conflictual familial relationships, multiple losses in the adolescents' lives and high exposure to community violence contribute to the kinds of relationships the mothers have with their adolescents. Also, the effect of maternal disability is embedded in a broader context where the mother's health condition with related impairments transact with person level activities as well as environmental factors to determine the extent to which the mother participates in the mothering process. Overall, the results indicated that factors external to the disability including the parent's and child's personalities, low socio-economic status, inadequate service provision and lack of support systems combined to render these families highly vulnerable in some areas, with unexpected strengths in others.

As suggested by other authors, very little is known about why parents choose specific parenting styles and the results indicated that individual parenting behaviour forms part of a milieu of other patterns of behaviour influenced by a range of factors (Darling & Steinberg, 1993). As early as 1936, it was noted that: “It is possible for the child to take a great deal of rather crude cuffing and spanking and still feel so fully the affection and warmth of the parents’ concern that no harm results. And it is possible for parents to do the technically correct thing with so little apparent affection that even their kind and patient words leave the child cold as well as confused and resentful” (Greenberg and Others of the Staff of the Child Study Association of America, 1936, as cited in Darling and Steinberg, 1993, p. 488). It is therefore reductionist to suggest that there is a clear unidirectional relationship between maternal physical disability and parenting style.

This section discusses the findings based on the results from the case histories in Chapter 3. It begins with the adolescent’s understanding of the mother’s disability in Section 4.1, and then proceeds to examine the likely impact on family roles and the adolescent’s caregiving duties in Section 4.2. Section 4.3 discusses the impact of the disability on the mother-adolescent relationship, followed by the factors associated with individual differences in the quality of the relationship in Section 4.3.1. Mother-adolescent conflict is examined in Section 4.4 and the implications of stigma for the mother-adolescent relationship are examined in Section 4.5. This is followed by the ways in which the mother’s disability, and other contextual factors, affect the mother’s involvement in the adolescent’s school and other activities in Section 4.6, followed by monitoring and supervision in Section 4.7 and the adolescent’s engagement in risky behaviour in Section 4.8. Lastly, recommendations for future

research are discussed in Section 4.9, followed by concluding remarks in Section 4.10.

4.1. The adolescent's understanding of their mother's disability

The results confirm that adolescents between the ages of 12 and 15 understand maternal disability in a manner appropriate to their developmental and cognitive capabilities. In particular, their appraisal of the experience is largely determined by their capacity for abstract reasoning. This finding is in accord with the literature which suggests that children understand and make sense of their mothers' health conditions in developmentally appropriate ways (Compas, et al., 1994; Newman, 2003). Maternal disability appears, from the data, to affect children differently depending on their age, as confirmed by findings of other studies (Prilleltensky, 2004). When asked what they knew about their mother's disabilities, four of the adolescents indicated that they had some knowledge of their mothers' health condition and understood the reasons for the disabilities. Sophie, aged 13, indicated that despite having learnt about her mother's disability in school she could not remember any information about it. The girl's lack of memory related to the disability could be attributable to having accepted it as "matter of fact". An alternative explanation includes the possible avoidance and repression of painful and anxiety provoking thoughts as defence mechanisms. One of the older adolescents in the study, Angus (15 years old), made reference to religious faith and has searched for meaning in a spiritual way: "It's the way God sent her to me". At the same time he reflects on occasional feelings of sadness, disappointment and a sense of uniqueness about the experience: "But sometimes, it makes me sad and I ask myself why the Lord gave me a

mother like that". This adolescent seems to be employing emotion-focused coping efforts to deal with his mother's disability, possibly because he feels unable to control the situation where his mother appears physically vulnerable (Worsham, Compas & Ey, 1997).

4.2. The impact on family roles and the adolescent's caregiving duties

Apart from Eileen, one of the older girls, the other four adolescents interviewed felt that they were not required to provide inappropriate care to their mothers. While they did play an active part in managing some aspects of household tasks, this was not associated with the provision of emotionally taxing and burdensome caring tasks as identified by the young carer's literature (Noble-Carr, 2002; Petersen, 1991). Most of the families indicated that there is an inevitable change in the traditional, customary roles ascribed to the different family members. As roles change there are shifts in the division of labour, with the adolescents being incorporated into some of the household chores and responsibilities. As expected, the extent of this is largely determined by the severity of the activity limitations and the affected processes of the mother. Looking specifically at the case of Eileen, one possible explanation for the degradation of the parent-adolescent relationship in this family might relate to the fact that both parents have disabilities with the adolescent taking responsibility for the majority of household tasks, which causes her to feel overburdened. This finding is consistent with Newman's (2003) finding that parental disability appears to affect children differently depending on their age and gender, with girls appearing to be the child subset most at risk due to the greater likelihood of their being elected into caring roles.

Jeremy, one of the younger adolescents, exemplifies the complexity about asking children for physical assistance. He expressed pride about his ability to help his mother, but on the other hand he also feels sad about having to collect his younger sister from the neighbours. As noted by other authors, the impact of requesting assistance from children is not clear and it is recommended that parents pay particular attention to both the frequency and the context in which it is occurring, as well as whether the children themselves experience this as burdensome (Cohen, 1998; Greer, 1985).

4.3. The impact of the disability on the mother-adolescent relationship

Perceptions of the redefinition of family roles indicated that children born to mothers with physical disabilities adopt a Cartesian dualistic approach to parenting. They show the unique ability to split motherhood into non-essential tasks associated with physical activities whilst retaining the essence of motherhood as the ability to make children feel loved. This theme runs through most of the case histories, and is most clearly articulated by two thirteen-year-olds who responded as follows: *“it doesn't matter that my mother can't do anything physically...I still respect and love her”* (Jeremy) and, *“ She (my mother) couldn't do anything for me physically...but I knew that she loved me...”* (Radia). Another possible explanation might be that the children develop the capacity to look beyond the mother's activity limitations to their ability to participate in creating loving and respectful relationships.

Looking specifically at the likely impact of disability, one of the older adolescents illustrates the dynamic and changing nature of the mother-adolescent relationship as

the child goes through different developmental stages. Angus says: “*we were shy to walk in the road with her sometimes. But not now, I’m over it now*”. With the exception of one adolescent, Sophie, all the adolescents downplayed the mothers’ disability status and shifted attention to motherhood as part of the women’s identities. Two other adolescents, Jeremy, aged 12 and Eileen, aged 15 employed subjective comparative measures and declared that their mothers are “*just like*” and perform “*all the other things*” that mothers without disabilities do. Jeremy then goes on to cite examples of his mother’s competence such as being clever and assisting him with his schoolwork. In doing this the adolescents challenge the notion of otherness due to physical difference, attempting to protect and defend their mothers from societal judgments where difference might be pathologised and treated as evidence of incompetence.

4.3.1. Factors associated with individual differences in the relationship quality

Looking at the data in the five cases as a whole there is sufficient evidence to suggest that within each family, there are a number of processes which mediate the impact of maternal disability on the mother-adolescent relationship.

4.3.1.1. General family functioning

The majority of the adolescents in this study reported feeling loved and emotionally supported. They often describe their mothers as their primary source of advice, encouragement, praise and affection. Maternal disability does not appear, from the

data in four cases, to impact negatively on the adolescent's perception of the parent-adolescent relationship. We see an exception to this finding, in the case of Eileen, a 15-year-old girl. After reflecting on the data as a whole, it was clear that Eileen is in many ways "at risk", and that there is a general degradation of the parent-adolescent relationship as evidenced by her statement: "...I feel as if my mother prefers other people above me... and then I don't tell them that I'm sleeping out, ...and I only come home the next day". There seems to be a breakdown in communication in this family system and the adolescent sleeps out without notifying her parents, which in turn hampers her parents' efforts in trying to keep her out of harm's way. This conflictual relationship was confirmed by the mother (Magdalene), who reported that Eileen spends most of her time with her peers rather than at home. A central feature of this case is the adventitious nature of the disability which resulted from a traumatic injury. The five-year-old Eileen and her mother were separated during the long period of hospitalisation. This might have caused deep feelings of abandonment and rejection to underlie the somewhat distant relationship evident today. Magdalene describes her daughter as an independent young person who does not need to have warm and responsive relationships with significant people in her life, but this contradicts Eileen's behaviour in turning towards her peers for love and acceptance: "*But her friends do care about her. Sometimes she goes to her friends for social events. And sometimes then she comes back home and then I can see that she has changed quite a lot and so on*".

While the majority of adolescents in this study are dealing with the disability of only one parent, Eileen has to deal with the disabilities of two parents. Looking at the nature and features of Magdalene's disability, we see that she has difficulty with

communication. In addition, Eileen's stepfather has a mental disability which might reduce the strategies used by the parents to parent in a consistent and firm manner and to set clear rules. This lack of family management strategies may have contributed to Eileen becoming friends with anti-social peers, engaging in alcohol use and eventually dropping out of school.

4.3.1.2. Mother's psychological functioning

Another important point which emerged from the data was that the mother's psychological functioning seemed to intersect with the adolescent's perception of the parent- adolescent relationship. In case number two, Debbie has acquired panic disorder which in addition to the activity limitations associated with physical disabilities, further reduces her participation in a range of parental activities. Looking at the data in this case, the presence of the primary congenital disability does not seem to cause disruption in the maternal role functioning, but rather it is the panic disorder and ongoing anxiety which severely restricts the mother's involvement in activities in and around the house. Jeremy describes the negative effects of maternal disability: *"She can't go opposite the street because when she's in the street she's nervous. When she's inside now then she can't also listen to loud music"*. In addition, Debbie experiences frequent bouts of pain and fatigue. Her chronic medication causes her to feel tired during the day, possibly making her unavailable to "mother".

This is in contrast to case number three, where the mother is a quadriplegic and experiences severe activity limitations, but her mental processes are unaffected. Both Fairuz and Radia emphasised how parenting is largely about creating a caring and

nurturing environment for children to feel loved and supported. Fairuz said: *“I believe that a mother should, should have a lot of love and you need to understand a child’s behaviour or why a child reacts the way he does”*. Similarly, Radia said: *“Me and my mother, we are closer, very close. She always tries to tell me it’s not material things that, that, that spending quality time and, and being there and, and stuff is more important. So she, so she always spend quality time with me and go somewhere and do stuff whatever”*. The results in these cases lend support to the assertion that the relationship between maternal physical disability and child wellbeing is mediated through the quality of the parent-child relationship.

4.4. The impact of the disability on mother- adolescent conflict

Another important point which emerged from the data was that parents with physical disabilities have to make adaptations to the ways they deal with conflict situations. The mother in case number three, Fairuz, highlighted that one of the key issues about parenting with a disability is related to the physical superiority of the child. All the families in this study reported that they deal with conflict on a verbal level and that most of their disagreements are amicably resolved. One of the younger boys, Jeremy, said that: *“Often, she (my mother) sits down and discuss things with me. She does it a lot to me. First she like gets cross with me but after she has cooled down she will speak nicely to me and tell me this is wrong and then she explain why”*. Sophie felt that mothers with disabilities use less punitive and harsh parenting methods than those without disabilities: *“My mommy is very kind and she’s loving. Not like some women that abuse their children. When I went to my friend’s house and so her mommy, her mommy grabbed her and took her hit her with a broomstick”*. It is also important to

note that while most of the families felt that they were dealing with conflict in an effective manner, both mothers and adolescents gave examples of times when this was not the case and that they shout at each other when they have disagreements. Other research conducted with mothers with physical disabilities implicates lack of parental support and chronic fatigue which reduces maternal capacity for consistent parenting practices (Prilleltensky, 2004). However, another possible explanation may be that the cumulative effect of stressors such as poverty, low maternal educational levels, lack of familial support and high risk living conditions, exacerbates the role of parental disability and erodes the parents' conflict management skills.

4.5. Disability-related stigma and the adolescent's appraisal of the mother's difference on the mother-adolescent relationship

The most prominent finding to emerge was that all the women, at some point during their lives, experienced incidents of stigma. In addition to the presence of visible physical disability, the fact that they are members of other minority groups (including race, gender and low socio-economic backgrounds) contributes to their compound stigmatised status. Looking at the responses to stigma, the data suggests that boys and girls respond differently with boys showing a willingness to physically defend their mothers. In the most extreme case, Aimee reported incidences where people have verbally abused her or her son Angus, aged 15, forcing him to resort to violence: "*He got a good relationship, but they swear at him or me, then he want to fight all the time*". Similarly Jeremy, aged 12, said that: "*I will fight with people, like my friends if they had to tell him that my mother is disabled. I am very for my mommy, and will always support my mommy*". While the adolescents recognise that their mothers

might deviate from social notions of normalcy, they do not accept the assumption that their mothers are less than legitimate. Furthermore, the data highlights the significant risks associated with stigma and courtesy stigma, particularly for male adolescents growing up in contexts of poverty, gangsterism and crime where violence is a desirable and acceptable means of interacting and problem solving.

In two of the cases, Angus and Radia, there were discrepancies between maternal- and self-reports on the impact of stigma and courtesy stigma on the adolescents, with the adolescents downplaying the frequency of the stigmatising events. Also, Debbie felt that her son Jeremy might downplay the frequency of the incidence of courtesy stigma: *“Now Jeremy is someone like when someone fights with him in the road he wouldn’t come and tell me. He will never ever come and tell me about it. I’ll find out from somebody else and I’ll deal with it”*. A possible explanation might be that the adolescents withhold information on the occurrence of these incidences in an attempt to protect their mothers from the negative emotions associated with incidences of discrimination.

Sophie, one of the younger female adolescents (aged 12), explained that she is more selective about her peer affiliations, choosing friends with positive and respectful attitudes towards people with disabilities. Looking at case number five, Eileen, aged 15, seems more capable of dealing with the stigma, rejection and teasing than the boys and the younger children. Eileen was very outspoken and challenged the negative stereotypes about people with disabilities held by some of her family members, friends and other members of the community: *“She’s just the same as us. There are a few people, who make jokes about my mom, and then I stress and I get angry. And*

then I say: I don't know why you take my mom for a joke, because she's a person just like we are". Her mother, Magdalene, explained that Eileen had been more vulnerable to stigmatizing and teasing when she was a young child. She highlighted the advantages of openly speaking about stigma with children, drawing their attention to the parents' abilities rather than what they cannot do: *"There was occasions when she was small and she came to me and say, Mommy they are making fun of you. Then I needed to inspire her and motivate her where I'm concerned. I said you've got a mother whether she's disabled or not, but she can do this for herself, she can do that for herself, and there is lazy people that can use every limb of their body but they, they just don't want to do it. So why worry what other people say about your mother basically".* Eileen also mentioned that maternal disability has forced her to think more deeply about life and people. She feels more mature than her friends and sees herself as different, perhaps part of an out-group. One possible explanation for these feelings might be that the minority status of people with disabilities also extends to their children.

4.6. The ways in which the mother's disability, as well as other contextual factors, affect involvement in the adolescent's school and other activities

The International Classification on Functioning (Schneider & Swartz, 2004; WHO, 2001) suggests that the extent of disablement is the outcome of a health condition, person level activities, as well as environmental factors which may act as facilitators or barriers. The families in this study gave various examples of how poverty, inaccessibility of school buildings, lack of appropriate transport and service provision negatively impacted on parenting by restricting their participation in their children's

school and other activities. Four of the families indicated that the mothers are not involved in the everyday activities due to a range of factors external to the disability. This finding is similar to other studies in this area (Blackford, 1999). Looking at the participants' responses, Jeremy mentioned the inaccessibility of the school buildings: *"I think she would like to go there (school) but there are too many stairs and stones to bump into"*. The mothers of the other two adolescent reported incidences when they were restricted from participating in educational activities due to the high costs of public transport. Pearl, a single mother said: *"She used to go with me on the Dial-A-Ride in the afternoons, but it was a bit too much actually, finance wise. But, you know, for the two of us it's R8 there and R8 back at a time. So now she goes alone."* Similarly, Aimee said *"At the moment, I don't know what's going on there, so I must go to the school again on Friday when I have money for the taxi to go look"*. On the other hand, Radia, aged 13, whose mother has quadriplegia, highlights how safe, affordable and reliable transport facilitates shared activities, and with it positive perceptions of parenting in contexts of physical disability: *"We got a car about 6 months after she start working. That was about 3 year ago and since then we can do basically everything we want. We can go here, we can go there. Before that we had to travel on transport, taxis and buses it was terrible"*. Apart from Eileen who has dropped out of school, all the adolescents in the study felt that their mother emphasized educational achievements and had high expectations about their school performance. A striking finding which emerged from the data was that four of the adolescents have never had to repeat a school year. This is despite the fact that many of them are attending schools characterized by severely under-resourced and overcrowded conditions.

4.7. The ways in which the mother's disability, as well as other contextual factors, affect monitoring and supervision of behaviour

Another important point which emerged from the data was that the adolescents appeared to be faring well in some domains while showing clear vulnerabilities in others. With regard to monitoring and supervision, the findings confirm that four of the mothers who participated in this study attempted to have a “psychological and emotional presence” in their children’s lives in order to positively influence their behaviour (Demuth & Brown, 2004, p. 78). They indicated that they know their children’s friends and try to keep track of their whereabouts. One of the mothers explained how, in the face of activity limitations, she tries to supervise her son’s whereabouts: *“Most of the time I know where he is. He’s by his friends in the street and when I don’t know I send his sister sometimes. Sometimes I give him a call back and ask where he is”*. The mothers of the two older adolescents, Angus and Eileen, both aged 15, reported difficulties with setting rules, enforcing curfews and monitoring behaviour. In high-risk environments, which poverty-stricken neighbourhoods often are, this might pose a significant risk to the adolescents’ safety and might increase the likelihood of eventual engagement in risky behaviour. One possible explanation for the findings in these two cases may be that, enforcing rules with the older adolescents is particularly challenging for mothers with disabilities. However, in the absence of a matched control group this is mainly speculative since it is not possible to say whether this situation is unique to mothers with disabilities or equally applicable to those without disabilities.

4.8. The adolescents' engagement in risky behaviour

In summary, this study found that four of the five adolescents of mothers with physical disabilities did not engage in risky behaviour. This reported low level of engagement in risky behaviour might be inherent in the fact that this study utilized self-reports which resulted in the adolescents' under-reporting their involvement. However, it might also be that maternal physical disability serves as a protective factor against risky behaviour. One possible explanation for this might be linked to the "joy and fulfillment" that women with physical disabilities derive from motherhood resulting in their strong and committed efforts to ensure the care and well-being of their children (Prilleltensky, 2004, p. 209). Although few studies have explicitly focused on identifying the strengths of families where one or both parents have disabilities, Grue and Laerum (2002, p. 671) found that because women with disabilities have traditionally been excluded from the discourse of motherhood, when they do become mothers, they feel compelled to succeed in their parenting endeavours and to "present themselves and their children as managing normally in order to be accepted as ordinary mothers". Looking at the data in case number five, where both the adolescent and the mother reported on the adolescent's involvement in antisocial behaviour, one possible explanation for this might be related to the insufficient monitoring of adolescent behaviour, coupled with antisocial peer affiliations: "*we only smoke cigarettes and drink one or two beers, but only on weekends. Some of the other girls but not my friends drink during the week also*". This result is consistent with past empirical research (Brown et al, 1993).

4.9. Recommendations for future research

This exploratory study utilized the case study method to generate some knowledge on the impact of maternal physical disability on parenting and precludes findings on causal relationships between the variables. The importance of quantitative data is thus apparent to test these research questions and draw definitive conclusions. Systematic quantitative research would need to establish, possibly in a stepwise fashion:

- (1) whether parental disability is associated with child functioning;
- (2) whether different types of disabilities have differential effects;
- (3) the mechanisms through which parental disability affects functioning;
- (4) moderating and mediating processes (including general family functioning, the impact of alternative caregivers in the household such as fathers and whether their presence had a differential impact on girls and boys, and the mother's ability to monitor and supervise behaviour in the face of physical vulnerability) and;
- (5) models for intervention programmes incorporating efforts to reduce stigma and increase awareness of disability amongst peers;
- (6) make recommendations on establishing school support systems to enable parents with disabilities to participate in school related activities and events.

In addition, longitudinal data would be useful in future studies on the impact of maternal physical disability on parenting and child well-being. The utility of such studies would be increased if the variables measured focused on a few domains of child well-being and were measured over different points on the developmental

continuum. This would need to incorporate the fact that different aspects of family functioning assumed varying levels of importance over the course of childhood and adolescence. Additionally, it is imperative to address the above-mentioned questions by looking at the different pathways through which parental disability might affect child functioning. This would be particularly important in determining how parental disability affects child functioning within the context of multiple stressors. To date, most research on parental disability has hypothesised negative outcomes and set out to verify them, while little attention has been given to effective intra-familial coping strategies or positive outcomes. In order to advance our knowledge in this area, there is a need for well-designed quantitative studies to assess both the protective and vulnerability factors in these families.

4.10. Conclusions

This qualitative study provided useful insights into the effect of maternal physical disability on parenting, the mother-adolescent relationship and the adolescents' engagement in risky behaviour. The methodology used captured the complexity of the lived contexts of these families, highlighting some areas of concern, as well as some of the mothers' efforts to parent in a warm, loving and consistent manner, despite the odds. Ultimately, it is evident from the case histories that the majority of the families in this study seemed to be doing surprisingly well given the challenges they face (including maintaining good parent-child relationships, consistent high expectations of children, involvement in adolescents' school and other activities, as well as supervision and monitoring of behaviour), but this task is made more difficult by factors such as poverty, single parenthood, lack of access to schools, inadequate

transport and other support services. Building upon some of the knowledge generated in this thesis, future empirical studies will help to grow a theoretical base for the design of policies and interventions. As it stands, the needs of disabled parents and their families are largely overlooked by policy makers, researchers and service providers alike. Given that a substantial number of children are raised in families, where one or both parents have disabilities, it is imperative that their needs, however specialist, are identified and addressed alongside those of families without disabilities.

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APPENDIX A. INTERVIEW SCHEDULE FOR MOTHER

Interview One: Section one

Personal Information of Caregiver

- 1.1. Age
- 1.2. Race
- 1.3. Home language
- 1.4. Marital status
- 1.5. Level of education
- 1.6. Employment status
- 1.7. Income

Household composition and financial situation

- 2.1. Household size
- 2.2. Each person's relationship to child
- 2.3. Household income
- 2.4. How many people are supported by household income
- 2.5. Other types of financial support available to household
- 2.6. Monthly expenses

Caregiver's disability details

3. 1. When did you acquire your disability?
3. 2. Age at onset of disability?
3. 3. Nature of your impairment?
3. 4. Which activities do you have difficulty with?
3. 5. Do you know what caused your disability?
3. 6. Do you use assistive devices?
3. 7. Is your disability stable, fluctuating or progressive?
3. 8. How would you rate your overall general functioning?
3. 9. When was the last time you were hospitalised?

History of caregiving
<p>4. 1. Has your child always lived with you?</p> <p>4. 2. Who else provides care to your child?</p>
Personal Information of Child
<p>5. 1. Age</p> <p>5. 2. Gender</p> <p>5. 3. Grade (if applicable)</p> <p>5. 4. Disability status</p> <p>5. 5. Number and age of siblings</p>
Personal Information of Partner
<p>6. 1. Age</p> <p>6. 2. Education</p> <p>6. 3. Employment status</p> <p>6. 4. Income</p> <p>6. 5. Disability status</p>
Partner's disability details
<p>7. 1. When did you acquire your disability?</p> <p>7. 2. Age at onset of disability?</p> <p>7. 3. Nature of your impairment?</p> <p>7. 4. Which activities do you have difficulty with?</p> <p>7. 5. Do you know what caused your disability?</p> <p>7. 6. Do you use assistive devices?</p> <p>7. 7. Is your disability stable, fluctuating or progressive?</p> <p>7. 8. How would you rate your overall general functioning?</p> <p>7. 9. When was the last time you were hospitalised?</p>

APPENDIX B. INTERVIEW SCHEDULE FOR MOTHER

Interview One: Section two

Knowledge, understanding and feelings about maternal disability

1. What does your child know about your disability?
2. What does your child think that means?
3. How does your child feel about your disability?
4. How do you think your disability affects your child?
5. How does your disability affect your relationship with him/her?

Involvement

1. How often do you do things together?
7. Once a day/once a week/once a month?
8. Can you give me examples of things that you do together?
9. How often do you and your child spend time talking?
10. What are your conversations about?

Relationships with others

11. How do you think your disability affects his/her relationships with other people? E.g. Family members, friends, neighbours or others?
12. How does your disability affect how he/she talks with others, listen to others, and express his/herself?
13. How does your disability affect how he/she feels about themselves?

Stigma and courtesy stigma

14. Do you think his/her friends treat you differently from how they treat other mothers?
15. Do you think family members treat you differently from how they treat other family members?
16. Do you think other people (teachers) treat you differently from how they treat non-disabled people?
17. Do you think his/her friends treat him/her differently from how they treat the others, because of your disability?
18. Do you think family members treat your child differently from how they treat the other children of the same age, because of your disability?
19. Do you think other people (teachers) treat your child differently from how they treat other children of the same age, because of your disability?

Educational

20. How do you think your disability affects his/her schoolwork?
21. How do you think your disability affects the time that he/she has to spend on doing homework?
22. How do you think your disability affects his/her school attendance?
23. Has your child ever repeated a school year?
24. How does your disability affect his/her involvement in extra - curricular activities?

Positive Outcomes
25. What do you think are the things most positively influenced by being raised by a mother with a physical disability?
Negative Outcomes
26. What do you think are the things most negatively influenced by being raised by a mother with a physical disability?

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APPENDIX C. INTERVIEW SCHEDULE FOR MOTHER

Interview Two

Warmth, support and acceptance

1. Who are the people that most support your child?
Can you think of an example?

2. Who are the people that mostly give advice to your child?
Can you think of an example?

3. Who are the people that give encouragement to your child?
Can you think of an example?

4. Who are the people that most praise your child?
Can you think of an example?

5. Who are the people that your child feels most affection for?
Can you think of an example?

Respect and trust

6. Who are the people that your child most respects?
Can you think of an example?

7. Who are the people that your child trusts the most?
Can you think of an example?

8. Who are the people that your child shares secrets with?
Can you think of an example?

Psychological autonomy granting

9. Who are the people that your child ask for guidance when he/she needs to make decisions?

Can you think of an example?

10. Do you allow your child to make his/her own decisions?

Can you think of an example?

11. What do you allow him/her to make decisions about?

Can you think of an example?

Educational

12. Do you have any expectations about his/her school performance?

Can you think of an example?

13. Do you think that your expectations are reasonable expectations?

Can you think of an example?

14. Are your expectations consistent or do you sometimes change your mind?

Can you think of an example?

15. How do you keep track of his/her school performance?

Can you think of an example?

16. How do you make sure that he/she meets your expectations about school performance?

Can you think of an example?

Conflict situations

17. How do you deal with conflict situations?

Can you think of an example?

18. Do you yell or shout at him/her?

Can you think of an example?

19. Do you give him/her reasons as to why what he/she has done is wrong?

Can you think of an example?

20. Do you try to help him/her see what is right and what is wrong?

Can you think of an example?

Monitoring and supervision

21. Do you keep track of what he/she does?

How do you keep track of what he/she does?

22. Do you know his/her friends?

How do you get to know his/her friends?

23. Does he/she have to be at home at a certain time?

At what time during the week?

At what time on the weekends?

24. What happens when he/she is not on time?

Can you think of an example?

Inappropriate caring

25. Does he/she need to help care for you?

26. If yes, what type of care does he/she provide?

27. Do you think your relationship is different to the relationship other children of the same age have with their mothers?

Risky behaviour

28. Do you know whether your child smokes, drinks alcohol or uses substances?

29. Do you know whether his/her friends smoke, drink alcohol or use substances?

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APPENDIX D. INTERVIEW SCHEDULE FOR ADOLESCENT

Interview One

Knowledge, understanding and feelings about maternal disability

1. What do you know about your mother's disability?
2. What do you think that means?
3. How do you feel about your mother having a disability?
4. How do you think your mother's disability affects you?
5. How do you think your mother's disability affects your relationship with her?

Involvement

6. How often do you do things together?
7. Once a day/once a week/once a month?
8. Can you give me examples of things that you do together?
9. How often do you and your mother spend time talking?
10. What are your conversations about?

Relationships with others

11. How do you think your mother's disability affects your relationships with other people? E.g. family members, friends, neighbours or others?
12. How does your mother's disability affect how you talk with others, listen to others, and express yourself?
13. How does your mother's disability affect how you feel about yourself?

Stigma and courtesy stigma

14. Do you think your friends treat your mother differently from how they treat other mothers?
15. Do you think family members treat your mother differently from how they treat other family members?
16. Do you think other people (teachers) treat your mother differently from how they treat non-disabled people?
17. Do you think your friends treat you differently from how they treat the others, because of your mother's disability?
18. Do you think family members treat you differently from how they treat the other children of the same age, because of your mother's disability?
19. Do you think other people (teachers) treat you differently from how they treat other children of the same age, because of your mother's disability?

Educational

20. How do you think your mother's disability affects your schoolwork?
21. How do you think your mother's disability affects the time that you have to spend on doing homework?
22. How do you think your mother's disability affects your school attendance?
23. Have you ever repeated a school year?
24. How does your mother's disability affect your involvement in extra - curricular activities?

Positive Outcomes

25. What do you think are the things most positively influenced by being raised by a mother with a physical disability?

Negative Outcomes

26. What do you think are the things most negatively influenced by being raised by a mother with a physical disability?

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APPENDIX E. INTERVIEW SCHEDULE FOR ADOLESCENT

Interview Two

Warmth, support and acceptance

1. Who are the people that most support you?

Can you think of an example?

2. Who are the people that you mostly ask for advice?

Can you think of an example?

3. Who are the people that encourage you to do things?

Can you think of an example?

4. Who are the people that praise you when you do well?

Can you think of an example?

5. Who are the people that you feel the most affection for?

Can you think of an example?

Respect and trust

6. Who are the people that you respect most?

Can you think of an example?

7. Who are the people whom you trust the most?

Can you think of an example?

8. Who do you share your secrets with?

Can you think of an example?

Psychological autonomy granting

9. Who are the people that you ask for guidance when you need to make decisions?

Can you think of an example?

10. Does your mother allow you to make your own decisions?

Can you think of an example?

11. What does she allow you to make decisions about?

Can you think of an example?

Educational

12. Does your mother have any expectations about your school performance?

Can you think of an example?

13. Do you think that her expectations are reasonable expectations?

Can you think of an example?

14. Are her expectations consistent or does she change her mind?

Can you think of an example?

15. Does she keep track of your school performance?

How does she keep track of your school performance?

16. How does she make sure that you meet her expectations about school performance?

Can you think of an example?

Conflict situations

17. How do you and your mother deal with conflict situations?

Can you think of an example?

18. Does she yell or shout at you?

Can you think of an example?

19. Does she give you reasons as to why what you did is wrong?

Can you think of an example?

20. Does she try to help you see what is right and what is wrong?

Can you think of an example?

Monitoring and supervision

21. Does your mother keep track of what you do?

How does she keep track of what you do?

22. Does your mother know your friends?

How does she get to know your friends?

23. Do you have to be at home at a certain time?

At what time- during the week?

At what time on the weekends?

24. What happens when you are not on time?

Can you think of an example?

Inappropriate caring

25. Do you need to help care for your mother?

26. If yes, what type of care do you provide?

27. Do you think your relationship with your mother is different to the relationship other children of your age have with their mothers?

Risky behaviour

28. Do you smoke, drink alcohol or use substances?

29. Does your friends smoke, drink alcohol or use substances?

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Appendix F: Information sheet for children



University of Cape Town: Department of Psychology

INFORMATION SHEET FOR CHILDREN

My name is Underé Deglon and I am student in the Psychology department of the University of Cape Town. I am conducting a study on the experiences of children who have grown up with mothers with physical disabilities. By conducting this project we hope that we will understand your experiences and that we can make recommendations on what type of support services and interventions families like yours might or might not need.

So what happens if you decide to participate in the study?

If you agree to participate, I would like to meet with you two times over the next two months, for about 50 minutes each time. We can speak to you here in your home or somewhere else if you prefer.

During our meetings, I will ask questions about your experiences of your mother's disability. I will also ask about your relationship with her and how you relate to each other. Then I will ask how things are at home, at school and with your friends.

What about people recognising your information?

All the information which I collect, including the audiocassette tapes, will be stored in a locked cabinet at our office and only the research team will have access to it. The information will remain private and confidential; we will not share your name or any of your personal information with anyone else. After I have collected the information from you and the other families I am speaking to, it will be put together in such a way that no one individual will be identifiable.

What will happen if you do not feel comfortable answering the questions?

You can say so and I will stop immediately. You can just say they you do not want to answer that question or you do not want to participate in the study anymore.

What will happen to you if you wish to withdraw?

Nothing. I am only a researcher and nothing bad will happen to you if you do not want to take part in the study anymore.

What can you do one of the questions make you feel uncomfortable in any way?

You can tell either me or your mom. Otherwise you can speak to my supervisor Dr. Lauren Wild on 021-650 4607. We will then put you in contact with someone who you can talk to.

If you wish to have more information about the study, you can phone me (Underé Deglon) on 021-466 7886.

Please remember that you can choose whether to participate in this study or not. If you want to take part in this study, please sign the attached consent form (you may keep this copy of the information sheet).

University of Cape Town

Appendix G: Assent form for children



University of Cape Town: Department of Psychology

ASSENT TO PARTICIPATE IN STUDY ON MATERNAL PHYSICAL DISABILITY

By signing here it means that you will let me interview you for the study on the experiences of children of mothers with physical disabilities. It means that you understand that you are participating freely and that the information will remain confidential. It also means that you understand that you can stop the interview at any time or refuse to answer one of my questions.

Signature of child:.....

Date:.....

University of Cape Town

Appendix H: Information sheet for mothers



University of Cape Town: Department of Psychology

INFORMATION SHEET FOR MOTHERS

My name is Underé Deglon and I am student in the Psychology department of the University of Cape Town. I am conducting a study on the experiences of children who have grown up with mothers with physical disabilities. By conducting this project we hope that we will understand your experiences and that we can make recommendations on what type of support services and interventions families like yours might or might not need.

So what will you have to do if you decide to participate in my study?

If you agree to participate, I would like to meet with you and your child separately two times over the next few months, for about 50 minutes each time. We can speak to you here in your home or somewhere else if you prefer. During our meetings, I will ask questions about your background, you and your partner's disability, socio-economic status, residential and other background information.

I will also ask about your relationship with your child and how you relate to each other. Then I will ask how things are at home, at school and with friends.

What about people recognising your information?

All the information which I collect, including the audiocassette tapes, will be stored in a locked cabinet at our office and only the research team will have access to it. The information will remain private and confidential; we will not share your name or any of your personal information with anyone else. After I have collected the information from you and the other families I am speaking to, it will be put together in such a way that no one individual will be identifiable.

What will happen if you do not feel comfortable answering the questions?

You can say so and I will stop immediately. You can just say they you do not want to answer that question or you do not want to participate in the study anymore.

What will happen to you if you wish to withdraw?

Nothing, I am only a researcher and nothing bad will happen to you or your child should you wish to withdraw from the study.

What can you do one of the questions make you feel uncomfortable in any way?

You can tell either me or you can speak to my supervisor Dr. Lauren Wild on 021-650 4607. We will then put you in contact with someone who you can talk to.

If you wish to have more information about the study, you can phone me (Underé Deglon) on 021-466 7886.

Please remember that you can choose whether to participate in this study or not. If you want to take part in this study, please sign the attached consent form (you may keep this copy of the information sheet).

University of Cape Town

Appendix I: Consent form for mothers



University of Cape Town: Department of Psychology

CONSENT TO PARTICIPATE IN STUDY ON MATERNAL PHYSICAL DISABILITY

By signing here it means that you will let me interview you for the study on the experiences of children of mothers with physical disabilities. It means that you understand that you are participating freely and that the information will remain confidential. It also means that you understand that you can stop the interview at any time or refuse to answer one of my questions.

Signature of Mother:

Date:.....

By signing here it means that you will let me interview your CHILD for the study on the experiences of children of mothers with physical disabilities. It means that you understand that HE/SHE is participating freely and that the information will remain confidential. It also means that you understand that HE/SHE can stop the interview at any time or refuse to answer one of my questions.

CONSENT FOR MY CHILD TO PARTICIPATE IN STUDY ON MATERNAL PHYSICAL DISABILITY

Signature of Mother:

Date:.....