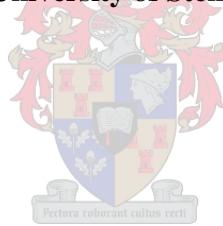


De-institutionalisation of people with mental illness and intellectual disability: The family perspective

by

ELIZABETH KOCK

**Thesis presented in partial fulfilment of the requirements for the degree of
Master of Philosophy (Community and Development)
at the University of Stellenbosch**



Supervisor: Dr R Carolissen

December 2009

Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Abstract

South Africa has transformed its mental health service provision from in-hospital care to community-based rehabilitation. Although the idea is sound, the process places the caregiving families under an immense pressure. The aim of this study was to explore the impact that the de-institutionalisation process has had on the families as they care for their child with intellectual disability.

The study was conducted by means of qualitative, unstructured interviews with families that have had a child de-institutionalised from Alexandra Hospital in the Western Cape. All of the patients were diagnosed with a dual diagnosis of intellectual disability and mental illness. Even though the patients were in group-homes or attended a day care centre, final responsibility for the patients lay with the parents.

Three main themes emerged from the interviews that describe the impact of de-institutionalisation, *viz.* the characteristics of the family member with intellectual disability (aggressive, abusive and self-destructive behaviour of the patient), the effect that these characteristics had on the family (marital stress and health risks to the caregiver), and community and resource factors.

The study placed the family central to its environment and discussed the impact de-institutionalisation had on its environment as a whole.

It was concluded that the burden that de-institutionalisation places on the families far exceeded their ability to cope with these circumstances. This *status quo* could be improved if adequate resources and skills are given to families prior to de-institutional

Opsomming

In Suid-Afrika is geestesgesondheidsorg van hospitaliserende na gemeenskaps-gebaseerde rehabilitasie, omskep. Terwyl hierdie stap wel as lewensvatbaar mag voorkom, plaas die proses 'n hewige las op die sorggewende gesin. Die doel van hierdie studie was om die omvang van die impak hiervan op 'n gesin met 'n lid met intellektuele gestremdheid en psigiatriese siekte, te bepaal – nadat so 'n pasiënt uit die inrigting ontslaan is.

Die ondersoek is uitgevoer by wyse van kwalitatiewe, ongestruktureerde onderhoude met gesinne wie se lede met die diagnose uitgeplaas is deur die Alexandra Hospitaal in die Wes-Kaap. Elkeen van die pasiënte is gediagnoseer met ernstige intellektuele gestremdheid, asook bykomende gedragsafwykings. Ten spyte van die feit dat die betrokke pasiënte deur groepshuise of dagsorg eenhede versorg word, bly hulle hul ouers se verantwoordelikheid.

Drie temas het ontstaan wat die impak van ontslag uit die inrigting omskryf, te wete die karaktertrekke van die gestremde gesinslid (aggressie, misbruikende en vernielsugtige gedrag van die pasiënt), die effek van hierdie karaktertrekke op die gesin (stres op die huwelik en potensiële gesondheidsrisiko wat dit vir die versorger inhou), en die gemeenskap en ondersteunende faktore.

Tydens die ondersoek is die gesin sentraal geplaas ten opsigte van die omgewing. Die impak van ontslag van die gediagnoseerde pasiënt uit die inrigting op die omgewing as geheel, word bespreek.

Daar is tot die slotsom gekom dat die vermoë van die gesin wat die las moet dra as gevolg van die ontslag, ver oorspan word. Hierdie toedrag van sake sou egter verlig kon word indien toereikende hulpbronne en vaardighede aan sulke gesinne beskikbaar gestel word alvorens so 'n pasiënt ontslaan is.

Acknowledgements

I would first and foremost like to thank Professor Molteno, for the funding, for giving me room to conduct the study in the manner I preferred. For your gentle guidance and all the assistance in the practical matters. This was truly an enriching experience.

Thank you to Dr Carrolissen, for her accessibility and guidance.

Thank you Liezel, for your practical advice, for help in ATLAS^{ti}® and for always being so calm about everything.

Thank you Annie, for introducing me to the idea of de-institutionalisation, for the spell checks, for the endless endless (ENDLESS) grammatical adjustments and for your unconditional support.

To my parents, for always reminding me that being able to study is a privilege, for all your support, financial and otherwise, to bring me to this point.

Thank you to the families that partook in the study, who opened their hearts to me, and allowing me to document some of this sensitive issue with which they struggle. I salute you for your courage and perseverance.

To my Creator, for all opportunities that You have placed on my path.

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CHAPTER ONE

Introduction

The Human Development Report of 1990 defines the aims of development as creating environments and surrounds within which people could spend well- and long-lived lives (UNDP, 1990). Development per se, links with improvement in quality of life (Coetzee, 2001) and furthermore, links to the goal of social development, that is, the achievement of human well-being, which rests on the development of people (Patel, 2005). Kilonzo & Simmons (1998) emphasize the importance of mental health and optimal mental functioning and suggest that it should be encouraged, fostered and maintained. The authors refer to a state of mind in which individuals experience continued joy of life whilst being productive in their work, having meaningful interactions with others and maintaining the ability to function in a socially appropriate manner. They also suggest that as a result of poor mental health, considerable burdens are placed on a country's economic, political and social functions.

The South African mental health service is shaped by principles of de-institutionalisation or a shift in focus from hospital institutional care to a more socially integrated community setting (Pinfold, 2000). The term 'de-institutionalisation' refers to the policy of discharging patients with mental health problems and/or intellectual disability (ID) from hospitals so that they can be placed in community, and the decentralisation of the mental health services thus integrated into primary health care (Petersen, 2004). These alternative treatment approaches would in turn reduce the number of new admissions (Nevid *et al.*, 2003).

Aderibigbe (1997) argues that although the concept of de-institutionalisation is sound, its implementation has been flawed. In cases where solid community-based health care services were not available prior to de-institutionalisation, admission rates at hospitals increased. Furthermore, incidences of relapses, homelessness and criminalisation were common amongst previous mentally ill patients (Janse van Rensburg, 2005).

As a direct result of the conversion from hospital- to community-based care, coupled with the restrictions of fiscal planning which were hampered by severe budget cuts by the government, South Africa is increasing efforts to de-institutionalise (Kritzinger & Magaqa, 2000). However, families are expected to take care of previously institutionalised relatives without being provided with the benefit of the necessary training and support which would adequately equip them for this task. The primary goal throughout the process of care-giving remains the safeguarding of the fulfilment of the patients' need for physical comfort and safety. The care-giver's work largely involves observing the patient, overcoming obstacles and explaining his/her behaviour to others (Kritzinger & Magaqa, 2000). Care-givers are also challenged with making decisions aimed at finding ways to enable the patient to act in a relatively independent way. Therefore, care-giving can be an under-valued occupation with no clearly defined areas of responsibility.

This study underpins the importance of mental well-being and thus explores factors which impact on families faced with a de-institutionalised member who has a dual diagnosis of intellectual disability (hereafter referred to as ID) and mental disorder. For the purpose of this study, psychiatric disability and mental disorder will be used as two interchangeable terms. ID involves significant cognitive impairment and defects in adaptive behaviour that manifests during childhood (Leonard *et al.*, 2005). Mental disorder refers to clinically significant behavioural or psychological syndromes or patterns associated with distress, disability or with a significantly increased risk of suffering death or pain (Sadock & Sadock, 2003). It is accepted that people with ID have higher rates of mental disorders compared to the general population of typical development (Deb *et al.*, 2001) and can experience a wide range of psychiatric disorders (Kirshore *et al.*, 2004). A family member with both ID and psychiatric or behavioural problems causes considerable distress and related difficulties which physically and emotionally impact negatively on the parents (Maes *et al.*, 2003). A study by Van Berkum & Haveman (as cited in Maes *et al.*, 2005) indicates that those parents who accommodate a child with ID and mental disorder at home, find care-giving and coping with his/her disruptive and challenging behaviour, particularly difficult.

The *aim* of this study will be to explore the experience of de-institutionalisation on affected families who are living with a family member with dual diagnosis of mental illness and intellectual disability.

The study is presented in six chapters. Chapter 1 provides a brief introduction, chapter 2 gives a synopsis and comparison of the history of de-institutionalisation, and the family experience thereof. Chapter 3 is a theoretical overview. Chapter 4 explains the research design and methodology, data-collection and analysis, limitations and ethical considerations. The results of the study are reported in Chapter 5, and Chapter 6 discusses the main factors which impact on the family and offers recommendations.

The introduction has suggested that families would need multiple levels of support in the face of the increasing tendency to de-institutionalise, and the challenges associated with these. The next chapter will thus focus on examining the literature on families who have members with dual diagnosis of the former categories, with specific reference to developments pertaining to de-institutionalisation.

CHAPTER TWO

Literature Review

2.1 Background

Rather than a problem, the nineteenth century and the first half of the twentieth century offered institutional care as a solution (Jones, 1988). ‘Asylum’ held its literal meaning, *viz.* a place of refuge at a time when life outside the asylum was harsh. At the start of the 1920’s care for people with disabilities was viewed as a humanitarian effort (Grunewald, 2003). However, these endeavours were negatively impacted upon when new views emerged which changed the way in which people with disabilities were viewed by society. The process of normalisation has therefore contributed towards the move away from governmental institutions for people with intellectual disability (ID) (Wolfensberger, 1992).

Jones (1988) notes a number of other developments that unfolded as a result of de-institutionalisation. These included circuitous publications, doctrines pertaining to being normal within the contexts of physical and mental handicap, beliefs in the healing power of communities, awareness that welfare policies had shortcomings, and that the extent to which services were relied upon by the public could not be provided by whatever the taxed public was prepared to pay, and also psychotropic drugs.

This phenomenon was observed in most countries in the Western World where de-institutionalisation was implemented.

2.2 De-institutionalisation around the world

Parmenter (2007) observes two significant outcomes which changed the way in which people with ID were viewed. In the first instance, the work of Niels Erick Bank, who paved the way to de-institutionalisation; and secondly, the lead taken by President J.F. Kennedy of the United States of America (USA), who not only addressed the issue of research in the field of ID, but also the status quo of institutions housing people with ID. Thereafter, the concept of ‘normalisation’ was created by Nirje of Sweden,

followed by Wolfensberger's theory of 'social role valorization', which promotes 'normal' roles as demanded by society.

De-institutionalisation thus originated in the USA, and the UK followed suit. In both countries the movement has succeeded in reducing psychiatric hospital beds and in providing community support, although many de-institutionalised people have been failed by the process (Lamb, 2001).

In their international overview, Fakhoury & Priebe (2002) argue that de-institutionalisation takes place at different rates in different countries because of traditions, socio-economic situations, etc. In Germany for instance, although many patients throughout the country remain in renamed hospital sections or establishments with little exposure to the community, large numbers seem to adapt successfully to community living (Von Cranach, as cited in Fakhoury & Priebe, 2002). In Sweden, it would appear that restructuring of resources restrict the adequate provision of community-based services (Silfverhielm & Kamis-Gould, as cited in Fakhoury & Priebe, 2002), whereas the situation in Greece presently cannot accommodate de-institutionalised people (Madianos *et al.*, as cited in Fakhoury & Priebe, 2002). Whilst hospitalisation in Finland seems affordable, various types of available community placements are also relied upon providing support in the form of trained staff, etc. (Rasanen *et al.*, as cited in Fakhoury & Priebe, 2002). The emphasis in Australia is on re-structuring existing housing structures to meet the self-declared needs of its residents (Horan *et al.*, as cited in Fakhoury & Priebe, 2002), while New Zealand seems to still face basic problem areas (Wilson, as cited in Fakhoury & Priebe, 2002). Several South American countries have shown progress towards de-institutionalisation (Larrobla *et al.*, as cited in Fakhoury & Priebe, 2002), whilst those in East Asia, show less progress due to socio-cultural and political factors (Yip, as cited in Fakhoury & Priebe, 2002).

Notwithstanding the above, community-based mental health care is deemed to be more lenient than traditional asylum and more therapeutic than hospitalisation (Lamb & Bachrach, 2001). These views however, could only materialise if certain measures are in place. It is important that de-institutionalisation be regarded a social process which may have repercussions.

Limited skills and competencies, and a lack of skill development affect people with ID to such an extent that they are unable to involve themselves in everyday activities on their own and they are reliant on staff or other care-givers to participate in activities (Jones *et al.*, 1999). It is evident throughout the Fakhoury & Priebe (2002) review, that although not easily implemented, de-institutionalisation is preferred to the traditional institutional setting, particularly if community-care is adequate. For example, trained staff would assist in playing a positive and vital role. People with ID and challenging behaviour (and in particular offending behaviour) or mental health problems, are also the most likely to be re-institutionalised after the move to community care (Alexander *et al.*, 2006). Hall *et al.*, (2006) argue that if the needs of people with ID and mental health problems are effectively supported in the community, they could achieve similar outcomes with regard to improved psychiatric status.

2.3 The policy in South Africa

In spite of certain obstacles, South Africa (SA) is actively involved in de-institutionalisation, making a shift towards community integration care and implementing the 'clubhouse model' across the country. SA is steadily moving away from the routine use of centralised institutions, towards a more constructive and comprehensive community-based mental health service approach (Lazarus, 2005). It is however important to note that it is not merely downsizing hospitals, but developing alternative, community-based services (Lazarus, 2005). The White Paper for transformation of the health system in SA (National Department of Health, 1997) illustrates SA's commitment to providing a service for more common mental health problems in addition to serious mental illness. Despite admirable policies, SA needs to address implementation issues which concern both hospital- and community-based care (Szabo, 2006). The main essence of the Mental Health Care Act according to Freeman (2002), comprises three basic elements, *viz.* human rights and the protection of people with mental disabilities. This indicates that care be provided in the best interest of the individual and in the least restrictive environment. Secondly, an integrated approach to mental health care which means that policies should be aimed at promoting community-based care and finally, the safety of the public. If a person is deemed by a close relative or associate to be likely to inflict serious harm to others,

he/she may be treated without his/her consent. A member of the South African Police Service or a mental health care practitioner may legally require a person to be evaluated if they are thought to be mentally ill and pose a danger to society. Concerns about implementation of policy have been raised by both policy commentators and activists. These concerns have included indiscriminate discharges, inadequate family and community preparation and support, inadequate community resources, inadequate continuity of mental health care, revolving door admissions and discharges, neglect and abuse, and homelessness (Lazarus, 2005).

While the endeavours by governments with regard to the formulation and implementation of policies and legislation are on-going, family perspectives also require consideration. Lazarus (2005) voices some of the policy imperatives. She observes the limited resources available for the change from institutional to community-based care, and that policy could not be structured without planning in consultation with all stakeholders including hospitals, chronic care institutions, acute care hospitals, community mental health services, placement options and government departments.

2.4 The family

People with ID and mental illness, living with their families, are reported to be happier despite actually being lonelier, than if they lived in residential accommodation (Rourke *et al.*, 2004). In these instances, the burden of care-giving rests on the family. This implies not only taking care of the physical needs but also those of development, integration and psychological well-being. It has been assumed that both people with disability and the state benefit from family living, but these arguments require verification (Cummins, 2001). Whilst it may well be true, the impact of stress as a result of care-giving, may have far reaching consequences, e.g. the care-giver being subjected to a higher intake of prescribed medication, and not being able to maintain or accept employment and may thus result in financial strain (Cummins, 2001). Tabatabinia (2003) reports that family members also have to deal with anxieties of their own deaths and care-giving restrictions as a result of aging and deteriorating health. Tabatabinia (2003) also highlights the paradox arising from this situation by noting that the care recipient is better off being cared for in his/her family environment, while on the other hand, the family is worse off for providing care in the

same environment. Walmsley (1996) describes the relationship between care-giver and person being cared for as controversial. This means that the relationship is characterised by conflicting emotions which clash, and by the same token, are reliant and tolerant.

Individuals with ID (and mental disorder) may develop increased behavioural and psychiatric disorders, particularly during young adulthood (Blacher, 2001), and it is important to establish the impact of care-giving on the family as an entity, especially since parent well-being determines the family climate (Kersh *et al.*, 2006). Olsson & Hwang (2001) find that mothers of children with disabilities are at an increased risk of suffering from psychological distress and depression. The high stress caused by difficult behaviour of the child in combination with restrictions in personal life, may be some of the factors that contribute to a higher risk of depression among mothers. In addition, they found that mothers show higher scores in depression than fathers. Smith *et al.*, (1995) report that age, marital status, employment, family income, education and health problems, have an influence on the health of the care-giving mother. Eisenhower & Blacher (2006) note that unemployed and unmarried mothers experienced less well-being as opposed to those who are supported by the very fact that they are employed and married, resulting in a negative impact on their socio-economic status. Marks (1998) argues that mothers of children with ID are susceptible to role strain, as they have many additional responsibilities, which consequently places their mental and physical health at a disadvantage. Care-givers are restricted when opportunities to advance in their own work environments are presented (Shearn & Todd, 1997). Leonard (2005) notes that families caring for members with developmental delays, are also at significant increased risk of exposure to adverse socio-economic circumstances. The individual care-giver's health is formed by his/her social environment and life experience (Seltzer & Ryff, 1994). The care-giver family is limited in its movements, which allows little scope for leisure and recreational activities (Tabatabinia, 2003). Greenberg *et al.*, (1993) suggest that family rewards could be two dimensional. Firstly, rewards through intra-personal qualities are important (e.g. strengthened faith, tolerance, and personal growth) are important. Secondly, inter-personal qualities such as strengthened family ties and expanded social networks) contribute to family rewards. Because of the co-existence of stress and rewards, care-givers experience times of tension as well as times of

gratification. Eventually, these lead to difficult decision making, e.g. a family may be advised to make use of respite care, but needs to address the feeling of guilt arising from the thought of ceding the responsibility of caring (Grant *et al.*, 1998).

Keen (2007) describes the family as an energetic entity with distinguishing features and requirements, while each family member has his/her own characteristics and needs. The centre of focus should therefore not be on the person with a disability but rather the family as an entity of which the individual with a disability is an integral part (Keen, 2007). This, however, rarely occurs and family activities often revolves around the child with disability.

2.5 Conclusion

The movement from hospital to community based care has left many people with ID and psychiatric illness in the care of their families, and drawn from all the above it is evident that personal, social and economic burdens resulting from living with a person with psychiatric illness and ID, controversially affects on both the household and the care-giver's own health. Previously, carers were not offered adequate practical support in order to cope with patients' symptoms and behaviour neither was the need for emotional support recognised as a priority (Fadden *et al.*, 1987; Muscroft & Bowl, 2000). Lefley (as cited in Lustig, 1999) notes that social support is an important resource and categorises such support into two categories, i.e. formal support provided by government, service agencies and especially self-help groups; and informal support provided by family, neighbours, co-workers and friends. In line with the above, the next chapter will give a theoretical background on the de-institutionalisation movement, as well as the experience of care-giving.

CHAPTER 3

Theoretical Overview

This section provides a discussion on some models which have been emphasized in the de-institutionalisation movement. The ‘social model’, which can be seen as an alternative to ‘bio-medical models’, will be discussed first so as to set the scene on how disability can be viewed. Social models used as alternatives to hospital-care include the linear, supported housing and clubhouse model. Theoretical perspectives on family and care are also discussed.

3.1 Models

Hughes & Patersen (1997) suggest a shift from a ‘bio-medically dominated model’ (with emphasis on physical inability) to a ‘social model’ (with emphasis on how disability is socially viewed), while differentiating between ‘impairment’ (i.e. loss of some function part of the body) and ‘disability’ (i.e. whatever is perceived by society as the impairment). Disability thus incorporates the prejudice created and maintained by society and confirmed by a spectrum of social practices (Chappell *et al.*, 2001). The social model originated with people with physical and sensory impairment, but now includes people with intellectual disability and has been extended to apply to people living with mental illness. Through this model, disabled people could have access to finding ways of empowering and maintaining themselves. This would include independent living although it may not always be possible to live entirely independent due to the degree of disability. De-institutionalisation models however, do reflect and provide support for different levels of independent living. These models include the ‘linear’, ‘clubhouse’ and ‘supported housing’ models.

The implementation of linear models post de-institutionalisation have emphasized the value of a staggered approach to independence, from an initial supervised environment to an increasingly independent environment (Hitzing, 1980). Differing levels of service, restrictions and supervision would typically be applied, depending on the level of independence (Ridgeway & Zimmer, 1991). Supported housing models, on the other hand, were deemed superior to traditional linear models, and

supported housing models provided an environment which stimulated independence, promoted social integration and normalised roles within the community. Rather than standardising criteria, it attempted to provide specific and individual needs. Preferred models of intervention include strengthening both the clients' skills and the level of environmental support. The approach to skill strengthening would involve social and independent living skills training, as well as symptom management (McReynolds, 2002). The clubhouse model is a well-known model for psycho-social rehabilitation for adults with mental illness. Clubhouses are community-based rehabilitation programmes for people with mental health needs offering skills and opportunities to enhance their own lives (McReynolds, 2002). This model places major emphasis on clients becoming empowered (Accordino & Herbert, 2000) and employment is viewed as the main focus within the clubhouse model (Norman, 2006). Empowerment is central to the social model which is characterised by a strong human rights-based approach to disability and does not accentuate the impairment of the disabled individual (Mansell, 2006). In the context of psychiatric rehabilitation, employment can be seen as both outcome and as a highly effective treatment modality in facilitating meaningful community integration (Ahrens *et al.*, 1999).

Although the social model has been criticised for being too theoretical (Dewsbury *et al.*, 2004), it remains important to recognise that the model emphasises the importance of self-sufficiency, and does not focus on factors that prohibit the person from being self-sufficient. In reviewing the literature, Hassiotis (2002) concludes that when implementing community based interventions for people with ID and challenging behaviour, a multi-disciplinary team approach is always the most desirable.

3.2 The family

The numerous problem areas SA has to face with reference to de-institutionalisation and limited related resources, necessitates many people in need of mental health care to depend largely on their families for support. Such families are placed under pressure to care for their member with a dual diagnosis whilst they simultaneously need to fulfil their daily tasks. Family stress levels are thus determined by the families' ability to cope with the demands placed on them (Lustig, 1999). Caring for a person with ID, who displays challenging behaviour, can have negative consequences

on the family (Maes *et al.*, 2003). The demand however, is determined by the families' vulnerability, resources, appraisal and approaches to problem solving. Failing to meet the demand is likely to result in maladjustment within the family (Lustig, 1999). McCubbin, Thompson & McCubbin (as cited in Lustig, 1999) note that a significant resource may well be derived from social support, which would entail support from relatives, friends and community institutions

It is also important to consider the 'ecological model', popularised by Bronfenbrenner (1975), which situates the individual in the context of his/her environment and thus provides a contextualised and systemic perspective on understanding individual behaviour. When applying the ecological model to ID and psychiatric illness, it can be used to understand how the family experiences the function of caring at different systemic levels. For example, the micro-level looks at the impact of the person with disability on the immediate family. If a person with disability becomes aggressive, family members will bear the consequences of the aggression. McIntyre *et al.*, (2002) confirm that challenging behaviour and mental illness increase stress. They also report that when challenging behaviour of a child with ID sets in, the negative perception thereof by the family, is increased. The meso-level focuses on the relationships between numbers of micro-systems (e.g. spousal relationships affect parent-child relationships). Both micro- and meso-systems are located within exo-systems which indirectly influence family interactions. The effect of the parents' jobs and employment status on the family, would serve as an example. In the last instance the macro-system comprises the effect of economic, political, cultural and social factors which influence the individual and his/her family. The family may also have to bear the financial responsibility for their child which is likely to contribute to fewer resources for the rest of the family, leaving the family as whole, financially burdened by having to care for a family member with a disability (Meyers *et al.*, 2002). All these factors which impact on the family can be synthesised in a cost formula popularised by Kegels (2007). This formula is commonly used in the field of health care development programmes and government. His formula which reads as follows, $\sum(\textit{suffering}) + \textit{cost}(\textit{social and economic})$, emphasises the importance of measuring the intangible extent to which suffering is experienced by the family.

Kegels' model can be applied to families with a child who has a dual diagnosis of ID and a psychiatric disability. This is central as it is important to measure impacts not only financially but also in terms of emotional and psychological impacts.

3.3 Conclusion

Countries that have successfully implemented a policy of de-institutionalisation have well-developed institutional capital, and can be observed in their extensive network of day-care and respite-care centres, and well implemented health and social security systems. Successful de-institutionalisation programmes are also characterised by sufficient human capital, which means that adequate skilled health care personnel (nurses, counsellors, paramedical professionals, etc.) ensure that families are not left to care for de-institutionalised family members without access to the resources they will require. Furthermore, those countries with successful de-institutionalisation programmes are often in more stable situations. Economic and political stability allows for higher prioritisation of 'luxury' services over programmes for basic health care, education and economic development. Developing countries often have to face more pressing and large-scale social problems (famine, civil wars, and epidemics) and cannot afford to allocate resources to more 'marginal' issues. The shift from institutionalised care to supported living may well appear to be to the advantage of the person with mental health problems. However, South Africa has been criticized for not having adequate resources in place and therefore, the burden placed on the family as primary source with regard to financial, physical and emotional support should not be under estimated.

CHAPTER FOUR

Methodology

4.1 Introduction

This chapter focuses on the methodology employed for this study. It explains why the case study as research design was selected and considers its advantages. It discusses the procedure followed in conducting the study and details the selection of the target population for data collection. The method of data collection and individual interviews are described, and a brief outline of the interview schedule is provided.

4.2 Research design - case study

This study utilised a qualitative research approach. Qualitative research aims to provide an in-depth description of a specific group of people or community (Babbie & Mouton, 2001). A typical feature of this type of research design is a detailed encounter with the subject of the study.

Qualitative research uses an idiopathic research strategy and is mainly concerned with understanding the particular and specific event or case within its own context. Researchers describe the research participant's actions in great detail and attempt to understand these actions in terms of his/her own beliefs, history and context (Babbie & Mouton, 2001). Dunn (1999) describes case studies as direct and in depth resumes of people's lives. It provides an overview of actual observation and feeling, and is an approach that endeavours to comprehend the experiences of an individual if the individual displays extra-ordinary characteristics. In the event of limited knowledge with regard to a certain issue, case studies provide a useful source of information.

This method could be criticised as it has no generalisation value. However, conducting the interviews with the families proved to be the best method for gaining insight into the daily lives as experienced by the families. And thus give an indication of the situation the families are placed in.

4.3 Research method

This section will explain the practical steps that were taken in order to conduct this study. It will outline how cases were sampled, the background of each case study used and the interview procedure.

4.3.1 Selection of cases

Punch (1988) emphasizes the importance of a sampling plan and that parameters are coherent and consistent with the logic and purpose of the research. Purposive sampling secures subjects relevant to the research.

For this study, purposive sampling was done, and the cases were identified with the assistance of a medical practitioner who at the time was in close contact with all patients at the hospital (Appendix 1). The selection of families for the sample group was based on the shared characteristic, i.e. in each case the child that was de-institutionalised had to have a dual diagnosis (psychiatric illness is present in the person along with intellectual disability). It is commonly accepted that people with ID are more vulnerable to psycho-social stress than people without ID, and therefore are more likely to develop psychiatric illnesses (Moss *et al.*, 1998). This is due to the large number of risk factors that are prevalent in this population group. Moss *et al.*, (1998) summarise these risk factors to include genetic abnormalities, brain damage, adverse effects of drugs, institutional upbringing, stigmatisation and social marginalisation.

4.3.2 Sample

A total of five families who each have a member with a dual diagnosis, i.e. intellectual disability and mental illness, were identified for the study. Families were

identified via a hospital in the Western Cape (which will be referred to as hospital X) where each family has a member who was discharged from this hospital. The families were selected with no regard to socio-economic or other background factors.

The particular hospital is situated in the Western Cape Province, South Africa and is involved in a de-institutionalisation process. It shifted from traditional custodial care during 1996. Since this time up to 2007, the hospital had de-institutionalised 134 patients, some of whom now live in group-homes and others with their families. The hospital still provides acute care for patients with a dual diagnosis of intellectual disability and psychiatric illness.

4.3.3 Interviews

The care-givers of the family member with a dual diagnosis were interviewed using a semi-structured questionnaire (Appendix 2). Questions were carefully constructed in order to avoid asking leading questions as the integrity of the study depends on the subjects' responses not being unduly influenced.

The interviews were divided into two main sections. Firstly, the families' background and demographic information were gathered. Secondly, experiences regarding the care of an intellectually disabled person were explored. The structure of the interview schedule used for determining background information was as follows:

1. Family structure (did both parents live in the same house, number of siblings);
2. Family's monthly income;
3. Age, sex, marital status and level of education of the care-giver(s);
4. Age and sex of the deinstitutionalised patient; and
5. Living arrangements (where did the patient reside at the time of the interview)

The interviews explored the care-giver's health (physical, mental and emotional), attitudes and beliefs. During the interviews the following family members were present:

Table 4.1 Interview attendance

Interview with reference to the person diagnosed with ID and mental illness in this study, identified as	Mother	Father
J*	√	√

K	√	
W*	√	√
T	√	
R	√	

*A collective response in cases where both parents were present

4.4 Description and data collection process

4.4.1 Interviews

In order to facilitate care-givers' accounts of their experiences, in-depth interviews were conducted in person. This enabled both the care-givers and the researcher to further explore the meaning of the questions asked and to elaborate on their responses immediately. Another advantage of in-person interviews is that there are fewer restrictions placed on the population under study (i.e. provided that there is a shared language between the subject and interviewer, literacy is not a requirement) (Bless & Higson-Smith, 2000).

The length of each interview was directly related to the subject's willingness to share information and the interviewer's success in eliciting conversation from the subject. Interviews lasted approximately forty minutes. This allowed adequate time to explore the topic and covered most of the questions in the interview schedule, allowing for 'rich' and detailed responses.

4.4.2 Data collection process

A tape recorder was used to record the interviews, after consent to do so had been obtained. This proved to be the most effective method for capturing data during the interviews. This method has the added advantage that it ensures that important issues raised during the interviews are effectively captured and included in the analysis and interpretation of the results.

The data collection process took place over one month during which time all of the five families were interviewed. Although not always possible, the interviews took place at the families' homes, although one of the interviewees preferred to be interviewed at her place of work.

4.4.3 Additional information

The data collected through interviews was analysed and discussed with reference to relevant literature on this topic. Furthermore, the clinical histories of the patients were obtained from the hospital records.

4.5 Data analysis

A content analysis was used to analyse the data. Once collected, the data was transcribed verbatim and then analysed using ATLAS.ti® 2nd version. The basis of the programme is a flexible coding and sorting system that allows easy collection and manipulation of data blocks. Episodes of talk or action are marked or coded according to the categories which have been created. This method was followed to qualitatively gain access and insight into the information gathered.

4.6 Ethical considerations

Ethics are concerned with fairness and justice. In research, ethics aim to provide guidelines on what constitutes moral behaviour in a sphere of science. There are numerous sets of ethical guidelines for specific categories of research and, even though they differ depending on the field of study, they work towards a common goal. It aims to protect the research, the subject, and the researcher by rules when a study is undertaken. Ethical statements provide guidelines for researchers in their respective disciplines and inform them about ethical issues that may arise during the course of their research. These rules encourage researchers to behave ethically and professionally whilst conducting their studies so that they can protect not only the subject of the study, but also themselves.

Discussions about ethics in social sciences hinge on various factors, namely voluntary participation, informed consent, confidentiality and guaranteed anonymity, and harm to participants.

4.6.1 Voluntary participation

Ethical consideration in qualitative research involves the subject's decision to participate in a study, which should be totally free of coercion, both direct and indirect.

Each family was given the choice to participate in the study. They were assured that there would be no negative consequences if they did not participate. No reward was offered if they did participate in the study.

4.6.2 Informed consent

Ethical research practice demands that a subject's consent (Appendix 3) is obtained before any kind of research can be undertaken. Hammersley & Atkinson (1994) propose that the group or person should be informed in detail with regard to the interview to be conducted, and that it be conducted by own free will. In this instance the subject's consent was sought and signed consent obtained when the researcher introduced herself and explained the procedure and the purpose of the study.

4.6.3 Confidentiality and anonymity

Confidentiality and anonymity are important to ensure that subjects communicate without any reservations. However, since the information for this study was collected in face-to-face individual interviews, it was not possible to maintain anonymity during data collection. The subjects were given assurances that the information they provided, would be treated with confidentiality. Upon being given this reassurance, the subjects seemed willing to give honest and complete information.

4.6.4 Harm to participants

Whilst it might appear possible to involve people in a study without their approval, a researcher has to ensure that they are not harmed in any manner: physically, psychologically or emotionally. The same ruling applies to people who volunteer to participate in a study, and Mouton (2001) suggests that they should not be subjected

to considerable chance of being harmed. In this study, every precaution was taken to avoid inflicting injury of any kind.

4.7 Potential limitations of the study

The verification of a study involves ascertaining the reliability of the subjects and the validity of the findings in a study. Thus, the information gathered is based on the knowledge and experiences of the family. It is possible that the families' perspectives of their situations and circumstances could be skewed in some way. An overall mapping and evaluation of services and support systems would be useful in assessing whether there are sufficient resources available.

The methodology has provided a brief background to the nature of case studies and their specific analyses. The next chapter will now focus on a presentation of the case studies involving the families of people who carry a dual diagnosis.

CHAPTER FIVE

Results

5.1 Introduction

An analysis of the semi-structured interviews highlighted a number of important issues facing families involved in de-institutionalisation. A clinical history and description of each family will be presented. The impact of the de-institutionalisation process as experienced by each family will then be detailed according to the characteristics displayed by the individual with a dual diagnosis of ID and mental illness, the effect that living with such a person has on the family, as well as community factors that play a role in their experiences. Family members' quotes will be included to support themes. An English translation of quotes will be supplied where participants were Afrikaans speaking.

5.2 Case study 1

5.2.1 Clinical history

J was born in SA in 1981, and in 1988 he moved abroad with his parents. While abroad, an assessment carried out in 1990 resulted in a 'statement of need' with a diagnosis of semantic pragmatic language disorder. Speech therapy was recommended and he was placed in a school for moderately learning disabled children. He was reassessed in 1994. The question of autism had arisen, but no evidence of this was found. Two years later he was diagnosed as having dyslexia with low IQ. He left school at 16 years of age and entered a residential junior college. J had his first psychotic episode in 1998 and a diagnosis of schizophrenia was made. He

was treated with thioridazine which was later changed to risperidone. During 1999 he returned to SA with his family. His behaviour deteriorated and he became extremely disruptive. He was then put on haloperidol. Because of his challenging behaviour he was admitted to the hospital in the current study which hereafter, will be referred to as Hospital X. It was decided to do a drug washout, but his behaviour deteriorated further – he manifested extreme akathisia, extra-pyramidal side effects with profound sweating and weight loss. It appeared that he had developed neuroleptic discontinuation syndrome. He became critically ill, catatonic and almost died. Over the next few years he had a fluctuating course with gradual improvement. He was eventually discharged on clozapine and Epilim. At this stage a diagnosis of schizo-affective disorder was made. J has required further admissions at times for behaviour and medication review, but has remained relatively well.

5.2.2 Family description

The family consists of four members: J, his biological parents and his sister. All of the members live in the same home, except for J. He is currently in a group-home, but he used to live at his parents' home. He does still go home often for visits. The father is 56 years old and the mother 51; both parents have university degrees. They live in an upmarket area in a predominantly white community. Their estimated annual income is R370 000 (it varies from month to month) from a business that they run from their home.

The interview took place in the family's home, with both parents present and actively taking part in the discussions. Both parents acknowledged that the mother did most of the care-taking.

5.2.3 Individual characteristics

J's parents described him as being difficult to place, as at first glance he seems healthy, but after talking to him for a short while it becomes clear that he is not. His father stated that:

“...he is hopeless; I mean he can't even write. He needs a high level of care, but he looks OK.... he is a difficult guy to place.”

5.2.3.1 Aggression

As J grew older, his displays of violent and aggressive behaviour increased. He is often overwhelmed by any anxiety he experiences, resulting in his 'lashing out'. During one of his psychiatric episodes, his aggression escalated to the point where he physically attacked his mother. This violent behaviour places considerable emotional strain on his family.

5.2.3.2 Constant need of attention

J is excessively demanding of his parents' attention. He constantly wants someone to play with him and talk to him. This is extremely difficult for his parents to manage, as they run a business from their home. Caring for their son and managing the business often impact negatively on each other.

Due to his behaviour, J needs constant supervision. He cannot be left alone for any period of time. His mother states that:

"... he would walk in the garden on his own, and I might be hanging up the washing or something, and talking to him from a distance that he knows we're still watching ... it's exhausting."

His mother has also learnt to read his moods, such as when he becomes anxious, and she is then able to distract him, provided she recognises it soon enough. This places a considerable burden on her, as she must remain continuously alert to her son and his moods. To avoid J getting bored and frustrated, a strict routine is adhered to. His mother works out a daily timetable that plans his day's activities in hourly sessions.

5.2.3.3 Running away

The parents are especially concerned about the fact that their son talks to strangers without being cautious of potential danger.

"He will go to everyone as a friend and he is so vulnerable. If he sees somebody walking along ... he will chat."

His parents believe that it will be extremely dangerous for him to leave the house without supervision.

“... he can't ride his bike on his own ... he's got no idea about the traffic...”

They are also concerned that he is totally unaware of the consequences of any of his actions. During a period of psychiatric illness, he would sometimes run away without any thought as to what might become of him.

5.2.4 Effect on family

5.2.4.1 Family structure

The family tries to live a normal life, despite the difficulties associated with living with a family member with ID and psychiatric illness. They have developed coping strategies for dealing with their situation. For example, they always walk along the same route with their son, with the result that when he runs away, he can usually be found along this route.

5.2.4.2 Quality of marriage

The family reported no serious marital conflict due to their son, but reported that the situation did place additional strain on their marriage and that this would be aggravated by their occasional opposing views on how to handle a specific situation.

5.2.4.3 Illness

The family did not report any illness due to the situation regarding their son.

5.2.4.4 Social restraints

J's parents have lost a number of friends as a direct result of having to care for their son.

“Some people just don’t understand, you know. But having a child with learning disabilities doesn’t mean that there is something wrong with you.”

As a result of their situation, they are severely restricted in their own social activities.

“... we have two kinds of separate lives. When (the patient) is here, it’s all about (the patient), and we go to a movie or we go out, whatever, to McDonald’s or something. When he is at (his group home), we do everything else we have to do in our social lives.”

5.2.4.5 Financial implications

Although the family believes that they will never have to buy J a car, pay university fees or sponsor him to travel, they still feel that he is a financial burden.

“He depends totally on us, and he will never get a job or earn money.”

They are especially concerned with having to make provisions for him when they have passed away. State support pays for the patient’s medication, which provides the parents with some financial relief.

5.2.5 Community factors

5.2.5.1 Support groups

J’s parents have had very little support in caring for him, their only source of support being the patient’s grandparents; since they passed away, they have had no other support systems.

5.2.5.2 Group-homes

The group-home in which J has been placed has impressed his parents. At the home

“... he can be his own person. When he is there, he has a number of chores that keep him occupied. He must complete these chores before he is allowed to entertain himself with activities of his choice. If he does

his job in the morning, he is allowed to watch TV in the afternoon ... I think that's brilliant, that they make him feel useful.”

The situation at the group-home is not without difficulties. Due to staff constraints, not all patients can be monitored at all times. This could allow circumstances to develop that might otherwise have been avoided, such as patients becoming violent when an activity could have diverted their attention. This may result in J's expulsion due to bad behaviour, which is a real concern to his parents.

5.3 Case study 2

5.3.1 Clinical history

K was born in the northern parts of South Africa during 1974. His development during childhood was delayed, but in early adolescence he developed body and vocal tics. A diagnosis of Tourette's Syndrome was made and haloperidol prescribed. He moved to Cape Town with his family in 2001 and was seen at Hospital X. At that stage he was taking very large doses of haloperidol and had severe dyskinesia, akathisia and dystonia. The diagnosis of medication-induced movement disorder was added. K was admitted to hospital for evaluation. Unfortunately, during the admission process he was being shown the ward by a fellow patient of similar age. While his mother was completing admission papers in the ward office downstairs, K was sexually abused by the other patient. This was very traumatising and has left him with persistent recurrent PTSD symptoms. K has developed obsessive behaviours, for example with certain smells. For the past few years he has required a number of admissions for behaviour management and medication review.

5.3.2 Family description

The biological parents of K are divorced, with the father and mother living far apart. K lives with his mother. His only brother used to live with them, but is now married and has moved out of the mother's house. The patient is currently in hospital, but will live at home again when he is discharged.

The mother is 58 years old and has a tertiary diploma in secretarial work. She is unemployed and receives money from her ex-husband, making the household income between R6 000 and R6 500 a month.

The interview took place at the mother's house. It is a middle class home, in a mostly white community. Only the mother was present during the interview.

5.3.3 Individual characteristics

According to his mother, K's challenging behaviour has been made particularly difficult because he looks outwardly healthy, and people therefore cannot understand his behaviour.

5.3.3.1 Aggression

The mother reported that her son is extremely aggressive.

"...he was (at home) for a week and he went absolutely mad - he actually ripped that door of his room right off the hinges."

She therefore no longer takes him to see his brother as he and his wife have just become parents.

"I am scared in case he starts to carry (on) around there. Not that I think he will, but you know, I cannot take a chance like that, and (his brother) doesn't want it anyway."

The mother reported that her son is abusive towards her, and that she has been injured by him.

"... when he came home it was like everything bang, slam, screaming all weekend – imagine how it hurts ... he hit me, punched me, kicked me...."

5.3.3.2 Destructive behaviour

He tends to be very destructive. During the interview she pointed out things in her house that he has broken.

"All my ornaments, every single ornament and vase I had have been"

broken. All my wall pictures... so basically all my worldly possessions are broken.”

5.3.3.3 Manipulative behaviour

He started to be manipulative after his brother got married and she was the only woman in the house. He does not understand that his brother can move out and get married, but he has to stay behind. He said that, should his mother not act as his wife, he would find himself one. This places his mother in a difficult position where, by her reasoning, sending him to the group-home causes him to believe that she does so because she does not want to be his wife.

5.3.3.4 Isolation

The mother reported that K is not keen on going out.

“Even when I say, let’s go for walk. ‘No!’ So I mean, there’s nothing I can do. Sometimes you think you will be able to go to church with him. ‘No I don’t want to go’.”

5.3.3.5 Sensitivity when spoken to

The mother reported that, as well as her son being very aggressive he is also very sensitive to the manner in which he is spoken to.

“...he does not like to be reprimanded, and you have to be careful how you speak to him, and you have to speak softly and cannot say ‘Stop it now!’ He will go into frenzy.”

5.3.3.6 Sexual frustration

The mother noted that her son's sexual frustration creates yet another difficult situation for her as it inevitably culminates in his destructive behaviour.

“He gets sexually frustrated and wants special music and if he cannot get it - he also cracked my radio. He smashed CD-players against the wall.”

She stated that due to the fact that he had been sexually abused in the past, he has a preference for men rather than women. She explained that he does not have social etiquette and makes inappropriate comments.

“(His preference for men) is a difficult situation, because he would meet this man and say something funny to him ... ‘Tickle me’ or ‘Can I see your feet?’ He’s got this thing about feet. It’s a difficult situation.”

She noted that he has intentions with the neighbour's son.

“The day he went crazy he said he wants to see the neighbour's son... ‘I want him to come here.’ I knew he was sexually frustrated.”

She implied that her son is not subtle about his sexual thoughts and actions, and stated that this has a very negative effect on her emotional state.

“... and he doesn't do it (masturbate) properly either. He'll lie on his stomach for ages like, till I want to go mad and scream.”

5.3.3.7 Delusions

The patient's belief that people are making fun of him results in him being very isolated. The mother reported that this has resulted in her being unable to take him anywhere.

“He can't do that anymore because people are making faces at him. He thinks people are saying things to him... when he gets worked up then you got to try and take him back to the car and bring him back home. Even going in the car sometimes he thinks the people in the next car are making faces at him; he'll start slamming the car. He once knocked my back window out.”

5.3.3.8 Embarrassment/lack of social etiquette

The mother felt that everybody was very aware of her situation and that she is a burden to the people around her.

“It affects everybody in the community eventually. All my neighbours could hear the banging and slamming and screaming and swearing and carrying on.”

The fact that she lives in a small house and that the houses are very close to one another increases the embarrassment she feels about her situation. Her son also does not understand that due to the tight living arrangements, people have to respect others.

“With the slamming and banging sometimes happen(ing) at 02h00 in the morning. The TV and radio going. You said ‘Turn it off’, he goes slam, crash and things like that. He bangs the door up and down in such horrific ways, screaming.”

The patient's mother is aware that this situation has a negative impact on her neighbours.

“They understand now, but I mean obviously they get stressed from it, you know?”

5.3.4 Effect on family

5.3.4.1 Quality of marriage

The mother is divorced from the patient's biological father, but she did not report whether this was due to circumstances connected to their son.

5.3.4.2 Illness

5.3.4.2.1 Stress

The mother reported that searching for a suitable group-home increased her stress levels. Her experience was that, although there are a few suitable group-homes, most of them were full and/or expensive.

“I've got stress trying to look for a group home for him ... most of them are full. These people are here for life – there's no hope and there's a

long waiting list, don't even bother... Even if (I am) happy with a home and it's full, what do you do?"

As most group-homes are full and have lengthy waiting lists, the stress of looking for a suitable group home has caused the mother to feel hopeless in her search.

5.3.4.2.2 Depression

The mother expressed feelings of depression.

"It's actually a depressing situation."

She still expressed an instinctive care for her child, but she felt depressed and hopeless.

"I mean, I love (my son). My heart was shattered, absolutely shattered this last time when (he displayed abusive behaviour), but you miss them terribly... You don't turn against them because they destroy everything, kick you, but it's just difficult - you don't know where to put them."

She also stated that she is always concerned about him.

"As soon as you've dropped him off (at the group-home), is he OK? You worry all the time."

5.3.4.3 Employment

The mother has sole responsibility of all the care-taking, and this prevents her from having a full-time job.

"He is capable of bathing himself but that's also so far, you have to look that he does get into the bath and everything else. I have to shave him, make sure that he brushes his teeth, and I cook and clean for him."

5.3.4.4 Burdens on the care-taker

The patient is very attached to his mother. This means that he comes home every weekend now that he is in a group-home. She reported that she found this situation disruptive.

“I fetch him on a Friday afternoon and take him back on Monday morning... this is a hassle for me.”

5.3.4.5 Social restraints

The mother’s social life is severely restricted. When her son is at home, she cannot go anywhere and has to stay home with him, as she cannot take him out with her.

“I cannot go shopping with him, I can’t go to the beach with him anymore... When he is here for a weekend you have to make sure that you’ve got everything because if you don’t then... we cannot really go out at all.”

When he is home, she lives in isolation and fear.

“I just run down the road, rush out here to the little shop, and grab whatever I need. There was even a couple of times when I came back, he was very excited and carrying on. And I said ‘What’s wrong?’ And he said ‘(Somebody) just phoned and swore at me.’ Or ‘Somebody walked past here and pulled faces at me.’ I pull the phone out when he’s here. Make sure the curtains are closed all the time and the doors locked.”

5.3.4.6 Financial implications

The mother reported that the financial implications would have been considerable when calculating the expense of replacing all the goods broken or damaged by her son.

“I cannot be bothered while I don’t have the money to replace it. We live like this.”

She stated that even though he gets a grant from the government, it is not sufficient.

“It’s expensive to pay that amount of money and then, you know, you still have to supply their toiletries, and they want this, and they want that, and he wants his books and crayons, and he goes through crayons and books terribly. I still have to pay for my house and everything else that goes with when you buy a house ... So ja, I just feel there should be more ... or the government should have done so a long time ago.”

5.3.5 Community factors

5.3.5.1 Group-homes

The mother’s experience was that there is a lack of appropriate accommodation for people with ID and psychiatric illness.

“Problem is that hardly anyone in the Western Cape takes people with intellectual and psychiatric illness in, and when they do, it is very expensive... people realise that there is something needed to be put in place which is affordable to the public.” This state of affairs is compounded by group-homes’ staff-members being unhelpful and rude. “He slammed the door a couple of times and because they (had) just plastered the top, some of the plaster fell down. They suspended him indefinitely, but the way it was done, you know, ‘Come and fetch him within an hour or I will put his things on the pavement’.”

This situation created a lot of additional anxiety for the mother as she was a worried about where her son would stay after she passes away, and she wants him to be content. However, she did feel that living in a group-home was indeed the best type of accommodation for people with intellectual disabilities and psychiatric illness. She was aware of cases where a child with ID lived at his parents’ home on a permanent basis, a situation which later turned out to be unsuitable.

“He lived all his life with his mother and father and he was beating them, but they were keeping, holding on to him forever. You cannot do that because they manipulate you. And being old people like that being bashed up by this guy. I don’t know what happened in the end. I don’t want to think about it.”

She cited another case of which she was aware, where an old lady took care of her son with intellectual disability by herself.

*“Thumping and kicking her, and she was a skinny, frail little thing ...
And she kept (her son) until she was just about to die.”*

She emphasised that putting one's child with intellectual disability and psychiatric illness into a group-home was a positive action as it enabled them to settle into a routine. She argued that even though she knew she could take better care of her son, he needed to be more settled. She regretted not placing him in a group-home sooner.

“There is nothing better than home life... I give him the best care but rather let him get second-best care and be settled. So, I'm sorry I did not put him in a home when he was eighteen.”

5.3.5.2 Other support

The mother's experience was that whilst her other son was living in the house with her and the patient, she could rely on him for support, but following his getting married and moving out of the house, she could no longer rely on him for help. In times of crisis, she has come to rely on her pastor.

“When he was home for a weekend he got very aggressive and I relied on my pastor for help.”

There is a lack of adequate emotional support forthcoming from the community. Although some organisations offer support groups, K's mother found attending such group meetings a negative experience. She reported feeling alienated, as there was nobody who particularly understood intellectual disability.

“You listen to all these problems and they were all psychiatrically ill. None of them knew what ‘mental retard’ meant. I first had to explain that to them. To listen to everybody's stories - this one's on drugs and that one's doing that, and that one's doing that, this one's run away from home and she doesn't see him for two years. By the time you finished ... there was not lot (of) support, it was more like a pity-party.”

There is also no practical help, so the mother feels that all she can do is try to best read her son's needs and pray.

“I have to try and defuse the situation, which you can’t really. Or you have to tranquillise him or just sit and pray. And that is all you can do.”

She showed concern for similar situations in other cultural groups, but felt that they were better off than she was as she believes that those cultural groups have more support from their family.

“I don’t know what the Coloureds do, because there’s a lot of Coloured families with these problem-children or adults, or whatever you call them, and a lot of them cannot afford to do anything, although I think there’s a system in place where the families help each other, because they are quite big families.”

The mother stated that her saving grace was her faith. She is Christian, and felt that had she not been, she would not have survived her situation emotionally.

“It’s a very difficult thing to go through. Thank goodness I’m a Christian. I couldn’t have handled it if I wasn’t. If you have nobody to turn to, not even a god, it would be far worse, I imagine.”

5.4 Case study 3

5.4.1 Clinical history

W was born in 1982. He was found to have mild intellectual disability and attended an LSEN (learners with special education needs – ID) school. During adolescence he developed disruptive behaviour. He was diagnosed as having Oppositional Defiant Disorder and Obsessive Compulsive Disorder. Medication was prescribed, but it had little effect. At 16 years of age he was admitted to a psychiatric hospital in Cape Town. Despite an intensive behaviour modification programme, W remained difficult to manage. In 2001 he was transferred to Hospital X for further management. A diagnosis of Bipolar Disorder was made and he was thought to have additional Axis II pathology. He was treated with Epilim and lithium and later haloperidol and then clozapine. Since 2001 W has required ten admissions to hospital for behavioural management.

5.4.2 Family description

The family consists of five members: both of his biological parents, the patient, and his two younger siblings, a brother and a sister. All of the family members live under the same roof, except for the patient who is currently in hospital. When he is not in hospital, he is in a group-home, but due to his behaviour has been expelled from a number of homes, and has had to return home. Both parents reported that the mother does most of the care-taking, although both actively participated during the interview.

The mother is 40 and the father 42. The family's monthly income is between R10 000 and R12 000. The father is a police officer. The mother is currently unemployed. Both parents completed high school.

The interview was held in the family's middle class home in a majority Coloured community.

5.4.3 Individual characteristics

W is self-sufficient and can cope. He can look after his own hygiene, dress himself and make his own breakfast. The parents felt that because their son looks healthy, people do not accept his challenging and disruptive behaviour. The mother feared that people would speak to her son whilst he is stable, but when he has an episode he would remember those people he had spoken to, and would go back to them and misbehave there. The family reported that it was difficult for them to explain their son's behaviour as he appears at face value, to be healthy.

“Dan sal ek sê dis W se problem, maar nee, hy's onbeskof net omdat hy normal voorkom. Die buitewêreld aanvaar iemand, jy moet heeltemal simpel wees.” (“Then I say it's W's problem, but no, he is rude just because he appears to be normal. The outside world accepts someone, you have to be stupid.”)

5.4.3.1 Aggression

The parents reported that their son had been aggressive from an early age, and that this behaviour escalated as he got older, to the extent that he would physically attack people.

“Hy het ‘n verskriklike humeur gehad. As hy in ‘n speelgroep is, sal hy nou hare trek of krap of bakleierig wees, maar ons het altyd gedink hy is hiperaktief. Soos hy ouer word, toe kan ons sien hy het ‘n probleem en dit het al hoe erger, en erger en erger geword ... want hy sal mense aanrand.” (“He had a terrible temper. When in a play group, he would pull hair, scratch or fight, but we always thought he was hyperactive. As he grew older, we noticed that he had a problem and it became worse and even worsened... because he would attack people.”)

They felt unsure as to whether he would ever attack them or one of his siblings, because his behaviour was so unpredictable. His parents were especially anxious about his behaviour in public. The mother explained that she would take him shopping with her, but that he would start swearing and yelling at people. He sometimes also made racist remarks. She felt that people do not expect this kind of behaviour as her son looks healthy. This behaviour has resulted in the mother no longer taking him with her to do the shopping. She worried that he was becoming increasingly isolated from the world.

5.4.3.2 Constant need of attention

The parents reported that the patient constantly demands their undivided attention. They mentioned that he was manipulative, but they did not expand on this. They also briefly mentioned instances where their son was sexually harassing the group-home caretaker. They did not, however, want to go into detail about this.

5.4.3.3 Self-destructive behaviour

The mother recounted instances of her son’s self-destructive behaviour.

“... sy kop stukkend stamp soos wat hy gedoen het die laaste tyd wat hy harsingskudding opgedoen of ‘n gekraakte skedel opgedoen (het) ...”.
(“He knocks his head like the last time when he was concussed or fractured his skull...”)

5.4.3.4 Isolation

The parents felt that even though the neighbours are understanding of their situation, they nonetheless try to minimise their son's contact with the people in the community.

“Omdat ons amper in ‘n townhouse-tipe area woon, is ons baie beperk. Om W uit die moeilikheid te hou, hok ons hom meeste van die tyd in die huis, of ons pak ‘n mandjie en ry die heeldag, die dag uit, enige plek toe.” (“Because we live in a townhouse-like area, we are very limited. In trying to keep W out of trouble, he is locked indoors most of the time, or we pack a picnic basket and take a drive for the day, for a day out, to anywhere.”)

5.4.3.5 Embarrassment/lack of social etiquette

The parents felt embarrassed by their son's behaviour and stated that they had reached the end of their tether as he is so unpredictable. They recounted an occasion where this behaviour was prominent.

“Die een keer het ons beach toe gegaan, strand toe gegaan, dit was so net na Kersfees. Ons het alles probeer om soos ‘n normale familie te lewe met W. Ons aanvaar hom met sy problem en ons wil hom intrek met alles wat ons doen. Ons sambreel is uit, ons mandjie is uit, ons cooler box is uit, en nou sit ons op die strand; die strand is vol, dis vakansie. Skielik spring W op en begin ons te gooi met skoene, met ons skoene wat ons uitgetrek het, en begin te gil en hardloop. Ons het opgepak, in die kar geklim, en W het skel-skel agterna gekom. Ons weet nie wat aanleiding gegee het tot daai uitbarsting nie.” (“Once we went to the beach, it was just after Christmas. We tried everything so as to act like a normal family with W. We accept him with his problem and try to involve him in everything we do. Then we settled on the beach under the umbrella, and unpacked the picnic basket and cooler box, and the beach was packed, it was holiday season. Suddenly W jumped up, and started throwing us with our own shoes, while screaming and running. We packed up, got into the car while W followed, swearing. We don't know what triggered that episode.”)

They reported that he has no social etiquette; which leads to embarrassment.

“Of ons sal miskien na ‘n plek toe gaan en dan sal hy sommer sy broek aftrek en begin pee.” (“Or we may be going somewhere and he would simply lower his pants and urinate.”)

The mother felt confused by his behaviour as it seemed to her to be in contradiction to his good vocabulary.

The mother pointed out that the social worker at the hospital questioned her assessment of the situation, as their son does not display the reported challenging behaviour when he is in the hospital. The mother argued that this is due to the more contained environment at the hospital.

“In die hospitaal is daar nie meubels nie, daar’s nie deure nie, en daar’s so min goed. Vat vir hom in ‘n woonbuurt of vat hom huis toe. Neem hom huis toe saam met jou vir ‘n naweek en doen dit wat julle as gesin moet doen en dan sê jy vir my hoe is W. Kyk, in die hospital is almal opgelei en almal aanvaar sulke gedrag; buite werk dit nie so nie.” (“The hospital doesn’t have furniture, there aren’t doors, and there’s so little stuff. Take him into a suburb, or take him home. Take him home with you for a weekend and do what a family normally does and then tell me how W reacts. Look, in hospitals everyone is trained and everyone accepts such behaviour, but in the outside world it doesn’t work that way.”)

5.4.4 Effect on family

5.4.4.1 Family structure

The parents explained that the situation is particularly difficult for their other children. Whenever W was home, his siblings were sent away to stay with their grandmother. The mother reported that the negative effect their situation has on the family unit is difficult to accurately portray.

“Ek dink nie ‘n mens kan ooit verstaan waardeur ‘n familie gaan nie.” (“I don’t think a person could ever understand what a family endures.”)

5.4.4.2 *Quality of marriage*

The parents did not report that the situation placed their marriage under significant strain, but did feel that it led to additional conflict.

5.4.4.3 *Siblings*

The mother mentioned that it was particularly hard for her younger son to deal with the situation. She reported that when the patient was home, she sent her other son and her daughter away.

5.4.4.4 *Illness*

5.4.4.4.1 *Stress*

The patient's parents reported that their son's aggressive and destructive behaviour had negatively impacted on their own health.

“... toe hy die bure se ruite almal stukkend ge-smash het, die motors se vensters stukkend ge-smash het, dit was my nou my (psychological) breekpunt.” (“...when he smashed the neighbours' windows, smashed the windows of the cars, now that was my psychological breaking point.”)

The mother reported that she is constantly occupied with her son's needs. She explained that it made her extremely stressful that she had to switch her cellular telephone off whilst working. She reported that she felt faint and nauseous whenever she saw the group-home's number on her phone.

“Onmiddellik raak 'n mens heeltemal laf, of jy word naar, want jy weet nou's daar 'n probleem.” (“One instantly feels helpless, or you feel nauseous, because you know there's a problem.”)

5.4.4.4.2 *Anxiety and depression*

The mother reported that she had been admitted to hospital a number of times due to

stress caused by her situation at home. She mentioned that she felt that, as long as her son is present, she would experience similar health problems.

She mentioned that she felt hopeless and that she could not see any solution.

“Daar’s nooit ‘n oplossing nie - word gestabiliseer, en dan doen ons maar weer die roete van voor af, totdat daar nou weer ‘n insident plaasvind, en dan is ons maar weer waar ons begin het.” (“There’s never a solution – after stabilising, we simply start the route all over again, until the next incident occurs and we find ourselves once again where we started.”)

She admitted to taking anti-depressant medication to help her cope with the difficult situation she finds herself in.

“... want dis vir my verskriklik moeilik om ‘n kind te hê wat van kleins af al onder dokter is, onder psigiaters is.” (“...because I find it very difficult having a child who has from childhood, has been under doctors, psychiatrists.”)

5.4.4.5 Employment

The father is a policeman, and reported that the situation with their son sometimes puts him in a difficult position. He also stated that his job made it easy for him to slip away whenever there was a problem at home as he is not restricted to an office. He stressed that slipping away like that is, however, an inconvenience.

The husband reported that his wife had to stop working due to the situation. He explained that even though the patient was in a group-home, his wife still had too much responsibility.

“Hoewel hy in ‘n groePHuis is, bel hulle of vir my of vir haar (his wife) en sê: ‘Kom haal julle kind, ons kan nie meer nie.’ En dan moet ons alles net so los en hom gaan haal.” (“Even though being accommodated in a group-home, I am or (his wife) is phoned and told ‘Come and collect your child, we cannot bear him any longer’. And then everything has to be dropped so as to fetch him.”)

5.4.4.6 Social restraints

W's challenging behaviour has resulted in the family losing many friends. His mother felt socially very restricted and stated that none of the family friends could just 'drop in', but they must always phone first. She felt that she has to apologise for her son's behaviour in her own house, and this made her uncomfortable. Their son was preventing his parents from socialising with their friends in their home, as he wanted to be part of the conversation and demanded all of the attention.

“Ek wil nie hê (friends) moet in my huis wees as W daar is nie en nie almal aanvaar altyd W se gedrag nie. Ek wil nie in my eie plek die heelyd om verskoning vra vir iets nie. (The patient) wil deel wees van die gesprek; as W nou hier gesit het, dan sou hy jou vrae geantwoord het.” (“I don't want (friends) in my home when W is there and not everyone accepts W's behaviour. I don't want to constantly be apologising for something in my own home. W wants to participate in the conversation, if W were sitting here now, he would have answered all your questions.”)

5.4.4.7 Financial implications

The family's financial situation is under strain due to their situation. They stated that the group-homes were expensive and that the costs for patients with challenging behaviour were even more expensive.

“Hulle wou sommer die prys opgestoot het omdat W baie uitdagend was.” (“They even wanted to increase the tariff because he has a challenging attitude.”)

They felt that the expenses arising from their son's needs had a negative impact on his siblings.

“Dit het vir ons as familie baie ge-deprive van sekere goeters, want ons kan nie, en natuurlik het my ander twee kinders daaronder gely...” (“It has deprived us as a family from certain items, because we cannot, and of course, my other two children suffer because of that.”)

5.4.5 Community factors

5.4.5.1 Support groups

The parents stated that they would have been able to rely on their family for support, had their extended family not lived so far away. The mother noted that she saw her immediate family (her parents and siblings) and the psychiatrist and psychologist that she is seeing, as her support system.

5.4.5.2 Neighbours

The parents felt that even though the community understood their situation, they could not compensate them for all the destruction their son caused. This resulted in their becoming isolated from their community.

5.5 Case study 4

5.5.1 Clinical history

T was born on during 1982 and was said to have had behaviour problems since birth. He was described as a restless and demanding infant. As a child he was aggressive and destructive. His early developmental milestones were delayed. Despite intensive investigations, no cause was found for the developmental delay. When he reached school age he was enrolled in an LSEN (learners with special education needs) school. He was later found to have attention deficit/hyperactivity and methylphenidate was prescribed, without any measurable benefit. After leaving school his behaviour deteriorated and he was referred to Hospital X, where he was admitted during January 2001. A diagnosis of mild intellectual disability, major depressive episode (MDE) and anxiety was made. Mianserin was prescribed. His behaviour remained problematic, necessitating the trial of carbamazepine and then clozapine. The clozapine was felt to be beneficial, but signs of tardive dyskinesia in the fingers and trunkal dystonia were detected. Later excessive weight gain with cushingoid features occurred, but this was attributed to the clozapine. His behaviour remained difficult to manage and because of his size and marked aggression, he was judged to be a danger to the staff. T was then transferred to a more secure unit at a Cape Town psychiatric hospital.

While in this hospital, he developed evidence of psychosis, leading to a diagnosis of schizophrenia. He spent a prolonged period in this hospital before being discharged home.

During a review at Hospital X, intrusive obsessive thoughts were reported and clomipramine was prescribed. These were later put down to misinterpretation of information due to his intellectual disability and the clomipramine was withdrawn. Some of the behaviour problems were attributed to Axis II pathology. He also had taken to heavy alcohol use. At that stage, his diagnoses included Bipolar Disorder, Intermittent Explosive Disorder, Substance Abuse and Medication Induced Movement Disorder on Axis I. He was being managed on Epilim and clozapine. When seen a year later as an outpatient his behaviour was improved but he was still overweight and had developed excessive salivation. The weight and salivation were attributed to the clozapine, but because of the improved behaviour, it was continued.

At an outpatient review the following year the diagnosis was revised to Schizoaffective Disorder, and topiramate was introduced. T has had a number of failed group-home placements and repeated hospital admissions. He was admitted six months ago and is still in hospital.

5.5.2 Family description

The interview was held in the biological mother's office. The patient's parents are divorced. The patient is the mother's responsibility, and he does not have contact with his father.

The mother is 55 and has a secretarial qualification, and is currently a senior manager. The household's monthly income is R17 000.

The mother is remarried and lives with her new husband. She has two other children who are no longer live at home. The patient is currently in hospital, but when he is discharged he lives in a group-home. Due to his behaviour he has been expelled from previous group-homes, and then returns to live at home.

5.5.3 Individual characteristics

The patient is self-sufficient and can cope; he can look after his own hygiene, dress himself and make his own breakfast.

5.5.3.1 Aggression

The mother regretfully stated that she and her family were under the impression that the situation would become more manageable as her son got older. She felt that the situation would have been much easier had her son merely been a person with ID.

5.5.3.2 Constant need of attention

The mother reported that her son cannot occupy himself and that she draws up a daily schedule for him, so that he has a new activity to occupy him every half an hour. She stated that he is not always pleased with the programme, and that there are days when he does not want to do anything.

5.5.3.3 Running away

The mother reported that her son sometimes runs away from the group-home, and that there was an incident when he was found on the highway after running away.

5.5.3.4 Mood-swings

The mother reported that her son is unpredictable and that he fluctuates from one extreme emotion to another.

“Hy is totaal onvoorspelbaar. Die een oomblik kan hy lag en gesels en vrolik wees, en vyf minute later ontplof hy absoluut.” (“He is totally unpredictable. He would be laughing and conversing one moment, and exploding five minutes later.”)

She felt that this kind of behaviour made it more challenging to take care of him.

5.5.3.5 Destructive behaviour

The patient has displayed destructive behaviour from a young age. His mother reported that he would guard his own belongings carefully, but has no respect for other people's possessions. She cited an occasion when he set fire to another patient's room at the group-home where lives.

“So met ander woorde, sy eie CD-speler en sy eie televisie wat in sy kamer is, sal hy nooit breek of iets aan doen nie. Maar hy sal in die groePHuis byvoorbeeld ‘n ander inwoner se kamer aan die brand steek. Die inwoner het hom niks gemaak nie, maar hy wou nie sy eie kamer aan die brand steek nie.” (“So in other words, he would never damage or break his own CD player or television in his room. But in the group house for example, but for example, he’d set fire to another resident’s room. The particular resident would have done him no harm, but he didn’t want to set fire to his own room.”)

His family bore the financial responsibility of paying for such damages incurred.

5.5.3.6 Manipulative behaviour

The mother reported that her son is manipulative, especially towards her. She does not allow it, but feels that when she is assertive towards him, he interprets this as a withdrawal of her love for him. She worries that this situation has a negative impact on their mother-son relationship.

“So, ons twee se verhouding is op ‘n all time low.” (“So, our relationship is at an all time low.”)

She feels that her son holds her responsible for his being in the hospital and that he blames her for his having to stay there. He threatens her by saying that he is going to go to live with his biological father. The mother reported that there was no relationship between her son and his father, but that he just wants to get away from her. Her son clearly states that he wants to be in charge of his own doings.

“Hy sê ook ‘Ek is my eie baas en julle gaan nie vir my vertel wat ek moet doen nie’.” (“He also says ‘I am my own boss and you are not going to tell me what I should do’.”)

5.5.3.7 Isolation

The mother felt that her son is not compatible with the group-home dynamic, as he does not want to socialise and instead wants to be alone.

“Hy staan vir my uit soos ‘n seer by die groePHuis. Hy is glad nie ‘n groePHuis kandidaat nie. Hy is absoluut ‘n loner. Hy is nie social nie. Hy wil nie sosiaal verkeer met ander in die saal nie. Hy wil alleen wees. Hy het dit al baie beskrywend gesê, hy wens hy was alleen op ‘n eiland met niemand om hom nie.” (“He isolates himself from others in the group-home. He isn’t a group-home candidate. He is an absolute loner. He doesn’t socialise. He doesn’t want to socialise with others. He wants to be alone. He has been very descriptive in saying that he wishes he could be alone on an island with no one around him”).

She felt that this was not a reflection of his being depressed, but rather a characteristic of her son. She also felt that a lot of her son’s misbehaviour was learnt from the other patients.

5.5.3.8 Sensitivity when spoken to

The mother reported that when her son did not get his own way, he was verbally abusive towards her.

“Daar is baie verbal abuse op die oomblik van sy kant af ook teenoor my. As jy met hom sag is die heel tyd en jy gee vir hom sy sin en jy gee hom wat hy wil hê, is hy fine.” (“He is verbally very abusive at the moment, also towards me. If he is treated gently and allowed his way, and also given what he wants, he is fine.”)

She feared that, should she speak to him more firmly, it might provoke him to be physically abusive towards her. She constantly has to monitor her own behaviour so as not to provoke her son.

5.5.3.9 Additional problems

The mother stated that her son has additional problems, that of excessive eating and drinking alcohol. She explained that she thought he has developed a taste for alcohol and uses it to soothe himself.

“Dis amper asof hy nog die smaak daarvoor het en homself medikeer deur die alkohol in te neem en dan voel hy ... lekker - no care in the world.” (“It seems he has a taste for, and medicates himself with alcohol, because it makes him feel good – not a care in the world.”).

She reported that he was intolerant of other people drinking alcohol, but she suspected that this was the case because he also wants to have a drink. She explained that they (his parents) cannot give him anything to drink, as it has an extreme effect on him.

“Hy gaan homself te buite as hy die geleentheid kry. So ons het besluit ons gaan hom glad niks gee nie.” (“He loses himself when the opportunity arises. So we have decided not to provide anything.”)

She explained that he cannot stop after just one glass and instead would just want more and more. She explained that his excessive eating and drinking was problematic as her family made a lot of effort at celebratory occasions and that, should they be visiting them at such a time, it made things very difficult for her.

The patient also has an inclination towards arson, and is obsessed with lighting fires.

5.5.4 Effect on family

5.5.4.1 Quality of marriage

The mother is divorced from the patient’s biological father, but did not specify whether this was caused by the situation arising from having a son with intellectual disability.

5.5.4.2 Illness

The mother felt that having her son living at home with her would have been impossible for her to handle.

“As hy altyd by die huis was, weet ek nie, ek weet nie waar ek sou opeindig het nie.” (“If he were to be at home constantly, I don’t know, I don’t know where I would have ended.”)

She reported being exhausted after her son had spent a weekend at home. She said that it was a constant battle to keep him calm.

“Jy moet aanmekaar probeer vir hom kalmeeer ... hy sê altyd ‘Ek is op ‘n stasie, los my uit’; hy’s altyd op ‘n stasie ... so, om hom af te kry van daai stasie is nogal effens moeilik.” (“You have to pacify him all the time... he always says ‘I’m at a station, leave me alone’; he’s always at a station... so, to get him away from that station is quite difficult.”)

She reported that she had no health-related illness due to her situation with her son, but that the stress sometimes caught up with her.

“Die stress vang my bietjie.” (“The stress catches up with me.”)

She was very emotional whilst talking about how she coped.

5.5.4.3 Guilt

The mother was worried about her son being moved to a more secure ward for the duration of her periodic absences. She explained that the other male patients tended to be very aggressive and she was concerned that the staffing level at this ward was inadequate. She stated that she felt a great deal of guilt about the situation.

“... as hy agter tralies moet sit en ons kerjakkter lekker rond vir vier dae.” (“...finding himself behind bars whilst we were holidaying for four days.”)

She reported that her situation was reaching a stage where she felt guilty about her son's behaviour.

“Deesdae dink ek nie aan wat ek in die wêreld gebring het nie, maar hoe kon ek so iets in die wêreld bring.” (“Nowadays I don’t ponder on what I brought into this world, but rather on how I could ever have brought such a being into this world.”)

She explained that his medication was not working effectively, and her high emotional state reflected her distress.

5.5.4.4 Employment

The mother explained that she has a demanding career, and that she is expected to travel at times. She explained that she worked hard to reach this position and that she felt that she was under a lot of pressure to fulfil a number of roles. She finds her career to be a lot more difficult than she believes it would have been if she did not have to cope with her son's mental disability.

“(Dit) is ‘n manswêreld, en ‘n ou moet regtig hard werk om te kom waar jy is. Met al die obstacles in jou pad, my situasie net nie makliker gemaak nie. Weet jy, wat veral moeilik is as mens ‘n beroepspersoon is, is dat jy jou werk moet verrig en ... jy is ‘n huisvrou, jy is ‘n ma, jy is ‘n vrou, ‘n eggenoot vir jou man.” (“(It) is a man’s world, and one has to work really hard to get somewhere. The obstacles in my way did not make things easier. You know, it is especially difficult being a professional, whilst still having to be a housewife, a mother, and being a woman, a wife for your husband.”)

5.5.4.5 Social restraints

The mother stated that socialising was challenging in her situation, as she felt that some issues with her son always got in the way.

“T met sy gedragsprobleme is bitter, bitter moeilik. In terme van socialising, in terme van uitgaan na familie toe, in terme van kuier, in terme van waarheen ons ookal gaan, is daar altyd iets wat sy kop uitsteek.” (“T with his behavioural patterns, poses difficulty. In terms of socialising, in terms of visiting family, in terms of wherever we go, something is always bound to happen.”)

She felt that due to her son's behaviour, she could never visit family or go to the shopping centre at her leisure. Such trips always had to be brief. She explained that her family's social life was not only hindered when her son was at home and

living with them, but equally impacted whilst he was at a group-home as there was always a chance that the hospital or group-home might phone to report problems or request that she come and fetch her son.

She reported that the family could not go on holidays, as whenever she had leave from work, her son had to come home. She felt that she has no time to relax and to attend to herself. She noted an example of when she and her husband would go away for a weekend. There were many logistics involved in such an excursion, and when they do go away for a weekend, she has to keep her cellular phone close by.

5.5.5 Community factors

5.5.5.1 Support groups

The mother felt that she could rely on her family; her husband (not the patient's biological father) understood the situation, and she has a lot of support from her daughter and mother. She emphasised the fact that this was emotional support and not physical support.

She felt that the more people she spoke to about her situation, the more people prayed for him, and sent her messages of support in prayer. She noted that even though she was being emotionally supported, she has no physical support, as she felt his behaviour too unpredictable.

“(I have support such as) terugval in terme van gesels, in terme van ondersteuning, maar nie in terme van kyk-vir-my-na-hom nie, hy's te onvoorspelbaar.” (“I can rely on support in terms of talking, but not in terms of look-after-him-for me, he's too unpredictable.”)

5.5.5.2 Group-homes

The mother reported that due to her son's challenging behaviour, he has been expelled from most of the group-homes he has been in, and that the group home which currently accommodates him, has given several warnings of expelling him. She felt that there is not enough stimulation in the group-home and hospital, and that this was a cause of frustration for some of the patients.

She reported that the fact that the group-home her son is currently in is subsidised by the state has been their salvation.

“As hy altyd by die huis was, weet ek nie, ek weet nie waar ek sou opeindig het nie.” (“If he were to be at home constantly, I don’t know, I don’t know where I would have ended up.”)

She mentioned that she likes the arrangement of having group-homes on the grounds of the psychiatric hospital, as they can assist each other well. She stated that one must pay for her son’s accommodation at the home even for the times that her son is in hospital in order to keep his room, and at times this proved to be a financial drain.

5.5.5.3 Hospital

The mother believes the staff at the hospital to be abusive towards the patients at times.

“T is ‘n baie eerlike mens. Hy sal altyd vir jou sê wat hy verkeerd gedoen het, maar as hy vir jou gesê het iemand het sy kop teen die muur gestamp, kan jy glo iemand het sy kop teen die muur gestamp.” (“T is a very honest person. He will always tell when he has done something wrong, and if he tells you that someone knocked his head against the wall, you can believe it.”)

She felt that this was a hopeless situation, as no witnesses were present to support such an allegation. She also reported that she knew patients encouraged one another to physically attack each other.

“Ek weet vir ‘n feit dat van die pasiente opgesteek word om mekaar op te voeter.” (“I know for a fact that patients instigate one another to fight.”)

5.5.5.4 Neighbours

The patient has been destructive in the complex that they live in, and this has not only had a negative effect on their relationships with the other residents, as some of them believe he is just undisciplined, but also had financial implications.

“Hy’t al vir ons baie skade aangerig deur vensters van karre te breek, ruite in die kompleks, wat ons natuurlik weer moes laat regmaak en betaal... baie mense glo hy is net stout.” (“He has caused a lot of damage – breaking car windows and windows in the complex – which we had to repair and pay for... some people believe that he is nothing but naughty.”)

His mother explained that he does this at night time when the household is asleep.

The mother stated that some of the people she has encountered do not ascribe her son’s situation to a medical condition, but rather believed that his behaviour was due to demonic possession.

The mother stated that her son’s behaviour was a disruptive influence on the family.

The family lives in a residential complex, with many houses which all share a communal swimming pool. When going to the pool, she feels embarrassed by her son’s behaviour; because she believes he has no regard for the other people. She expressed her fear that he may be a danger to the young children at the pool, as they tend to stare at him and this provokes him. She explained that her son has always known that he is different to his peers, and that this saddens both her and him.

“Ek dink dis moeilik vir hom ook, omdat hy weet hy is anders ... van jongs af weet hy’s anders en die vraag hoekom kan hy nie soos sy suster of broer wees nie.” (“I think he finds it difficult too, because he is aware of being different... he has known this since childhood and asks why he cannot be like his sister or brother.”)

5.6 Case study 5

5.6.1 Clinical history

R was born to a 32 year-old single mother in 1980. The pregnancy was normal and he was born at term. Foetal distress was detected in labour, but the delivery was quick and he weighed 9lbs 6oz at birth. His developmental milestones were delayed; he walked at 15 months, but only spoke at 30 months. When he was 18 months old there was concern about delayed language development and speech therapy was commenced. At 8 years of age he started attending a LSEN school. His intelligence

was tested on the JSAIS and found to be in the moderate range of ID. He was seen by a neurologist at a children's hospital in Cape Town, who diagnosed William's Syndrome. During a consultation later at the Genetics Department of a tertiary hospital in Cape Town, this diagnosis was not confirmed but it "could not be ruled out". While at school he was judged to have ADHD and was treated with methylphenidate. At the time he was said to be poor in a group but good in one-to-one situations. The methylphenidate was not helpful in reducing his hyperactivity and thioridazine was tried and later, haloperidol. He had also developed epilepsy (both major and partial seizures) for which carbamazepine was subscribed.

During August 2001 R was admitted to Hospital X. The referral was prompted by his aggression towards his mother and, to a lesser extent, his brothers. His mother reported that she was "scared of him and he knew it". Apparently he had been sexually abused a few years prior to this and the symptoms commenced soon after the abuse.

During the admission, he was found to be friendly, but rather over-familiar. He had a tic and evidence of tardive dyskinesia and akathisia. While in the ward, he also had obsessive symptoms. His diagnoses were:

*Axis I – Mood Disorder (BPD II), Medication Induced Movement Disorder (akathisia, tardive dyskinesia), OCD

*Axis II – Moderate ID

*Axis III - William's Syndrome, Epilepsy

During the admission he was treated with carbamazepine and haloperidol. Later propranolol was introduced and Lamictin was commenced in place of haloperidol. He also received a behavioural therapy programme devised by a psychologist. Later the propranolol was discontinued and he was discharged home on 13 November 2001, on carbamazepine and Lamictin. Since discharge he has been followed as an outpatient. His behaviour has improved generally.

5.6.2 Family description

The family consists of four members: the biological mother and her three sons. R is the youngest. The two older sons have left the home. Currently, R lives in a group-

home, but this is a recent development, as the mother reported that she had trouble finding a group-home that had an opening. R thus lived at home for a long period.

The mother is 59 and does the care-taking. She is also the sole provider, as her husband passed away when their children were still very young. The family's monthly income is R12 000.

The interview was held in the mother's up-market house in a majority white community. She was the only family member present.

5.6.3 Individual characteristics

5.6.3.1 Aggression

The mother of the patient reported that when all of her children were young, she regarded R as the easy one. She reports that he later became very aggressive and she felt that this was the core problem.

“Hy het begin aggressief raak, en dit is die eintlike ding. Dit was disastrosus; dit was ‘n baie slegte ervaring vir my.” (“He became very aggressive, and that is the very problem. It was disastrous; it was a very bad experience.”)

She reported that she felt helpless in the face of his abuse and that it was a traumatising experience.

“Dit was ‘n geweldige slegte ervaring en ‘n traumatiese tyd van my lewe. Ek was blou geslaan party keer deur hom.” (“It was a very bad experience and I was traumatised. At times I was bruised by his beating.”)

She reported that she is constantly on the look-out for signs that would indicate a violent episode.

“Ek kan agterkom as hy begin goed slaan. Hy sal sommer hier teen die deur loop en slaan, en dan sal ek dadelik, as ek goed sien rondlê soos skêre of messe ... hy't nooit nooit vir my daarmee gedreig nie, maar ek was altyd onderliggend.” (“I could notice when aggression was fierce. He would bang against doors and I would immediately, if I saw scissors

or knives lying around... he never, never threatened me with those, but I was apprehensive.”)

She felt that had he not been put in a group-home, she might have been killed.

5.6.3.2 Running away

The mother stated that her son had a predilection to walking the streets of their neighbourhood by himself. He would go out and only return late at night, and if he did not return early, she would have to go out on her own to look for him. She reported that this was also a disturbance to the community she lived in, as he would knock on the neighbours' door and would want to talk to them. She explained that in the area she lived in, this was regarded as unacceptable behaviour.

5.6.3.3 Manipulative behaviour

The mother reported that in addition to his aggressive behaviour, her son was manipulative as well, and because she was a woman without a stronger man in the house, she allowed it to happen.

“Hy wil nou gaan stap, en of dit nou in die aand is, of in die nag is, hy wil nou vir hom ‘n koeldrank of Coke gaan koop, so baie manipulerend. Ek het dit nie toegelaat nie maar omdat ek alleen is - ek het nie ‘n sterker persoon gehad nie, en ek is ook nou nie die sterkste en grootste mens nie - kon ek hom nie eintlik hanteer nie. So ek het maar altyd toegegee - verkeerdelik - omdat ek nie ‘n keuse gehad het nie; as jy weet iemand gaan jou slaan of iets aandoen, gaan jy ook se: ‘OK, OK, OK, gaan koop maar die koeldrank, hierso is die vyf rand, vat maar.’ So die konteks moet ‘n mens sien.” (“He would want to go for a walk, and be it evening or at night, he would want to go immediately to buy a cool drink or a Coke, so manipulative. I didn't want to allow this but because I am on my own – I didn't have a stronger person around and I am not the strongest of people – I could not handle him. So I would give in – wrongly so – but I didn't have a choice; if you know someone's

going to hit or hurt you, you say 'OK, OK, OK, go ahead, here is five rand, take it.' See it in context.”)

She reported that he would physically attack her in the car, while she was driving, the intention being to forcing her to stop somewhere.

5.6.3.4 Sensitivity when spoken to

The mother reported that her son with ID is emotionally sensitive. She reported that the manner in which one speaks to him has a big impact on him. She felt that whilst she could recognise his emotions, outsiders could not. She explained that when someone says a harsh word to him, he will think and talk about it for hours, and demand that his mother go and talk to them. She then pretends to phone this person.

5.6.3.5 Additional problems

The mother reported that her son had gone through a stage during which he constantly phoned the police. The police threatened to take the phone away and even to bring a civil case against her on one occasion when he phoned and falsely reported a murder in their home. She reported that she thought that her son did this in order to socialise.

5.6.4 Effect on family

5.6.4.1 Quality of marriage

The mother reported that she believed that her late husband would not have coped with the stress of caring for a child with ID, had he still been alive.

5.6.4.2 Siblings

The mother reported that she thought that the patient's brothers have a big influence on his behaviour. She felt that her two healthy sons do not have sympathy for the situation, and stated that they are abusive towards their brother with intellectual disability.

“Hulle het hom seergemaak, hulle het hom regtig geslaan omdat hulle hom nie kan verstaan het nie, want hy maak vir my seer of hy doen verkeerd. Jy weet hoe’s ‘n tiener op daardie ouderdom ook, en nou is hulle almal na mekaar so hulle is maar almal tieners. Hulle eie frustrasies, dan haal hulle, ek dink, op hom uit. Hy mag niks verkeerd doen nie of hulle het hom geslaan.” (“They hurt him, they really hit him because they didn’t understand him, because he hurt me or because of something he did wrong. You know what a teenager’s like at that age, they are close in age and all teenagers. I think they took their own frustrations out on him. He was not allowed to do anything wrong or they’d hit him.”)

The mother felt that her son with ID had learned in this way to use violence when he is not content with a situation.

She felt that due to this history of abuse from the healthy brothers, her son with intellectual disability still does not like to see them. She reported that he will get very destructive when he gets the notion that they will be visiting. She reported that this is damaging to the family.

5.6.4.3 Illness

The mother reported that, although she has never experienced depression, she did experience anxiety due to her situation. She felt that her life with her son was more than she could bear.

“Ek het ‘n baie moeilike lewe onder hom gehad; ‘ondraaglik’ is die minste wat ek kan sê.” (“I have led a very difficult life with him, intolerable to say the least.”)

She reported that she lives in constant fear of her son. She cited an incident when she locked her son in the house and she hid under a bush in the garden, but that she would still hear him scream and slam the doors in the house. She reported that some days she was too scared to go home and would have to ask someone to drive home with her.

“Ek het party keer aan die huil gegaan. My senuwees was tot niet; as ek weet ek moet huis toe gaan het ek altyd iemand gekry om agter my aan

te ry.” (“I would sometimes start weeping, my nerves shattered knowing that I must go home and had to ask someone to accompany me.”)

She reported that she did, however, enjoy having him at home when he was calm, and that she enjoyed looking after him on the weekends that he came home.

“Hy word regtig bederf; hy kry nou filterkoffie en beskuit in die bed. Ek doen dit vir hom want dit is vir my lekker om dit te doen. Ek hou daarvan, I really like it, ek sal vir hom bacon en eier maak op sy bestelling. Dit is vir my baie lekker om dit te doen.” (“He gets spoilt now, with filter coffee and rusks in bed. I like doing this for him, I really like it, I’ll even make bacon and egg, if that be his order. I like doing it.”)

5.6.4.4 Social restraints

The mother stated that her situation has an isolating effect on her life.

“Maar dit is geen plesier - die mense wat sê jy is geseën om ‘n gestremde kind te kry - dit is nie so nie, dis nie ‘n seën nie. Die Here het jou nou raakgesien en jou nou uitgesonder - it's not true; dit is geen plesier nie. Jy is ingekerker, jy is geïsoleer. Toe dit so erg gegaan het, toe’t ek eendag vir hom gekyk en gesê: ‘Weet jy, jy’t steen vir steen, muur vir muur het jy in agt jaar ‘n tronk om my gebou.’ Dit is presies hoe ek dit ervaar het.” (“It isn’t a pleasure – people say those who have disabled children are blessed – it isn’t so, it is not a blessing. The Lord has identified you and you are the chosen one – it’s not true – it isn’t a pleasure. You are limited, isolated. Once, when we were going through a bad patch, I looked at him and said: ‘Do you know that in eight years you have built a prison around me, stone by stone, wall by wall’. That’s exactly how I experienced it.”)

She felt that she had to educate her other children and the people around her about how to interact with her son; this made the family socials more pleasant.

“So moet ek nou maar middelman speel, maar daar is definitief, definitief verbetering, maar no easy way - niks wat maklik is nie. Dit is nie lekker nie.” (“So I now act as middleman, but there definitely, definitely is an improvement, although no easy way – nothing is easy. It’s not easy.”)

She reported that she is a healthy, attractive woman and felt that she could have offered a man a lot, but that her situation with her son, especially his challenging behaviour, prohibited her from finding male friends.

5.6.4.5 Financial implications

The mother reported that from time to time her son demands to be allowed to go to the mall and walk around by himself. She explained that the security personal monitor him on their cameras. She felt that this was a great favour that they showed to her, but that she always felt she needed to give a token of gratitude to them. She explained that this was becoming financially draining.

5.6.5 Community factors

5.6.5.1 Support groups

The mother reported that she has no support from friends or family nor from other social structures in her community. She did mention that her niece is a social worker and that she could confide in her. She reported that the rest of the family does not like being involved.

“My familie is nie eintlik lus daarvoor nie.” (“My family doesn’t like being involved.”)

She also stated that the patient’s brothers do not display a sympathetic attitude towards their brother with intellectual disability. She reported that she did not want to trouble the neighbours with her problems but that whenever she felt herself to be in a dangerous situation, she could call them.

She is a religious person. She reported that she prayed about her situation.

5.6.5.2 Group-homes

The mother reported that her son's group-home had transferred him from a home for people with a higher level of functionality, to a home for people with lower functionality. The rationale behind this decision was that he was being "bullied" in his current home. She felt that this was not a good move and that it had a disturbing effect on her son. She did not give further details about this.

The mother reported that the group-home would punish her son if he was in the wrong. They would take away some of his belongings for a period of time. She felt that this was wrong as she knew her son has no grasp of time.

“En dan vat hulle al sy goed af as hulle hom wil straf; sy radio, sy kospakkies, hy mag niks doen nie. Kyk, vir 'n gewone mens is dit moeilik. En nou vir 'n gestremde mens, en nou vir 'n kwartaal lank. Hy't mos nou geen begrip hoe lank is 'n kwartaal nou nie.” (“And then they take away his belongings as if to punish him, his radio, his food rations, and he may not participate in anything. Look, such punishment would be difficult for a normal person, let alone for a disabled person – for an entire term. And being disabled – he doesn't even grasp the length of a term.”)

She felt that the group-home should work on a reward-based system rather than a punishment-based system they currently favour. She felt that the group home taking his possessions away ultimately only served as further encouragement for her son to run away from the home.

“Kyk, musiek is sy lewe, so jy sal hom heeltemal ontwrig as jy sy musiek wegvat in 'n totaliteit. En hy't weggeloop Tygervallei toe; ses, sewe keer agtermekaar; loop hy weg van die koshuis - hy spring oor mure en drade - loop weg Tygervallei toe, want 'dit is waar ek mense kan sien wat vir my gaan geld gee, waar ek by die CD-Select...' hulle laat hom toe om op die ear phones musiek te luister. Verstaan jy? Toe't ek gesê: 'Gee net sy radio terug' - nog nooit weer gebeur nie, nog nooit weer nie. (“His life centres around music, he will fall apart totally without his music. And he ran away – to Tygervallei, six, seven times, ran away from the hostel – jumped over walls and fences – to Tygervallei because

‘that is where he will see people who will give him money, so that at CD-Select...’ they allow him to listen to music over the ear phones. Do you understand? So I asked them: ‘Please give his radio back’ – never happened again, never again.”)

The mother reported that, overall, she felt there was an improvement in her son and in their circumstances ever since he moved into the group home.

“Soos nou, lang vakansies, moet hy bietjie by sy broer gaan bly. Dan gaan dit rasend goed - no problem. Hy sal natuurlik vra wanneer hy kan kom, maar ek kan hom nie langer as ‘n week hier laat bly nie want dan begin hy nou. En waarvoor ek bang is, nou gaan ons terug na die aggressiewe deel toe, en dit wil ek ten alle koste verhoed.” (“During longer holidays, he visits his brother for a while. It works out fine – no problem. He asks as to when he can come, but I cannot accommodate him here for longer than a week, then he starts... And I am afraid of returning to an aggressive point, which I want to avoid at all cost.”)

5.7 Conclusion

In this study, the families’ description of their experience of their de-institutionalised family member is categorised, *viz.* the characteristics displayed by the individual with ID; the effect which a member with ID has on his family; and community factors which impact on the family with a member with ID.

The family with a member with ID and/or mental illness needs to cope with a wide range of challenging behaviour, as reflected in Table 5.1. Aggression, abusiveness and attention-seeking were most prominent.

Table 5.1 Characteristics displayed by a family member with intellectual disability

	Family 1	Family 2	Family 3	Family 4	Family 5	Total
Aggression	X	X	X	X	X	5
Abusiveness	X	X	X		X	4
Attention-seeking	X		X	X		3
Destructive behaviour		X	X	X		3
Manipulative		X		X	X	3
Overly sensitive		X		X	X	3
Isolation		X	X	X		3
Running away	X			X	X	3
Self-destructive			X	X		2
Sexual misbehaviour		X	X			2
Low functionality	X	X				2
Lack of social etiquette		X	X			2
Severe mood swings				X		1
Delusional		X				1

Care-giving causes problem areas within family relationships, and affects the family unit. Table 5.2 summarises these, and those mostly perceived are social restrictions, financial burdens and increased stress levels between the marital partners.

Table 5.2 Effect of a member with intellectual disability, on his family

	Family 1	Family 2	Family 3	Family 4	Family 5	Total
Social restrictions	X	X	X	X	X	5
Financial burden	X	X	X		X	4
Marital stress	X		X		X	3
Negative impact on career		X	X	X		3
Disruption of family structure	X		X			2
Negative impact on siblings			X		X	2
Negative impact on care-taker						
- <i>Stress</i>		X	X	X	X	4
- <i>Depression</i>		X	X			2
- <i>Anxiety</i>			X		X	2
- <i>Guilt</i>				X		1

Table 5.3 shows the interactions between the families and their surrounding communities affected by living with a family member with ID. These were both positive and negative, with the community being both a source of support (e.g. religion) as well as a potential factor for distress (e.g. isolation). The two pertinent factors recognised by the families were their negative perceptions of group-homes, and the negative effect that their family member with ID had on the community.

Table 5.3 Community factors

	Family 1	Family 2	Family 3	Family 4	Family 5	Total
Negative perception of group-home	X	X	X	X	X	5
Negative effect on community		X	X	X	X	4
Positive perception of group-home	X				X	2
Support groups available						
- <i>Family</i>			X	X		2
- <i>Church/Pastor</i>		X				1
- <i>Paid support</i>			X			1
- <i>Other</i>				X		1

The families thus faced a broad spectrum of factors as a result of living with a member with ID. These factors originated internally within the family, and also externally, from the wider community. While some positive factors were identified, in general these made living with a family member with ID more challenging, and increased the stress and burden on the family.

CHAPTER SIX

Discussion

6.1 Introduction

It has been widely recognised that the family of a child with disabilities plays an integral role in the child's well-being (Wheeler, 1996). However, the family system itself is part of a wider network of interacting systems and does not operate in isolation (Knox, 2000). All environmental factors contribute to forming the framework within which the family system functions and as such, impinge directly or indirectly on not only the affected child, but the entire family. It is therefore necessary to consider the functionality of the entire family within the context of this wider system. Caring for people with disability is best done by providing an environment where not only the material needs of such people are met, but their development, integration, and psychological well-being are fostered. In his review, Cummins (2001) reflects on several studies which view the ideal environment for the person with disability, as a family environment. He points out that the negative effect on the family, however, should also be assessed. For the purpose of this chapter the family has been viewed from an ecological perspective. Using this perspective, a contextual map will emerge which would aid understanding of the many different factors which all contribute towards the impact of de-institutionalisation on the family.

The following sections will thus highlight the patients' characteristics which impact negatively on their families and communities, and reflect on social interactions. Support systems and resources available to such families are also discussed, and this chapter then concludes with recommendations.

6.2 Factors which impact negatively on families and communities

6.2.1 Patient characteristics

Although the degree of intellectual disability (ID) and psychiatric illness can vary across a wide spectrum, in all of the cases selected for this study the patient had been classified as having ID with severe mental illness. Although the type of mental illness

differs from case to case (e.g. Obsessive Compulsive Disorder to Schizophrenia), the similarity in the severity of the psychiatric illnesses suggests that the families are in comparable situations.

6.2.1.1 Problem behaviour and aggression

It has been established that psychiatric and/or unruly behaviour is more prevalent in persons with ID as opposed to people without ID (Moss *et al.*, 1998), and that family members are interrelated and affect one another (Knox, 2000). In conducting this study, it was found that the patients, as part of the micro-system, exhibited challenging behaviour which had a significant impact on the family. The families spent a substantial proportion of their interviews describing the behaviours that they found most difficult to cope with (refer to Table 5.1).

The most prominent forms of problem behaviour were aggression, abusiveness and attention seeking. All the families that were interviewed reported that it was particularly difficult to cope with aggression. It led to tension, feelings of anxiety and hopelessness amongst the family members. The patients were likely to become abusive when they became aggressive or irritated. Single parent mothers reported that they thought that their children were abusive towards them because they were female, but families with both parents present reported having experienced abuse as well. It became clear through all the interviews conducted that aggressive behaviour posed a very real risk to the overall welfare of the families who take care of such individuals.

One mother (in Case study 5) noted that she thought that her son became aggressive and abusive in response to her other sons bullying him. His aggressive behaviour could also be reinforced when the mother submitted to his requests because she saw no other option but to do so.

6.2.1.2 Stimulation and/or the lack thereof

Aggressive behaviour could also be provoked by a lack of stimulation and recreational activities. The families reported that when their children with a dual diagnosis were at home, they did not go out, due to their unpredictable behaviour. This in turn started a cycle, with the child becoming even more aggressive due to a

lack of stimulation, discouraging any further excursions. Some of the families noted that finding suitable recreational activities and stimulation was a big task. Shearn & Todd (1997) report that finding and implementing social and recreational activities were a substantial part of the care-giving task. Similarly some families participating in this study also noted that it took considerable time planning the daily activities of their diagnosed child. One mother reported that even though she planned her son's day, he did not always approve of his schedule. She felt that his aggression may also have been caused by his inability to verbalise his emotions.

6.2.1.3 Functionality

Although the level of functionality seemed to be a determining factor with regard to the level of care required by the individual, the families whose children had a high level of functionality reported that this did not ease their situation, as aggressive and abusive behaviour still had a severe, negative impact on the family, especially when enacted in public.

6.2.2 Intervention

A variety of interventions can be used to reduce or control behavioural problems in people with ID and mental illness. These include crisis intervention and counselling. Currently, positive behavioural interventions that identify the function of aberrant behaviour and then train the person with functionally equivalent adaptive skills, are the most highly recommended interventions (Feldman, 2002). This training teaches the individual to exhibit more socially appropriate behaviour, thereby aiding their integration into society. Psychotropic medication could also assist in containing such aggressive behaviour (Meador & Osborn, 1992). Despite the existence of this evidence, the families mentioned that they did not know where to turn to for help. The implication was that they were unaware of accessible services that they could rely on for help or support. They felt that after de-institutionalisation they were left to deal with challenging behaviour without being provided with the necessary skills and resources to cope with their situation.

6.2.3 Care-giving

The families in this study reported that caring for the patient and having to deal with the diagnosed member's challenging behaviour had a negative impact on the family unit (refer to Table 5.2). Major risks to the family unit was an increase in marital stress, social restrictions on the family, financial burdens and an impact on the health of the main care-giver.

6.2.3.1 Marital and family stress

In terms of the meso-level, most families reported that their situation placed their marital relationship under increased strain. One mother reported that she did not think her late husband would have been able to deal with having a child with ID (Case study 5). Kersh *et al.*, (2006) found that parents of children with ID have a poorer quality of marriage than comparable couples who were married for a similar period of time with typically developing children.

This situation became more severe if the person with ID had a dual diagnosis or mental illness as well. Stressful aspects of parents' situations may lead to believing that they are incapable of strategising, or they may deem themselves not sufficiently resourceful in order to cope with their situations (Lazarus & Folkman, 1984). All of the couples that were interviewed ascribed the increase in marital stress to the fact that each parent thought that his/her way of handling the child with a dual diagnosis was the more effective one. This again suggests that the families have been left to follow their own intuitions when dealing with their children who have been diagnosed with a dual diagnosis, rather than being provided with the appropriate skills and tools to better cope with their situation.

The families reported that having a family member with a dual diagnosis affected the siblings. One mother reported that her other sons found it difficult and frustrating to deal with their brother with the dual diagnosis and that they typically responded to him by beating him. One of the families noted that their other children felt ashamed of their brother with ID. Giallo & Gavidia-Payne (2006) indicate that siblings of people with ID run a significantly increased risk of having adjustment difficulties, experiencing emotional symptoms and peer problems. Again, this could escalate in a case where the sibling had a dual diagnosis and not only ID.

Other parents noted that their attention and resources were depleted by the demands of the patient and that little was left available for their other children.

6.2.3.2 Social restrictions

The families reported that the need for constant supervision severely restricted their engagement in social activities. A literature study substantiates this, showing that mothers of individuals with ID experience lower rates of job stability, lower income and more limited social participation than mothers of typically developing individuals (Seltzer *et al.*, 2001).

In the case of a dual diagnosis, the severity of this situation would be intensified and this is aggravated by their perception that there are no forms of physical support. The mother (generally the main care-giver) could therefore also not follow a career without an effective support system being in place.

6.2.3.3 Financial burden

Emmerson (2004) reports a number of reasons for low socio-economic status under people with ID and their families. One reason is the added financial and social expenditures related to raising a child with ID. In the case of a dual diagnosis, expenditure increases in line with added medical expenses. Not only does this study confirm the above, but sheds light on other causes for financial hardship.

Most of the families reported that caring for their family member with ID had serious financial implications, and some mentioned the crippling effect of costs related to replacing broken goods, or payment in respect of accommodation at the group-home.

Other families were concerned about the impact of such implications on the future. They stated that their children would never be independent from them, and that they would have to support their children financially throughout their lives. This is consistent with a study by Seltzer *et al.*, (1997) which reports that people with intellectual disability had progressing dependency needs.

The strain placed on families' resources because of caring for a member with dual diagnosis, needs to be considered when analysing the motives for implementing de-institutionalisation. If the primary motive is a financial saving to the government, this

represents merely a shift of financial responsibility, as the family now bears the brunt of the burden. If the motive is that the home is a better environment for the patient, then the family should be equipped with adequate skills to empower all family members, including other siblings, to be more resilient in dealing with the family member with a dual diagnosis of ID and mental illness.

6.2.3.4 Risk to health

The families interviewed for this study expressed their emotional distress and reported that such continued stress posed a very real risk to their health. The families typically reported depression, anxiety and feelings of guilt. This could be attributed to the fact that the families had no coping strategy or reliable support network that they could turn to for support. This should be a serious consideration for those who regard home-care as an inevitably superior experience for all care- recipients.

Caring for a child or an adult with ID with challenging behaviour at home has been clearly demonstrated to result in a higher level of family burden (MacIntyre *et al.*, 2002). In all of the interviews conducted, the mother was identified as the main care-giver and it was also the mothers who suggested that having to care for their children with a dual diagnosis was detrimental to their health. Families of a child with a disability, who displays behavioural problems, experience lower quality of life (Maes *et al.*, 2003). Outcomes of various mental health studies pertaining to parents of children with disabilities reveal that the mothers of such children are subjected to higher rates of depression symptoms than those mothers with normally developing children (Veisson, 1999). Such mothers may have many roles to fulfil: having a career, being a wife and a mother for her other children, and then in addition to this, having the duty of looking after her child with a dual diagnosis.

The conflicts between her various roles can be detrimental to her health, which then in turn has an influence on the quality of care that she provides. Some mothers reported that their situation prohibited them from being employed, as their role of care-giver was too demanding. The mothers who were employed noted that it had both direct and indirect influences on their jobs. They constantly worried about their children and they had to be available constantly to take calls from the group-home or hospital. When their child was at home, they could not leave them unsupervised and had to

monitor them constantly. Many mothers reported that the multiple roles they had to fulfil had a negative impact on them, and prohibited them from optimal functioning in pursuit of their own ambitions. This reflects the exo-system of the ecological model, as her situation directly influences her interactions outside of the family.

6.2.4 Community and social interactions

All of the interviewed families commented on the negative effect that their family member with ID had on the community, except for one family. This family resided on a spacious stand, not too close to neighbours, and in a rural area, which may have allowed for less contact with the community.

It remains a constant source of stress for families to deal with the reaction and condemnation of the community when their children may appear “normal” and functioning (refer to Table 4.3). The influence that care-giving has on the family has a direct impact on how the family interacts with its surroundings. During the course of the interviews, the families reported that undue strain was placed on their social ties because of the situation in which they found themselves. They reported that, even though they were not necessarily rejected by the people in their community, they still felt that their children’s behaviour had a negative impact on how people viewed the family. Shearn & Todd (1997) refer to this as ‘parental public work’. It is the part of parental work that involves managing other people’s view of the family and in particular, that of intellectual disability and mental illness. Many families felt that the communities, in which they resided, did not fully understand their situation.

Stigma is an important aspect to take into consideration prior to de-institutionalisation. It has to be addressed and the community in which the patient is going to stay needs to be properly prepared through education and awareness. Stigma has an influence not only on the patient, but on the rest of the family too. This reflects the macro-level of the ecological system, i.e. the extent to which a person with ID and mental illness, and society, relates to one another. The families are thus left at risk, feeling isolated and unsupported. The families reported that they were restricted in their social or leisure activities. This was largely due to their child’s lack of social etiquette, unpredictable behaviour and the outside world’s perception of them. Even when their children were not living with them, were they restricted, as they were of

the opinion that the group-home was not always capable and competent in dealing with their children. They reported that if their children showed challenging behaviour in the group-homes, they were liable to be contacted in order to help solve the situation.

Accessibility to social support networks could appreciably be affected by the extent to which the member with disability impacts on the family. Where the community, neighbours and friends are unable or unwilling to assist in dealing with the patient, the impact on the family is considerable. In the course of conducting interviews with the families, they explained that in such situations they had to either rely on government institutions or make use of private institutions.

6.2.5 Support systems and resources

It seems important to identify resources which would assist the family in overcoming the burden of taking care of members with ID and psychiatric problems. Forms of respite care may afford the family members a short period in which to become resilient and to feel more able to return to, and cope with the situation. While Maes *et al.*, (2003) agree that respite care could assist in coping with care-giving, Aniol *et al.*, (2004) suggest that it could also lessen stress levels within the family.

The interviews demonstrated contradictory views held by the families on the effectiveness of the hospital-care setting. Some of the families reported it as having been a negative experience whilst others praised it, but in all the cases the hospital was the first source of aid when the families needed support. The group-homes also provided an important source of support for the families, although there was a clear distinction between privately financed group-homes, which were praised, and state-funded group-homes, which were viewed very negatively. It was evident that those families which viewed group-homes positively, were the wealthier among those interviewed and could better afford such services.

The families expressed concern for their children while they were accommodated in a hospital or group-home, that they were too readily expelled from these homes without appropriate warning, and were they also not provided with support when their children returned home. It is also important to note that the families struggled to find suitable accommodation for their children with a dual diagnosis. Some families

reported that their main challenge was to find a group-home with a vacancy, whilst others reported that the group-homes did not cater for their child's specific needs. This could indicate a shortage in adequate accommodation. It could also indicate that there is a shortage of services and/or trained individuals to operate the group-homes for this specific population group. However, the possibility exists that this is merely the families' perception.

Regarding other forms of support, only one family reported that they were aware of assistance offered by civil society, although they did not think that the support groups available to them offered suitable solutions for the problems they faced. All of the other families interviewed for this study, reported that there was no support available to them. One family reported that they had sought help from a private psychiatrist and psychologist. This indicates that the available services are not sufficient to meet their needs, and do not render a service to the point where the family can adequately cope with their circumstances.

6.3 Summary

Without exception, the families reported on the substantial difficulties in their experience as care-giving families, and that caring for a family member with a dual diagnosis had a ripple effect which in turn, had a crippling effect on all levels of the ecological model.

6.4 Recommendations

It is clear that the process of de-institutionalisation holds a number of risks for the families involved. The families faced novel challenges and were forced to deal with these on their own. It is essential that the families not be viewed in isolation, because the difficulties that they face due to the de-institutionalisation process, hold implications for the family members beyond the immediate family life.

6.4.1 Implication of cost

De-institutionalisation in the Western Cape is hampered by the lack of institutional, social and financial capital. Despite the fact that institutional care is available, it is limited and does not necessarily improve the families' resilience. In order to address the problem, it is important to consider certain issues. The first step is to note the importance of the problem, as it has far reaching consequences.

A commonly used formula in government and development programmes in the field of health-care is:

$$\sum(\textit{suffering}) + \textit{cost} (\textit{social and economic}) \text{ (Kegels, 2007*)}$$

The sufferers in this instance are the families. The economic costs include the financial expenses related to caring for a child with intellectual disability, as well as the loss of potential income due to the care-taker not being able to follow a career optimally. An example of the social cost would be the loss of participation in leisure activities, which could easily be overlooked as it is intangible and difficult to measure but is an important indicator of the impact of de-institutionalisation on the family.

6.4.2 Support and intervention

In an effort to increase or strengthen resilience, an appropriate intervention should be selected that is effective, efficient and accessible. The families did however, express that such an intervention did not exist, and that they did not know where to turn to in times of need. Families reported inadequate availability of group-home services for the number of people who need access to this resource. They are often too expensive, and have long waiting lists. Furthermore, expulsions are commonplace.

This is one area of support that could be improved in South Africa. The differences in service provision between state and private group-homes were often remarked upon during the interviews. These discrepancies should be assessed to determine if they do differ, and what these differences are. The services provided by state group-homes then need to be expanded and improved, to fall into line with the quality of service encountered in private homes.

*Dr Kegels, Institute of Development, Policy and Management, University Antwerpen

6.4.3 Respite care and day centres

Respite care could promote family resilience, giving the families time to recuperate. Minimum standards should be set regarding type and quality of service provision for both public and private domains. This would ensure equitable access to basic level of service. Day centres could also play an important role in lessening the burden on the family, and furthermore provide opportunities for family members to follow a career and to partake in social activities.

It may well be that limited respite care is available, and that day centres exist. This could be a topic for further research, so that the extent to which these are available could be determined and also whether or not the services rendered meet demand and expectations.

6.4.4 Stigma

External factors that may play a role, e.g. culture and stigma, need to be taken into account and should be researched. Here civil society has an important role to play in improving the lot of families with a member with a dual diagnosis. It should assist in creating awareness in communities regarding those community members with ID and/or mental illness by way of actively working against stigmatisation. Such action would result in relieving families' feeling of being isolated.

6.4.5 Appointment of case managers

A practical solution to the problem might be to assign each family to a suitably qualified case manager. This manager would provide advice on the availability and accessibility of support services that the family can rely on. Nuy (as cited in Maes *et al.*, 2003) suggests that such a service would provide equally in the needs of the member with disability, as well as the family. The managers would not only serve as links between the families and service providers (i.e. ensuring that the needs of the families are identified and met), but also assist the families in planning for the future by taking the family as an entity into consideration, i.e. each member with his or her needs, strengths and resources which he or she could avail to the family.

In accordance with the findings of this study (that caring for a child with ID and mental illness impacts on all aspects of the family), the case manager assisting the families should focus on each family's ecology. The perception of the extent of the problem may differ between service providers and the families, and this difference needs to be explored. It is thus also important to note that when allocating resources and providing services, these need to be acceptable to both parties involved.

6.5 Conclusion

This study provides an exploration of the families' experiences and identifies some areas which could form the basis of future research. The findings suggest that caring for a family member with ID and mental health problems is a significant negative experience for the families. The problem extends to other areas within the care-giving family, and the ripple effect thereof is in line with the ecological model. It was found that the patients' behaviour, the families' response to this behaviour, and the reaction of the communities in which they lived, all contribute towards the negative perception of the situation.

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APPENDIX 1

UNIVERSITY OF CAPE TOWN



Department of Psychiatry and Mental Health

Groote Schuur Hospital
Observatory - 7925
South Africa
Tel: + 27 21 404 2164
Fax: + 27 21 448 8158

25th September 2006

Dear Ms Kock,

RE: De-institutionalisation of people with mental illness and intellectual disability: The impact on the family

You have permission to recruit patients discharged from Alexandra Hospital for the above mentioned study.

I would like to draw your attention to the following;

- Any information pertaining to past or present patients must be de-identified – potentially identifying information removed
- Strict confidentiality must be maintained in relation to all data collected for the study
- All data collected must be secure e.g. stored in locked filing cabinets

I wish you all the best for the study.

Yours sincerely,

C D Molteno

Vera Grover Professor of Mental Handicap

APPENDIX 2

Questionnaire

What relationship is the person with ID of the interviewee:

Son	Daughter
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How old is this person:

How old is the interviewee:.....

What is the street address:.....
.....
.....
.....
.....

What is the family's monthly income:

How many people live in this house?

-Siblings:

-Spouse:

-Other:

What are the living arrangements i.t.o the person with ID?

Do other family members live close by?

Who does most of the care-taking?

What is the care-giver's occupation?

What is the education level of the care-giver?

Phenomenological Information

Social support networks:

What is your life experience in terms of living with a person with ID?

Briefing

I am a Master student. I got your name from the Prof Molteno at Alexandra Hospital. I am not familiar with your family member with ID's condition. Although I might need some minor details, it is more the family I am interested in.

My research is about the life experience of the family living with an ID person. The information that I receive will be treated with the utmost confidentiality. No names will ever be used.

I will ask some procedural information and then I would like you to explain to me your situation, e.g what is difficult for you, what is rewarding. This is a safe space for you to talk freely about your experience. There is no time limit, it is all up to you.

The tape recorder is just for me not to forget what is said. I might also be making notes myself. Please do not be intimidated by this, as it is just for myself to remember what we spoke about.

If you have any questions later or during the interview, please do not hesitate to ask.

If you are ready, then we can start.

APPENDIX 3

Consent form

I hereby consent to taking part in this research study. I am aware that I am participating voluntarily and that I am under no obligation to do so. I am also aware of this interview being recorded and later documented.

I have also been assured that I will remain anonymous and that I may end the interview at any time.

Signed

Date