Empowering Partnerships:

The development of a model of empowering partnerships in the context of devolution

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DEDICATION

I am dedicating this thesis to the memory of my very dear, life-long friend

Patricia (Tricia) Esther Quinlivan
11.9.58 – 14.1.05
Taradale, New Zealand

Tricia’s life was spent engaging and empowering people.

“Devote yourself to loving others, devote yourself to your community around you, and devote yourself to creating something that gives you purpose and meaning”.


Tricia
Arohanui
Angela
STATEMENT OF AUTHENTICATION

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this thesis material, either in full or in part, for a degree at this or any other institution.

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Angela Dew
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ABSTRACT

There is an ongoing trend in Western societies, including Australia, to move people with developmental disabilities out of institutions and into community based accommodation. When deinstitutionalisation occurs it impacts not only on the person with a disability but on their significant others and also on the organisation/s providing them with support.

While government departments and support organisations say that they involve family members in deinstitutionalisation, little previous research has focussed on family members’ experiences of deinstitutionalisation to know if it is an engaging and empowering experience for them. Most previous studies of deinstitutionalisation, where they have spoken to significant others, have focussed on their perceptions of the benefits or disadvantages of deinstitutionalisation for their son or daughter with a disability directly rather than considering how it impacted upon the significant others.

I identified this as a gap in our current knowledge and set out through this study to find out what deinstitutionalisation was like from the viewpoint of some significant others involved in it.

In order to do this, I conducted in-depth interviews with significant others (predominately fathers) of a group of people with severe multiple disabilities who were living in a small, non-government institution (provided with the pseudonym of Taradale) earmarked for devolution by the NSW Department of Ageing, Disability and Home Care (DADHC). Five significant others were interviewed initially prior to the movement of their son/daughter from the institution managed by Taradale and three fathers participated in follow-up interviews 18 months later, by which time their son/daughter had been living in the community for over 12 months. My research methodology was informed by a Symbolic Interactionist approach whereby I wished to investigate the meaning attached by significant others to the process and the outcomes of deinstitutionalisation through in-depth interviews. I adopted Grounded Theory as a method to analyse the data from the interviews and through the application of open and axial coding, I identified three main categories:
1) Getting it right
2) Parents Forever
3) Changing Lives

The application of selective coding procedures led to the development of the core category - for some significant others devolution is a disempowering process. This is a different viewpoint to that expressed in the majority of studies of devolution. Those few studies which do consider the viewpoint of family members of deinstitutionalisation report a parental shift from pre-deinstitutionalisation antipathy to post-deinstitutionalisation support of community living.

In considering why this study revealed a different story, I identified through the data and from reviewing the available international literature, that deinstitutionalisation rekindles feelings of guilt regarding the decision to place their child in an out-of-home placement. When this is coupled with the experience of negative changes in their own lives, it may result in feelings of loss of control, low self efficacy and a reduced resilience in the face of these changes.

I proposed that organisations, family members and the person with a disability needed to develop a relationship based on five principles:

1) respect;
2) communication;
3) shared values;
4) common goals;
5) individualised approaches.

Application of these principles might result in Empowering Partnerships which would in turn benefit all three players. I translated the three major categories and five principles into a Model of Empowering Partnerships in Devolution.
Chapter 1.
Introduction and Background

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1.1. Introduction

Thomas (not his real name) is a 10 year old boy who has lived at Taradale (a pseudonym for a residence for 38 children and young adults with disabilities on the outskirts of Sydney) since he was seven. Thomas has been diagnosed with a severe intellectual disability, he cannot verbally express his needs, but those who know him well interpret his needs through his facial expressions and body language. Thomas uses a wheelchair for mobility and he is medically frail requiring frequent hospitalization for chest infections and for infections related to the nasal-gastric tube through which he is fed. Thomas spends his days at a special school where he is engaged in sensory stimulation and programs aimed at maintaining his movement and flexibility. When not at school, Thomas sits in his wheelchair in the lounge room at Taradale and watches the staff and other residents.

Thomas’ father, Timothy (not his real name) is in his late 30’s and is divorced from Thomas’ mother. Timothy is unemployed and has full time care of Thomas’ two younger brothers. Timothy has had limited contact with Thomas since his placement at Taradale as he finds visiting Thomas within the institutional setting difficult with two young children.

Due to government policy, Taradale will be closed and its residents, including Thomas will move to community based accommodation (group homes or family homes). Taradale will be restructured to accommodate this dramatic change in service delivery. Thomas is to move into his grandmother, Tanya’s home which has been modified to accommodate his physical care needs. Tanya, who works in a service for people with disabilities, lives 10 minutes away from Timothy and the other two children.

How will Thomas and his father, Timothy be affected by this change? What are the main issues for Timothy? How will his views change once the move has been completed? These are some of the questions that have motivated the research reported in this thesis.
1.2. Terminology

A number of terms are used in this thesis. An explanation is provided for the reader who may be unfamiliar with some of the terminology. The definitions of these terms are themselves contended, each with involved historical and contemporary arguments. The purpose here is to provide simple descriptions.

Disability is an ‘umbrella’ term for impairments, activity limitations and participation restrictions. The definition provided here is one of a number of possible definitions. This definition is according to the International Classification of Functioning, Disability and Health, 2002 which was developed through international consultation by the World Health Organisation. This is one broadly accepted definition (World Health Organisation, 2002).

- **Impairments**: problems in body function or structure such as a significant deviation or loss.
- **Activity limitation**: difficulties which a person may experience in executing a task or activity.
- **Participation restrictions**: problems an individual may experience in involvement in life situations.

Developmental Disability is defined as a permanent cognitive and/or physical impairment that usually occurs in the early years of life or before the age of 18 years. A developmental disability usually results in significantly reduced capacity in three or more major life activities (communication, learning, mobility, independent living, decision making or self care) and results in the need for support. Many people with developmental disabilities experience a number of impairments. Conditions included in this term are intellectual disability, cerebral palsy, autistic spectrum disorder, spina bifida, cystic fibrosis, learning disability, muscular dystrophy and epilepsy (Centre for Developmental Disability Studies, 2003).

Intellectual Disability is a specific form of developmental disability affecting the person’s cognitive development. There have been two main approaches to determining whether a person had an intellectual disability. The Developmental Approach included assessment of the person’s intelligence quotient or IQ. The lower the IQ score the more
severe the person’s intellectual disability. Developmental scales were also commonly used to observe the presence or absence of key developmental skills in relation to the person’s chronological age. These developmental approaches to assessment have particular problems when applied to people with severe and profound levels of disability and hence the Adaptive Behaviour approach was developed (Brown, 1987). This approach considered the environmental demands, including age and cultural background, in order to determine what skills, including personal independence and social responsibility, should be assessed (Brown, 1987). Some people with intellectual disabilities also have physical and/or sensory disabilities, in which case they are then described as having multiple disabilities.

**Mental Handicap, and Learning Disability** are alternative terms for intellectual disability which are more widely used in the United Kingdom. **Mental Retardation** is the term more commonly used in the United States of America. These terms appear in much of the literature from these countries, some of which is referred to in this thesis. In Australia the term intellectual disability gained wide usage from the mid 1980’s.

**Sensory Disability** refers an impairment of the ears (hearing impairment) or eyes (visual impairment) which affects the person’s ability to carry out their daily functions.

**Level of impairment** relates to the affect of the disability on the person’s ability to perform tasks or participate in activities of daily living (World Health Organisation, 2002). It is common to ‘grade’ the level of impairment according to the following divisions:

- *Mild problem* – slight or low effect on a person’s ability to participate;
- *Moderate problem* – medium or fair effect;
- *Severe problem* – high or extreme effect;
- *Complete problem* – total effect.

**Medical Frailty** relates to the person’s propensity to require medical intervention on a regular basis in order to maintain their physical health. Medical frailty may include physical, medical, neurological, or motor difficulties which necessitate ongoing daily care (Bruns, 2000).

The people, whose parents participated in the research described here, have severe, multiple disabilities and many, are medically frail. They have a combination of
disabilities including intellectual (within the severe range), sensory (hearing and/or visual impairments) and physical disabilities.

**Deinstitutionalisation** refers to the movement of people with disabilities from a congregate care setting (known as an institution) to community-based accommodation. 

**Devolution** refers to the change of support undertaken by an organisation. In the current example, the organisation Taradale was providing congregate care to people with severe and multiple disabilities across a wide age span. The organisation closed this congregate care setting and assisted people to re-establish themselves in a mix of supported accommodation settings (group homes, family homes, foster placements and shared care). The process of this change was known as ‘devolution’ and was the term preferred by Taradale to describe the process the organisation and its clients underwent. This thesis uses both deinstitutionalisation and devolution.

**Transition Plan** is a plan required by the state governments which provides a timetable for existing services to transit to the approved service types. Ongoing funding for these existing services is dependent upon the acceptance of their transition plan.

**Significant Others** For people with life long disabilities, particularly those who have been institutionalised for a long time, parents may not be the primary or only people involved in making decisions about their lives. The disability field uses the term ‘significant others’ to refer to people who may, or may not be biological family members of the person with a disability, but who are intimately involved in the person’s life. ‘Significant others’ could include biological parents (mothers and fathers), step parents, foster parents, adult siblings, legal guardians, officially appointed advocates and others who played a major and long-standing role in the person’s life. In acknowledgement of the possible role of ‘significant others’ of the people with disabilities living at Taradale, this was the term used to seek participants in this study. I have called the person with a disability their son or daughter as this is the nature of the relationship between the people I interviewed and the person with a disability with whom they were intimately involved.

**Community-based accommodation** refers to a range of accommodation options available to people with disabilities who are not living in their family homes. Within this study the following are referred to:
• **Group home accommodation** – 4-6 unrelated people living together in a house in a residential street, usually with rostered staff providing support and assistance;

• **Foster home accommodation** – the person with a disability lives within a family setting which is not his or her biological family. Foster carers are provided with financial support to assist the person with a disability.

• **Shared care arrangements** – between the biological or foster parents and a respite placement either in a group setting or with foster carers.

**Private, not-for-profit organisations:** In Australia there are a range of organisations which receive funding from the State/Territory or Commonwealth government/s to provide services to people with disabilities. These organisations usually supplement their government funding with fund raising activities however, they do not operate for profit and, due to the funding regulations, are required to adhere to government policies and guidelines in their operation.

### 1.3. Statement of the problem

The move from institutional or large, congregate care accommodation for people with developmental disabilities to community based accommodation represents a major shift in how services for people with disabilities are provided. The proclamation of the New South Wales Disability Services Act, 1993 provided the principal legislative base for the provision of services to people with disabilities within New South Wales (NSW), Australia. The Act incorporated seven principles and fourteen objectives against which services and programs would be measured. The Commonwealth/State Disability Agreement (a joint agreement between the Federal, State and Territory governments to streamline the delivery of disability services throughout Australia), has as a stated goal, to enable people with disabilities and their significant others to be more involved in making decisions about the operation of the services available to them (Parmenter, Cummins, Shaddock, & Stancliffe, 1994). The legislation in Australia is in line with international trends towards ‘normalisation’, deinstitutionalisation and the importance of the significant others in making decisions about the care provided to their sons or daughters who have developmental disabilities. The recognition of the importance of
significant others reflected a move away from past practices whereby parents of people with disabilities were often encouraged to relinquish the care of their son or daughter to an institution.

When people with intellectual disabilities leave an institutional setting as a result of deinstitutionalisation, it is not only the individual who is affected by this change; their significant others are also affected. Government departments, advocacy groups and peak bodies in the area, all state that they believe that significant others of people involved in deinstitutionalisation should be engaged in the process of making decisions about the future accommodation of their son or daughter with a disability.

While the focus of this thesis is on the journey of significant others whose son or daughter with a disability has been placed in an institution, it must be remembered that the majority of people with disabilities live with their families especially as children and young people (Blacher, 1994). For those who were institutionalized, significant others may have maintained contact and involvement in their son or daughter’s life throughout their period of institutionalisation. However, for other significant others there may have been little or no contact. For these significant others a process of re-engagement (getting to know and be involved with their son or daughter) may occur as a result of the announcement to close the institution. For those significant others who have maintained contact, the process of deinstitutionalisation represents a change in the types of decisions and involvement which are asked of them on behalf of their son or daughter with a disability.

Despite this stated position of significant others’ inclusion and involvement, very little is known about how they engage in the process of deinstitutionalisation and whether or not they are empowered through their engagement. This represents a gap in the knowledge of how to best engage and empower significant others. Literature which discusses significant other/family empowerment will be introduced in subsequent sections of this thesis.
1.4. **Aim of the study**

To address the gap in understanding, the aims of this study were to explore engagement and empowerment through the experiences of significant others whose children have moved from institutional to community based settings. Specifically the aims were to explore:

- the extent to which these significant others were engaged in the process of deinstitutionalisation of their son or daughter with a developmental disability;
- the extent to which the supporting organisation involved these significant others in decision making regarding their son or daughter with a developmental disability;
- whether these significant others’ engagement and involvement led to feelings of empowerment for them.

1.5. **Scope of the study**

To engage and empower significant others in the process of deinstitutionalisation, organisations providing support to people with intellectual disabilities need to value the input of significant others and be convinced of their right to have a say. While there is considerable (entirely appropriate) emphasis given to the involvement of people with disabilities in decisions about their future, there appears to be less emphasis on the importance of significant others. Significant others’ inclusion is important when the person is a child, and/or has a severe intellectual disability including communication impairment which hinders their ability to advocate for their own needs and wants. The children and young adults whose significant others were interviewed for this qualitative study all had severe intellectual disabilities, complex medical care needs (including being fed by tube, suffering spontaneous fractures from not being seated correctly in their wheelchairs and frequent epileptic seizures) and communication impairments. The literature reviewed in this thesis points to the importance of significant others to all people, but especially to people with severe, multiple, lifelong disabilities. The literature on empowerment, points to a need for a model of empowering partnerships to
assist significant others, people with disabilities and the organisations supporting them to ensure that they are acting in the best interests of all.

1.6. Overview of the thesis

To achieve the aim of exploring significant others’ engagement, involvement and empowerment in the deinstitutionalisation process, this thesis moves through a number of phases.

In chapter 1, I provide an historical perspective on the philosophical, social and legislative changes underlying the deinstitutionalisation movement. These are trends within Western countries which have changed the way in which services to people with intellectual disabilities are currently delivered.

In chapter 2, I review the literature as it relates to significant others (particularly families) and to the empowerment of significant others (particularly families) to provide a critique on current theory and practice regarding how significant others of people with disabilities are viewed and treated by disability organisations and society in general. Understanding this is critical to understanding the results and conclusions of this study.

In chapter 3, I discuss the methodology used in this study with particular reference to the underlying epistemology of Symbolic Interactionism and specifically the use of Grounded Theory. I will argue that this methodology is the most appropriate one to apply to this study, which is about the interactions between significant others, people with developmental disabilities and support organisations.

In chapter 4, I describe the recruitment of participants, I present the participants to the reader and I describe my data collection methods with discussion of the interview guides and questions used.
In chapter 5, I describe the grounded theory approach to data analysis using examples from the study. This chapter demonstrates my application of this method in order to gain the results which are presented in chapter 6.

The results from the analysis of the data are presented in chapter 6 by describing and discussing three major categories which emerged from this study and reflecting on these results within the context of international literature.

In chapter 7, I discuss the story told to me by participants and describe the use of selective coding to identify the core category. This chapter goes on to describe how the three major categories and the core category led to the development of the five principles of empowering partnerships and the development of the Model of Empowerment in Devolution which is presented and discussed at the end of this chapter.

Chapter 8 discusses the limitations of the study and then presents the implications of this study in terms of practice, policy, education and research.

**1.7. Background**

Taradale (a pseudonym) is a privately run, not-for-profit organisation which, at the commencement of this research in 2001, accommodated 38 children and young people with severe intellectual and physical disabilities in a purpose-built institutional-style facility on the outskirts of Sydney, New South Wales, Australia.

In collecting this background information about Taradale, I interviewed key people within the organisation:

- the Chairman of the Board of Directors;
- the Chief Executive Officer (CEO);
- the Accommodation Manager;
• a staff union representative who attended Board and devolution planning meetings in this role;

• an advocate for a young woman living at Taradale. (While this initial interview was intended to form part of the analysed data for the study, the information gained from this interview demonstrated the advocate’s more systemic advocacy role and lacked the intimate personal contact with the young woman with a disability which was evident in the significant others interviews. The data from the advocate’s interview is included in the background information about Taradale presented here.)

In addition to these interviews, I was given access by the CEO of Taradale to documents relating to the initial Transition Plan, which is discussed below.

Under the NSW government’s deinstitutionalisation program, the institution managed by Taradale devolved to provide support in community-based accommodation (group homes, foster placements and shared care arrangements with significant others). This process began in 2000 and was completed in April 2004. Taradale as a part of the devolution process changed its operational structure in order to provide community based services (as opposed to its previous institutional model of service delivery).

In the mid 1990s, Taradale submitted a Transition Plan to the then Minister for Disability Services with a proposal to build separate accommodation on an adjoining block of land for the young adults who were sharing the institution at Taradale with children. The Minister approved the plan in the mid 1990s; however this decision was appealed against by advocacy organisations in the late 1990s on the grounds that congregate care was not in keeping with the NSW Disability Services Act of 1993. The appeal was successful and the Transition Plan approval was revoked. When first interviewed for this research in 2001, significant others, Board members and staff from Taradale still expressed their disappointment and often anger at the process of the appeal and the final decision. However, in the intervening years since the decision, the organisation had embraced the need to devolve in a different way and had been
successful in negotiating with the Department of Ageing, Disability and Home Care (DADHC) to manage the devolution process in consultation and conjunction with the Department.

In line with current policy directions of the NSW Government, the children and young people were offered a range of community based alternative accommodation. In addition to the more widely utilised model of group homes, some residents went to family or foster homes with support from community services or in a ‘shared care’ arrangement with Taradale. This research examined the impact of the process and outcomes of the devolution on some of the significant others who were affected by it.

1.8. Historical perspective

1.8.1. Institutional Care

Institutions for people who were viewed as ‘mentally defective’, ‘subnormal’ or ‘innocents’ developed in the Western world from the late 1800s and early 1900s as a way of segregating those who were ‘unfit to bear children’ (according to the then popular Social Darwinian theory of natural selection) from the rest of the population (Cummins, 2001; Fyffe, 1999; Wolfensberger, 1975). Wolfensberger, Nirje, Olshansky, Perske and Roos and Wolfensberger (1975) identified seven roles which have been ascribed to people with disabilities over the past 200 years. They defined the ‘retarded person’ as:

- sick;
- a subhuman organism;
- a menace;
- an object of pity;
- a burden of charity;
- a holy innocent;
- a developing individual.
The first six roles portrayed people with disabilities as ‘deviants’ who were best segregated from the rest of society for their own good and for the greater good, and this view formed the basis of institutionalisation. Wolfensberger et al. (1972, p. 80) stated institutions, “emphasize separateness from the community mainstream”. They identified a number of key features of institutions:

- deindividuation or treating everyone according to ‘the lowest common denominator’ (i.e. if one person was unstable or destructive, all residents were subjected to a restricted or locked environment);
- congregation into larger residential groups than those normally found within that community (with nuclear families the norm within Western societies in the 20th century, residential groupings of more than 6-8 people were uncommon);
- reduced autonomy and increased regimentation with people being treated, viewed and moved about en masse.

Institutionalisation was seen as a viable alternative to family-based care, and parents were often advised to institutionalise their son or daughter as soon as a disability was diagnosed, before attachment occurred1. They were told by medical professionals that this would be in the best interests of the child who would then have access to specialised medical care, and in the best interests of the parents, particularly the mother who could go on to have more (non-disabled) children (Blacher, 1994; Cummins, 2001; Young, 2003).

In Australia, both government and non-government organisations have traditionally run institutions. The majority of large institutions were run by the government. However many of the, usually smaller, non-government institutions were started and run by parents of children with disabilities. When looking for alternative accommodation, these parents were unable to find anything suitable and so joined together in groups to purchase and run accommodation, schools and day activity centres (Braddock,

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1 The theory of Attachment is described in Chapter 2, Section 2.1.1.
Emerson, Felce, & Stancliffe, 2001). Taradale was started by concerned parents in the 1970s to provide a special care hospital for children with severe, multiple developmental disabilities. Some of the people living in the institution managed by Taradale came there as babies or young children at that time and lived there until its closure, by which time they were aged in their 20s and 30s.

### 1.8.2. Legislative Changes

While the Commonwealth government was providing funding for non-government residential settings for people with developmental disabilities from the 1960s, there was little in the way of monitoring the quality of these services. In the early 1980s pressure on government to reform services resulted in the Commonwealth Disability Services Act (1986) which set service standards and introduced accountability. Further reform occurred with the Commonwealth/State Disability Agreement (CSDA) in 1991 which made all accommodation services the responsibility of the States/Territories (Braddock et al., 2001). In NSW, the NSW Disability Services Act (1993) specified Principles and Application of Principles from which ten Disability Services Standards were derived, to which all services funded by the NSW Government needed to demonstrate conformity. Those who did not conform were required to submit a Transition Plan outlining how they would meet the Standards. The Minister continued funding for those services which proved (via their Transition Plan) that they were moving towards conformity with the Standards and the Act (Griffin, Dew, & Parmenter, 2000; Parmenter et al., 1994). As described in the introduction to this thesis, Taradale developed two different Transition Plans outlining how they would continue to provide a service to people with disabilities.

### 1.8.3. Normalisation

One of the major impacts on the philosophy and practice of service delivery to people with disabilities was the formulation of the principle of normalisation, which profoundly influenced and hastened the process of deinstitutionalisation in Western countries (Nirje, 1970; 1976). A Dane, Bank-Mikkelsen is credited with being the first
person to define this concept in 1969 and to ensure that the principle of normalisation was incorporated into Danish law governing services for people with ‘mental retardation’. Bank-Mikkelsen’s definition, further elaborated on by Swede, Nirje (1970), was “letting the mentally retarded obtain an existence as close to the normal as possible” (cited in Wolfensberger et al., 1972, p. 27). Bank-Mikkelsen and Nirje proposed that this would be achieved by emulating patterns and conditions of everyday life for people with developmental disabilities which were as close as possible to those found within mainstream society. The Scandinavian countries were the first to both espouse the rights of people with disabilities being accorded roles within society and to enshrine these rights in legislation. At the basis of the Scandinavian work were issues of equality and human rights. They set the agenda for change for people with disabilities within the broader focus of how a society treated all its citizens (Culham & Nind, 2003).

Following the Scandinavian lead, North American writers took up the normalisation cause, the most notable being Wolf Wolfensberger who refined the normalisation principle to include the idea of people’s behaviours and characteristics appearing culturally normative . According to Wolfensberger, the definition of normalisation must be culturally specific as norms will vary from culture to culture. He also pointed out that ‘normative’ as a term should not be taken as a moral judgement but rather as equating with ‘typical’ or ‘conventional’. Regardless of the clarifications, the term ‘normalisation’ created difficulties in the way in which people across the world sought to operationalise the concept within their service provision and inevitably a questioning ensued of what is ‘normal’ and why we should aspire to ‘normality’ (Wolfensberger et al., 1972).

In their early writings on normalisation, Wolfensberger et al., separated out the physical integration from the social integration components of normalisation for people with disabilities. Wolfensberger et al., highlighted the physical differences between services for people with disabilities and those for others in the community (e.g. institutions were often situated on the outskirts of a town, surrounded by high walls,
near industrial estates or cemeteries). These physical conditions identified the service and its users as ‘different’ from the rest of society. Wolfensberger stated that to meet the requirements of normalisation, services should pay attention to the location, physical context, access and size of the services they provided to people with disabilities to ensure that they approximated valued community services.

Wolfensberger also identified program features, derogatory labels and the physical appearance of the buildings housing people with disabilities as important pointers to normalisation. He stated that labelling and segregating people with disabilities from their peers in the community only highlighted and reinforced their differences and alienated them from the society in which they lived. As an alternative, Wolfensberger identified five major implications of normalisation for the delivery of services to people with disabilities: integration; smallness; separation of the domiciliary function; specialisation; continuity. These have informed the development and provision of community-based residential services for people with disabilities in Australia today and as such are further elaborated.

Integration refers to both the physical placement of the residential service within a local community with access to community-based facilities such as public transport, shopping centres, libraries, swimming pools being taken into account when locating a residential service for people with disabilities. It also refers to the opportunities for people with disabilities to interact with non-disabled people in those environments. Wolfensberger equated smallness with integration based on the premise that large numbers of people with disabilities will not be absorbed into a local community.

Separation of domiciliary function referred to the fact that most people in the community live in one place, work in another, socialise in other places and have diversity in their lives. Within institutions, people with disabilities were often performing all these functions within the same environment and with the same people. Typically service organisations for people with disabilities offered a ‘cradle to the grave’ approach. With the development of normalisation, this was seen as undesirable as it restricted people’s opportunity to experience diversity.
Specialization referred to the principle of only offering an individual the services required by them. For example, Wolfensberger stated that all people with disabilities were often exposed to restrictive practices due to the behaviours of a few who might have been destructive. Specialisation would mean that only those people requiring a more restrictive environment would receive it. Likewise only those people requiring specialist medical treatment would receive it rather than all people with disabilities being treated as ‘sick’ and requiring medical intervention.

Continuity referred to the ability of people to move within a service system. For example, if people obtained skills in one environment which would enable them to live more independently in another, Wolfensberger proposed there should be flexibility for them to move from one environment to another.

Based on these principles Wolfensberger developed Program Analysis of Service Systems (PASS) and Program Analysis of Service Systems Implementation of Normalization Goals (PASSING) (Wolfensberger, 1992). These were tools by which services themselves, or those monitoring them, could assess the extent to which that service met the criteria for normalisation.

Partly in response to concerns about the use of the term ‘normalisation’ and its connotations of there being a ‘normal’ way for people to look and act within a given society, Wolfensberger in the 1980’s developed the term Social Role Valorisation (SRV). The principle of SRV stated simply is that “people who are accorded positive roles despite their impairments can lead almost totally integrated, highly valued, productive and full lives” (Wolfensberger, 1991 p. 20). According to Wolfensberger (1991) the attainment of these roles will be achieved by “the enablement, establishment, enhancement, maintenance and/or defence of valued social roles for people – particularly those at value risk – by using, as much as possible, culturally valued means” (p. 23). Critics of Wolfensberger’s model of SRV argued that for many people
with more severe disabilities, (such as those at Taradale) the option of integrating was not possible and hence they remained in devalued roles (Culham & Nind, 2003).

Normalisation has remained an important albeit often misunderstood concept within the disability field and its pre-eminence has influenced the development of other ways of viewing people with disabilities including the social model of disability. The social model of disability\(^2\), which is particularly prevalent in the United Kingdom, rather than seeing the ‘fault’ lying with the person with the disability themselves, proposed that society disabled the person by not accepting and accommodating itself to differences amongst people (Culham & Nind, 2003).

### 1.8.4. Deinstitutionalisation

There is no doubt that normalisation had a significant impact on the way human services were delivered to people with disabilities in the Western world. However, a call for more humane treatment of people with disabilities was also fuelled by the American Civil Rights Movement of the 1960s, which advocated equality for all minority groups. These movements advanced the push towards family-centred and community-based services for people with intellectual disabilities. At the same time there was media attention which showed the appalling conditions prevalent in some institutions and the resultant community outrage coupled with the high cost of improving institutional settings, led to deinstitutionalisation or the closure of institutions and the development of community based accommodation (Fyffe, 1999).

In Australia, it has been the policy of State and Federal governments since the mid to late 1980s to limit admissions to institutions, particularly for children, and to

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\(^2\) The social model of disability is described in more detail in Chapter 2.
progressively close institutions in favour of community based options. The closure of Taradale is part of this trend.

1.8.5. Studies of Deinstitutionalisation

There have been many studies reporting on deinstitutionalisation particularly looking at the outcomes of deinstitutionalisation for the people with disabilities themselves. Scandinavia and America led the world in moving people with disabilities out of institutions and hence the research into those moves. Britain followed suit and then Australia (Emerson & Hatton, 1996; Kim, Larson, & Lakin, 2001; Lakin, Prouty, Polister, & Coucouvanis, 2003; Mansell & Ericsson, 1996b; Stancliffe, Emerson, & Lakin, 2001; Young, Sigafoos, Suttie, Ashman, & Grevell, 1998).

Mansell and Ericsson (1996b) provided an overview of deinstitutionalisation studies in Britain, Scandinavia and the USA. They concluded that “there can be no doubt that, in general, people with intellectual disabilities have benefited from deinstitutionalisation” (Mansell & Ericsson, 1996a, p. 247) with empirical evidence demonstrating an improved quality of life for people in community settings. Emerson and Hatton (1996) reviewed the literature on service user outcomes of deinstitutionalisation in the UK and Ireland through an examination of 71 publications from 46 studies which were published between 1980 and 1994. They concluded that smaller, community-based accommodation was generally associated with improvements in service user engagement in activities, contact with care staff, adaptive behaviour (e.g. personal competence), choice making, contact with family members, community access, standard of living and acceptance in the community.

Stancliffe et al., (2001) provided an overview on community living and people with intellectual disability in Australia, the UK and the USA and concluded that in all three countries, despite differences in definitions of ‘institutions’, the numbers of people with intellectual disabilities living in institutions was declining and the numbers of people in community accommodation was increasing.
Lakin et al., (2003) extended this analysis of the USA data by examining available statistics between 1982 and 2001. They reported a major shift in the way residential services were provided to people with developmental disabilities with most people placed outside of their family homes living in small community settings rather than in institutions. In a review of US studies conducted between 1980 and 1999, which looked at measured behavioural outcomes for people with intellectual disabilities who have been deinstitutionalised, Kim et al., (2001 p. 35) reported there were “statistically significant increases in overall adaptive behaviour scores associated with deinstitutionalisation”.

In Australia, Young et al., (1998) provided a review of studies on the deinstitutionalisation of people with intellectual disabilities. They identified thirteen published studies from eight separate projects. From an analysis of these studies, they concluded that community-based placements were associated with increased adaptive behaviour, greater community participation and improved contact with family and friends. However, there was reportedly little or no change in problem behaviour, health or mortality. They stated that these results were consistent with reviews of studies conducted in the USA and the UK (Emerson & Hatton, 1996; Kim et al., 2001).

As the current study occurs within Australia, I was particularly interested to review three major studies in Queensland, Victoria and NSW since 1990 which have reported on the deinstitutionalisation of people with severe/profound intellectual disabilities and which demonstrate the trend of deinstitutionalisation within the Australian literature.

In Queensland, Young, Ashman, Sigafoos and Grevell (2000; 2001), Young (2003) and Young and Ashman (2004) reported on a quantitative study of the closure of the Challinor Centre, a large state-run institution for people with developmental disabilities in Ipswich, Queensland. The process of deinstitutionalisation and eventual closure of the Challinor Centre spanned approximately 18 years and these studies collected data on 95 of the last 144 people to leave. The data collected prior to people’s move, and then

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at one, six and 12 month intervals after their move, included assessments using
standardised instruments of adaptive behaviour, life circumstances and choice making.
This was supplemented for some people with direct observations of behaviour by the
researchers. After 12 months of data collection, Young and colleagues reported
significant changes in life circumstances and increased choice-making for individuals.
They also reported that people participated more in activities and exhibited more
appropriate behaviour. They did not however, record an improvement in adaptive
behaviour (e.g. independent functioning, economic activity, domestic activity) which
the authors suggested indicated a need for support agencies to focus on opportunities for
learning adaptive behaviour skills. In their overall findings Young et al., (2001, p. 64)
concluded that “life in the community has generally changed in a positive way for these
adults with intellectual disability during the first 12 months of transition from an
institution to community living”.

In Victoria, Cummins and Dunt (1988), Dunt and Cummins (1990), and Cummins,
Polzin and Theobold (1990a; 1990b) reported over a four-year period on a quantitative
study of the closure of St. Nicholas Hospital. This was an institution for people with
intellectual disabilities in Melbourne, Victoria which closed during 1984-5. The
researchers followed a group of 87 residents who moved from the institution to
community residential units in Melbourne and surrounding country towns. Data were
collected on residents prior to their move, 12 months, 1 ½ yrs and 4 years after their
move. The assessment instruments included: a Progress Assessment Chart (PAC)
which gathered data on eating, mobility, daily living skills, communication and
socialization; a Residents’ Routines and Activities Questionnaire which sought to assess
the extent of normalization and individualization achieved by the residents over a range
of common daily activities. The researchers, following the analysis of the four year
data, concluded that “this study has demonstrated a continuation in the life-skill
development of these ex-St. Nicholas residents” (Cummins et al., 1990a, p. 231) at a
rate which exceeded the expectation of their development had they remained in the
hospital environment. They also concluded that residents had experienced “increased
personal freedom...together with enhanced opportunities for personal development and more frequent social contact with family and friends” (Cummins et al., 1990b p. 320).

In NSW, Griffin and Dew (2000) evaluated the closure of a privately run institution for people with intellectual disabilities, The Hall for Children, located on the outer fringes of Sydney. We conducted both a quantitative and qualitative review of the impact of the closure on the residents, their families and the staff working with them. Consent to participate in the evaluation was received for 31 of the 60 residents living at ‘The Hall’ at the time of the closure. Quantitative data were collected using the Inventory for Client and Agency Planning (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986) which assessed both adaptive and challenging behaviours and a Participation and Choice assessment scale which assessed residents’ participation in domestic life, local activities, formal services, holidays, choice making, and social networks and family contact. The quantitative data was collected prior to the residents’ move and 12 months after their move. This data, consistent with other local and international studies of deinstitutionalisation (Emerson & Hatton, 1996; Young et al., 1998) showed little change in either adaptive behaviour or challenging behaviour, but significant increases in participation and choice-making. Emerson and Hatton (1996) analysed the lack of change with challenging behaviour and concluded that a research artefact is that challenging behaviour was more likely to be reported and less tolerated in community settings. The study we conducted (Griffin & Dew, 2000) also captured parents’ perceptions and this will be reported on in the next section.

**Studies of family perceptions of deinstitutionalisation**

There have been far fewer studies of deinstitutionalisation from the perspective of family members on the personal impact of deinstitutionalisation. Web of Science searches using the following combination of key words revealed only six published articles: “deinstitutionalisation/disability/family/parents/significant others (each of these combinations was used separately)”; “deinstitutionalisation/mental handicap/family”; “deinstitutionalisation/mental retardation/family”; and “deinstitutionalisation/learning
disability/family”. Four of those six articles related to people with mental health problems and so have not been included here. The other two articles were by Mirfin-Veitch, Bray and Ross (2003) and Johnson (1998). These two studies are discussed below along with five other studies which I became aware of through alternative search methods. These seven studies examine the impact of deinstitutionalisation from the family members’ perspective.

Mirfin-Veitch, Ross and Bray (1998; 2000) and Mirfin-Veitch et al., (2003) reported on the experiences of family members of people who were moved from The Templeton Centre, a large institution for people with intellectual disabilities near Christchurch, New Zealand. The people with intellectual disabilities were resettled in the community as a result of the closure. Mirfin-Veitch et al.’s., (2003) longitudinal study spanned four years from prior to the closure to one year after their move and included in-depth interviews with the family members (mainly parents) of 36 of the 480 people living at the Templeton Centre at the time of the resettlement. One of the aims of the study was to learn about families’ experiences of deinstitutionalisation so that “lessons” could be passed onto other families facing a similar situation. While not able to identify a list of “must dos”, the authors reported that positive outcomes for people with intellectual disabilities were much more likely when their families were actively and positively involved in their deinstitutionalisation and they concluded that there was a need to ensure the inclusion of family members of people with intellectual disabilities in decisions relating to their futures (Mirfin-Veitch et al., 2003).

Johnson (1998) reached somewhat different conclusions as a result of an ethnographic study of the closure of a large institution in Melbourne, Australia. The main focus of the study was to examine, through participant observation techniques, the ‘management’ of the rights of a group of 22 women with intellectual disabilities who were leaving a locked ward at the institution. Johnson (1998) also interviewed staff and family members of the women about their perceptions of the process. Johnson concluded that while processes were put in place to actively engage the person with the disability, their family members or advocates and staff in the planning process, the
inevitable tension between the rights of the person with a disability and the management imperatives to effect the closure were incompatible and she noted that “deinstitutionalisation is a problematic process” (p. 375).

This conclusion was particularly important in light of the current study. In her observations of the consultation processes between management, family members and the people with disabilities, Johnson (1998, p. 380) observed there was “an assumption that all families were the same, and had their relative’s rights and interests as their top priority. However, families varied in the degree to which they knew their relative”. She also hypothesised those families “carried with them unresolved issues of guilt and pain which influenced the decisions they made” (p. 380). Johnson (1998) surmised that at least part of the reason why management included families in decision making was in order to make them “witnesses to deinstitutionalisation” and to “defuse some of the anxiety and anger about the closure of the institution expressed by some families” (p. 380). Johnson proposed the need for independent advocates to be involved in the deinstitutionalisation process in order to both represent the interests of and monitor the outcomes for the person with a disability, and to support families members through the process so that they can “work through some of the fears, pain and guilt which may have been locked away with their relative behind institutional walls” (Johnson, 1998, p. 385). This raises the issue of whether a person can act as an advocate for both the person with a disability and their family as there may be occasions where the best interest of one may not be the best interest of the other. In arguing the case in this way, Johnson perhaps falls into the trap she warns against of assuming that all families are the same. However, Johnson’s (1998) conclusion that “families who were never consulted about their relative before do not necessarily have the skills and the knowledge to make such decisions unaided” (p. 385) is valid in some cases and her work highlights the importance of some form of family support such as that employed in the closure of the Hall for Children (Griffin & Dew, 2000).

Funnell (2002) compiled the stories of families of the people who had left the Challinor Centre in Queensland. The Community Resource Unit (CRU) in 1996 undertook a
project called *Focus on Families* to support families of people with disabilities who were then living at Challinor Centre but were destined to move from there as part of the Queensland government’s deinstitutionalisation program. As Funnell (2002, p. 2) described it, “when working with families who were struggling with the announcement that Challinor Centre was to close, it became clear to CRU that other, earlier struggles had taken place in the lives of those families”. Funnell added that very often those stories had remained a secret even within the family concerned. Funnell collected the stories of twelve families so that “the narratives in this book bear witness to what happened” (p. 2). Overall Funnell reported a mixed response from these families to the deinstitutionalisation of their family member with a disability. Some were hugely relieved and happy that their family member was to leave the institution; others were fearful and angry at what they saw as a betrayal by government of them and their family member whose ‘home’ they were closing. The stories retold in the book provide a moving and insightful picture of what institutionalisation and deinstitutionalisation means to some family members of people with disabilities.

From a pre-deinstitutionalisation perspective, Tabatabainia (2003) reported on semi-structured interviews conducted with 22 families of people with disabilities who were living in an institution which he called the ‘Zafar institution’ (an assumed name) in Queensland. He examined families’ perspectives and attitudes about institutionalisation and deinstitutionalisation and concluded that despite demonstrated benefits for people with disabilities themselves from deinstitutionalisation many families remain unconvinced about its efficacy. Tabatabainia (2003) proposed four components should be built into future deinstitutionalisation programs: clarification for families about the reasons, processes and outcomes of deinstitutionalisation; reassurance to family members about the future for their family members; education of family members about the principles underlying deinstitutionalisation; funding at a level which will satisfy families’ concerns about instability in community based accommodation.

Tuvesson and Ericsson (1996) reported on the relatives’ opinions on the closure of a large institution in the county of Skaraborg in Sweden. The relatives of 36 people who
had moved out of the institution were interviewed to find out their views about the information they had received prior to the closure of the institution, to see what they thought about the new accommodation their relative had moved into and to evaluate whether they had kept or changed their early views about deinstitutionalisation. Their conclusion was that while family members held varying views about the process and even the outcome of the deinstitutionalisation, a crucial aspect was the opportunity afforded to them to participate in the process of the change and to have some influence over the future for their family member with a disability, in many cases by forging a new type of relationship. They stated that their study demonstrated that there is “a very strong bond between the family and their relative…..an expression of the person belonging to a family” (Tuvesson & Ericsson, 1996, p. 208).

Booth, Simons and Booth (1990) devoted a chapter to the viewpoint of relatives in their book *Outward Bound* which examined the relocation and community care for people with learning difficulties in the United Kingdom. They described the change in parental views of community living over a twelve month period from opposition to the move from the institution to support for their relative’s new, community based accommodation. Booth et al., (1990) highlighted the importance of family for the person with a disability and the need for service providers to ensure that families are involved and reassured as part of the deinstitutionalisation.

Griffin and Dew (2000) in addition to the quantitative data collected in our evaluation of the closure of the Hall for Children described above, gathered qualitative data from key ‘stakeholders’ including family members. Thirty-one family members and the staff providing support to their sons and daughters (initially at The Hall and at then in the group homes) were interviewed prior to the residents’ move and at 3, 6 and 12-month intervals after their moves. The interviews were conducted via the telephone, or in person, using a semi-structured interview format. Using an emergent interviewing technique, the format was adapted at each interview sample time to reflect the issues identified by both individuals and across individuals at prior interviews. After each set of interviews, the data were analysed using a modified constant comparative method in
order to generate issues which were regarded as important by those interviewed (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

This analysis yielded nine major issues: quality of life, staffing, family contact, compatibility of residents, health care and medication, community access and participation, service management and complaints, individual planning and programming, school/post school options. The majority of the stakeholders interviewed believed that the quality of life of the residents had increased as a result of their move into the community. There was an analysis of visits by parents to their son/daughter which showed that these increased substantially and along with the qualitative data, pointed to a significant re-engagement between the residents and their family members (repatriation of residents to live near their families, who were spread throughout NSW and southern Queensland was a key feature of the closure). The re-engagement resulted in family members reporting that they felt closer to and more involved in their sons/daughters lives. In analysing both the quantitative and qualitative data, we concluded that “for the majority of the 31 consumers…..the move into community group homes produced positive outcomes and generally improved quality of life and participation in the community” (Griffin & Dew, 2000 p. 8). My involvement in the evaluation of the closure of The Hall for Children and in particular the emerging issues of re-engagement and pointers to empowerment of the family members involved in this deinstitutionalisation, provided the background to this current research with family members from Taradale. I was interested to explore whether engagement in the process of deinstitutionalisation resulted in the empowerment of significant others (empowerment will be reviewed in this next chapter).

In summary, the relatively few studies which have examined the impact of deinstitutionalisation on family members/significant others have revealed that they were concerned about the prospect of deinstitutionalisation as it challenged their belief that their family member with a disability was settled ‘for life’ in the institution. However, where significant others were actively engaged in the process and possibly re-engaged in the life of their son/daughter with a disability as a result of the deinstitutionalisation,
the long term outcomes for both the person with a disability and their significant others were positive.

1.8.6. Models of care

An analysis of studies of deinstitutionalisation revealed the predominance of the group home model as an alternative to institutional or family-based care (particularly in Australia). This model has been questioned in recent years as the most appropriate model, particularly for children and young people. Discussion of the various models of out-of-home care which provide an alternative to group homes or institutional care is useful. Reflecting this criticism, the significant others of people living at Taradale were offered a range of accommodation options including group homes, returning to live with biological family and foster care placements. The last two options included availability of regular respite care in a group home setting to family and foster carers provided by Taradale. The significant others of four of the 38 people living at Taradale opted for non-group home placements with two returning to live with biological family members and two to foster or ‘alternative family’ placements.

Approximately 82% of people with developmental disabilities live in their family homes with their biological parents where many remain for most of their lives, often until their parents’ old age or death necessitates them finding accommodation outside of their family home (Llewellyn, Gething, Kendig, & Cant, 2003). However, as will be explored further in the literature review on families, a small proportion of people are not able to remain living in this environment and an out-of-home placement is sought for them. There has been a rapid decline in the institutionalisation of people with intellectual disabilities over the past 30 years. An Australian analysis of 1996 data collected on funded accommodation services for people with intellectual disabilities revealed that 32% resided in ‘institutions / large residential (i.e. more than 20 beds) (Griffin & Parmenter, 1999; Wen & Madden, 1998). By 2000 this had been reduced to approximately 24% (or 5,000 people) and by 2002 4,380 were reportedly still living in
large residentials / institutions (approximately two-thirds of these people were believed to have intellectual disabilities) (Australian Institute of Health and Welfare, 2003; Griffin & Parmenter, 1999; Wen & Madden, 1998).

With the availability of institutional care declining, out-of-home care is provided in community-based settings. Group homes are the most common form of out-of-home care for people with developmental disabilities in Australia (Van Dam & Cameron-McGill, 1995). According to Stancliffe (2002) there had been a gradual increase in the numbers of people living in group homes in Australia. Stancliffe (2002) stated that between 1997 and 1999 there was an increase of 401 people living in group homes, an average increase of 2.8% per year over those two years. Group homes are ‘ordinary’ houses in suburban or rural areas providing accommodation to people with disabilities which approximate a normal home environment. The houses may be modified to meet the physical care needs of the people living in them. They usually accommodate from two to six people who are unrelated to each other and are supported by paid workers. Staff hours are ideally matched to the individual needs of the residents. For people who are more independent staffing may be on a drop-in basis to assist with specific tasks such as meal preparation, budgeting, and personal care. For more dependent people staff may be rostered on to cover 24-hours of care and be involved in all aspects of the person’s care and support (e.g. bathing, grooming, feeding, and toileting). However, this style of ‘one size fits all’ living with issues of compatibility between house mates has been questioned and has raised the need for increased individualised supports (Van Dam & Cameron-McGill, 1995). This model with rotating staff has been identified as inappropriate for children and adolescents and other models of out-of-home placement have been sought (Department of Ageing Disability and Home Care, 2004; Gordon, 1999).

The NSW government released a document entitled “Supporting children and young people with a disability and their families: out-of-home placements” (Department of Ageing Disability and Home Care, 2004). It stated that while the ideal place for a child with a disability to grow up is in their own family home, when this is not possible,
“family-based care is the preferred model of care for all children and young people, especially children under 12 years of age. Models of family-based care include foster care, shared care and family or kinship placement” (p. 7).

Foster Care is a system of long-term placement for a child with a disability whereby the child goes to live with a family other than their biological family. The placement is brokered by a Foster Care agency and funded by a government department. The foster parents are strictly vetted, receive training and support and receive payment for the care of the child. It is hoped that a foster placement will provide a secure, permanent and loving environment for the child to grow up, approximating that which a child might receive from its biological parents. In reality however, foster placements are difficult to maintain both for children with and without disabilities in the long term (Gordon, 1999). For a child with a severe disability, the foster family will be placed under the same pressures and tensions as the biological family experienced in providing care without necessarily the long-standing familial love and commitment to making the placement work (Griffin & Dew, 2000).

In the early 1990’s another model of care emerged which is known as Shared Care and Shared Family Care. The latter is a system of short or long term respite care for children with developmental disabilities and their families. The respite care may be provided by foster carers who receive an allowance to cover expenses but are otherwise unpaid (Baxter, Cummins, da Costa, & Vollard, 1991). Alternatively, the respite care may be provided in a group home setting through a disability support agency and this is known as Respite Care or Shared Care. Both forms of shared care allow the biological parents of the child with a disability to have planned care. The hope is that sharing of care will enable the child to be maintained within their biological family in the long term without recourse to permanent out-of-home placement.

A study conducted by Baxter et al., (1991, p. 373) into a Victorian shared family care service concluded that “family placement is a viable alternative to congregate care when out-of-home care is required”. Gordon (1999) raised concerns about the effect of
shared care on the child with possible impacts on the development of the child’s emotional well-being and sense of identity. However, Gordon (1999, p. 231) concluded that “the key issue would appear to be whether a permanent commitment to the child’s upbringing exists by both parties, rather than whether or not the child actually lives with one parent all the time”. Gordon (1999) pointed to the rise of shared care amongst divorced parents in the general community. The issue of consistency is a key argument against the placement of children in group home settings where there is often a high turnover of staff and certainly a number of different staff providing care on a rostered basis.

In the context of deinstitutionalisation, foster care could be a ‘threat’ to the biological parents and smaller congregate care maybe more palatable for this reason. In the study of the evaluation of the Hall for Children (Griffin & Dew, 2000) only one of the sixty residents went into foster care despite this being offered to all parents instead of group home placement. As already mentioned only two of the 38 residents of Taradale went into foster care placements. Gordon (1999) suggested that, whatever form of care is provided, the biological parents of the child ideally should remain an important and frequent physical and emotional presence in their child’s life.

**1.9. Chapter Summary**

This introductory chapter has provided an overview to this thesis by placing this study within the context of the current trend to move people with developmental disabilities out of institutions into community based accommodation. This trend is known as deinstitutionalisation or devolution where, as in this study, the organisation is reconfiguring itself by closing its institution and establishing group homes in the community or supporting significant others to take their ‘child’ with a disability home.

Most of the studies conducted looking at deinstitutionalisation have considered the process and outcomes of deinstitutionalisation in relation to the person with a disability with only passing comment on the effect of deinstitutionalisation on their significant
others. This is probably due, in part, to the principle of normalisation with a focus on the rights of the person with a disability.

The philosophy of normalisation has greatly influenced the development of community based accommodation. However, in Australia particularly, this has translated to a predominance of care in group homes. A recent recognition that this model is not the most appropriate one for children has led to the development of Shared Care and Foster Care alternatives. However, these models are not without their problems, are difficult to maintain in the long term and presently do not seem to be a preferred option for most family members. Group homes are also problematic for some adults with intellectual disabilities particularly due to issues arising from incompatibility between people and size (4 or 5 unrelated people living together in a house).

Precipitated by the evaluation of the Hall for Children, this current research on the devolution of Taradale examined what happened in the lives of some significant others whose son or daughter with a disability was relinquished to institutional care at some time in the past. In line with current government policy and philosophical principles, Taradale implemented devolution. This study examines how this devolution has impacted upon the lives of some of the significant others of some of the people living at Taradale.

This chapter identified that there has been little research into significant others’ views of deinstitutionalisation. Due to the importance of the relationship between people with developmental disabilities and their significant others in ensuring their on-going support, this is a deficit in the current literature to which this thesis seeks to contribute.
Chapter 2.
Review of the Literature on Families and Empowerment

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2.3. Chapter summary

The focus of this study was the impact of the devolution of Taradale, an institution for people with severe, multiple developmental disabilities from the viewpoint of significant others. From previous work (Griffin & Dew, 2000) I had a view that the level of engagement of the significant others would be related to their feelings of empowerment or control over the process and therefore the outcome of this devolution for their family member with a disability. To study this, I needed an understanding of the importance of significant others in the lives of all people and in particular in the lives of people with a disability. I also needed to understand what engagement and empowerment meant and how it might be manifested by the significant others I was talking to. While I have used the term ‘significant other’ throughout this thesis in order to encompass the range of people who may be involved in the life of a person with a severe disability, the literature reviewed here uses the terms ‘families’ or ‘parents’. In
order to encompass the traditions of both family and empowerment, this literature review is divided into two parts.

The first part will examine the literature relating to how families operate within western societies and especially within Australia, and it will also consider the literature which distinguishes families who have a child with a disability and discuss how this impacts upon the functioning of the family.

The second part will examine the literature on the empowerment of family members which is an emerging model within the disability field. Empowerment equates with a family’s desire to become actively involved (engaged) and instrumental in changing the lives of their son or daughter with a disability.

2.1. Families

The family is the most important social system in our society for transmitting culture and for meeting basic human needs across the lifespan….it presents the most ‘normal’ environment for children…..and has always been the most prevalent form of care for handicapped persons (Krauss & Giele, 1987 pp. 213-214).

What impact does having a child with a disability have upon a family? According to Haveman, van Berkum, Reijnders and Heller (1997, p. 417) “Having a child with mental retardation is a non-normative event and raising a child with a disability is a non-normative process”. Nevertheless, there is increasing recognition that children with intellectual disabilities are ‘children first’ (Bradley, Knoll, & Agosta, 1992). It has always been the case that the majority of children with intellectual disabilities are raised within their family homes, with only a very small proportion (less than 5%) ever being placed into institutional or other ‘out of home’ care (Blacher, 1994; Blacher & Baker, 1994; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999).
I first examined the main normative age-related or developmental influences
(attachment theory, ‘family systems’ model and life course and life cycle theories)
which have predominated in the mainstream literature on families. I then compared
these influences with the non-normative or unusual influences impacting on families
with a child with a disability and how this affected the family’s ability to function as a
unit and possibly pre-empt the institutionalisation of a person with a disability.

Literature discussing the stress and burden experienced by families was reviewed along
with more recent literature considering some of the positive aspects of having a child
with a disability.

2.1.1. Normative Age-Related and Developmental Influences on
Families

Attachment Theory forms the basis of the theoretical rationale for family-based care of
attachment theory, with its basis in biology and evolutionary theory, offered an
explanation for the drive for mothers to keep their child/ren safe from predators and
other dangers. The importance of an infant bonding with his/her parent/s and the
emotional security provided by a family is integral to the psychological and emotional
development and well-being of the child and their ability to interact with the external
environment (Gordon, 1999). Bowlby’s (1969; 1988) hypothesis was that early
relationship experiences would affect a person’s subsequent development of adult
relationships. Attachment theory has continued to have significant influence on theories
and practice relating to childhood development.

Family Life Cycle Theory proposed that families, like individuals, have a reasonably
predictable pattern or life course affecting their development and functioning (Seltzer,
Krauss, & Janicki, 1994). Despite differences among family development theorists
regarding the stages of family life course, the following events are recognized as
important: marriage; birth and rearing of children; launching or departing of family
members; changes in the status of the primary wage earner (Carter & McGoldrick,
At each of these stages, family members fulfil different developmental tasks. For example, in the early years, the family is preoccupied with the tasks of bearing and raising young children, establishing a home and career/s to support this family. As the children grow, the role of the family changes to educate and socialize the children and to consolidate the parents’ roles in their working and social lives. Once the children have left home, the role of the parents is to maintain the extended family with ongoing support and care (Carter & McGoldrick, 1989).

Family composition and experiences are very different now to 20 or 30 years ago. Higher divorce rates, more ‘blended’ families, the acceptance of people having and raising children outside of marriage either as a couple (de facto) or as a single person, children living with same sex adults, and so on (Australian Bureau of Statistics, 2003). However, despite these changes, the family life cycle theory is still applicable to many families in Western countries including Australia.

**Family systems theory/model** takes into account inter-relatedness of family members (Knox, Parmenter, Atkinson, & Yazbeck, 2000). This model is expanded upon later in this work and applied to families who have a child with a disability. According to this model, the family is not simply a collection of individuals but rather it is a complex and dynamic system with its own unique characteristics and needs, made up of individual members who also have their own unique characteristics and needs, which influence one another. An extension of this model is the Transactional Model as described by Ainge (1995) whereby each family member both changes other family members and is changed by them.

**Changing Family Make-Up.** Knox et al., (1995) argued that the diversity of individual families, including families of a child with a disability, has increased substantially over the past few decades particularly throughout the western world. These changes are due to factors such as improved health care resulting in more children surviving to adulthood, a longer life expectancy for adults, fewer children on average per family and
the older age of people having children. Along with these demographic changes are societal changes such as the greater disparity of income and resources between families with greater affluence for many people, greater geographic mobility and the changing nature of marriage especially the changing roles of women and men in relationships (Australian Bureau of Statistics, 2003). These influences have all contributed to a change in the way families operate and are perceived. Society has adapted itself to these changes so that the diversity of families is accepted within many Western societies.

It is difficult therefore to define ‘family’; however the main theories described here have influenced and reflected both the traditional view of family and the changing view of family. In this thesis, the term ‘significant other’ is used to embrace the diversity of meaningful, long term relationships for people with severe, multiple disabilities. For the purposes of this thesis, it was important to describe the mainstream theory development prior to discussing the non-normative or unusual influences impacting on families which have a child with a disability. These families continue to operate within the context of the society in which they live; however they are seen by others in society (and can come to see themselves) as ‘different’ to the norm.

### 2.1.2. Non-Normative or Unusual Influences on Families

In accordance with the **Family systems theory/model** and **Transactional Model**, the child with a disability affects her/his parents and her/his siblings but, in turn, each of the parents and siblings affects the child with a disability, and each other. Families with a child with a disability experience family life differently to other families due to the different and additional impacts of disability. However, the experience of having a child with a disability in the family does not *necessarily* result in high levels of family stress, family dysfunction and long-term out-of-home placement (Gordon, 1999).

Turnbull, Summers and Brotherson (1986) and Turnbull and Turnbull (2001) have used family systems theory as a framework to consider the experiences of families with a
disabled member and how these experiences are influenced by the society in which they live. They identified ‘structural dimensions’ or the family’s membership characteristics, cultural, and ideological style as having an impact on the family. A family’s cultural background and value systems affect how the family (and the community they live in) views people with disabilities (e.g. contemporary urban Australian society is multi-cultural with many different cultural and religious groups existing side-by-side). How a family from a particular cultural or religious group is supported within their community will differ according to the community’s view and acceptance of disability (Gordon, 1999; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1996). In line with the social model of disability, the family would be influenced by their cultural and religious beliefs but would be operating within the larger social and political system, which may espouse service delivery philosophies very different to those of the family. This may create tensions between the family members and the professionals supporting them (Dowling & Dolan, 2001).

Dowling and Dolan (2001), for example, argued that families of disabled children often experience unequal opportunities and outcomes in work, leisure, finance and quality of life due to the social construction of disability which constrain and limit the family. Dowling adopted the social model of disability whereby the disability per se is not the problem, rather society’s view and lack of accommodation of the person’s ‘disability’ is at fault: “being unable to walk does not, in itself, prevent an individual from going shopping, but public transport that is inaccessible to wheelchair users does” (Dowling & Dolan, 2001, p. 23).

The diversity of modern Western society has had both positive and negative impacts on a family with a disabled child. While society may be more accepting of difference and legislate against overt discrimination of people with disabilities, families with a child with a disability may find that they are unable to take advantage of many of the benefits of this diversity (Cuskelly, Pulman, & Hayes, 1998). For example, a woman who had a career prior to the birth of her child with a disability may find herself unable to return to that career as easily as a woman with a child without a disability, as finding appropriate
day care may be much more problematic. Cummins (2001) pointed out that smaller family sizes and limited contact with extended family members places much more responsibility on the parents of the person with a disability to provide sole support to the child with a disability and to rely more upon formal support services.

Turnbull, Summers and Brotherson (1986) and Turnbull and Turnbull (2001) identified the ‘family life cycle dimensions’ whereby each life stage has particular stressors associated with it for families of children with disabilities. Seltzer, Krauss and Janicki (1994) and Seltzer, Krauss, Hong & Orsmond discussed how this family life cycle may differ for a family with a child with a disability particularly at ‘milestone’ events which may be delayed in the child with a disability thus placing additional stressors on the family (e.g. both parents may not be able to resume their careers due to the additional pressures - financial and practical - of having a child with a disability). There may also be a delay in the timing of the ‘launching stage’ with this occurring much later, or not at all, than for a son or daughter without a disability due often to parental concerns about the dependence of their son or daughter with a disability and so how they will cope outside of the parental home.

Clearly then, having a child with a disability impacts upon a family, but not all families will experience and respond to this event in the same way. Much has been written about the impact of a child with a disability upon a family. Academics and service providers have attempted to classify and explain the reactions of parents to this event in order to offer appropriate support and intervention. This has given rise to a number of different Models of Family Coping. In line with family systems theory, all families are made up of individuals reflecting their unique histories, social backgrounds and experiences. Families who have a child with a disability have been subject to numerous studies looking at the way in which parents react to the diagnosis (initial news) that they have a child with a disability. While no one model is seen as definitive, an exploration of the main models espoused is useful as they represent views that have impacted upon the way services are delivered to people with disabilities in the past. Case (2000) provided a useful review of these models.
The Stage Model argued that parents experience a series of emotional stages before accepting a diagnosis. These stages are reported as similar to reactions to death or dying – shock, denial, anger/sadness, adaptation and re-organisation. This model was particularly popular in the 1970’s and 1980’s drawing on the previous work by Elizabeth Kubler Ross (1968) who proposed a five stage grief model related to death and dying. According to Case, the stage model is methodologically weak in its expectation of an orderly progression through the stages as parents may experience different reactions at different times or may not experience a particular stage at all. The model is useful if considered as a broad construct which is not applied literally.

The Personal Construct Model proposed by Cunningham and Davis (1985 as reviewed by Case 2000) focused upon the cognitive interpretations of disability rather than emotional reactions. Under this model, parents experience different reactions because they bring different interpretations to the situation based upon their previous expectations of themselves and their child. For example, the parents may have a brother, sister or cousin with a disability who was placed in institutional care at an early age. This may influence the parent to believe that this is an appropriate (or inappropriate) care option. According to Case (2000), the weakness in this model is that, as in the example given above, it does not take into account the unconscious determinants of behaviour and the emotional impact of the diagnosis.

The Social Construct Model espoused by Seligman and Darling (1989 reviewed by Case 2000) argued that beliefs, values and knowledge are socially determined through interaction. Therefore, the reactions of parents who have received the diagnosis that they have a child with a disability will be determined by the reactions of those around them (e.g. the hospital staff, their family networks, and their friends). A poor experience at this time, with possibly the withholding of information about the extent, the prognosis and the likely long term impact of the disability may instil in the parents feelings of powerlessness which may affect the development of their relationship with the child (Bradley et al., 1992). Conversely, a positive and responsive reaction by
professionals and family/friends may enhance a positive relationship with the child. There are many examples, particularly during the 1950s and 1960s (and unfortunately, extending to more recent times), where a parent was persuaded to relinquish the care of their child while still in hospital due to advice that they would not be able to cope with a child with these disabilities at home (Funnell, 2002). The social milieu of the parents influences the parent’s initial reaction to a diagnosis and so discussion of this model highlights the importance of nurses, doctors and other health professionals receiving training in sensitively giving a diagnosis of developmental disability to new parents and having knowledge of the support services available to assist them in their new role (Kearney & Griffin, 2001).

**The Medical Model** as described by Brown (1998, quoted by Case 2000, p. 274) argued that “almost every aspect of the disabled child’s body and behaviour is medically-structured in language of dysfunction and pathology”. According to this model, there is a focus on the ‘symptoms’, that detracts from seeing the child as an individual and heightens the impression that the child with a disability, whose body does not conform to society’s ideal of a ‘healthy body’, is somehow deviant. A family who sought to question the medical authority may be disempowered by the medical profession who discouraged the family from seeking answers for themselves and maintained the professionals’ superiority of knowledge (Case, 2000). The pre-eminence of the medical model is most often evident when the child has multiple or complex disabilities necessitating a high level of medical intervention. This is especially relevant for the families who participated in this study whose children had multiple and complex disabilities. The higher the level of medical intervention, the more parents may feel ‘side-lined’ and possibly experience difficulties in successfully bonding with their child (e.g. a baby born prematurely and as a result experiencing multiple health problems may spend months in an intensive care unit where parents only have physical contact through an incubator) (Bruder & Cole, 1991).

**The Expert Model** as described by Cunningham and Davis (1985, reviewed by Case 2000), stated that the traditional relationship between parents and professionals focused
upon the child, with the professional in an expert role controlling the resources (e.g. service allocation) and power (e.g. knowledge and expertise) while the parent’s function was limited to providing information rather than being part of the decision-making process. This model is closely aligned with the medical model however ‘experts’ may be drawn from a wider range of professions (e.g. social workers, therapists, educationalists). The parent is a passive ‘client’ or ‘patient’ deferring to the judgment of the professional/s which leaves the parent subordinate and powerless with little control over their own lives. This theory and the medical model are the antithesis of the empowerment model, which will be discussed in the second part of this chapter.

The medical and expert models have been prevalent in the disability field and formed the basis of institutional care where the child/person with a disability was removed from their parental care to a place which could provide for their medical, physical and psychological needs (Case, 2000; Cummins, 2001). Most institutions, including the one operated by Taradale, were set up and run along a medical model.

The Social Model described by Donoghue (2003) argued that society created a negative social identity for people with disabilities and that this view then legitimised their exclusion from society. It was therefore up to society to remove the structural constraints and hence provide people with disabilities with opportunities to participate in society and gain status and access to social resources. This model was in direct opposition to the medical/expert model. Donoghue (2003) proposed that while this model has gained wide acceptance among people within the disability movement, it has had little impact on the wider society. Nonetheless, there have been some successes with the adoption of anti-discrimination legislation which makes it illegal for disability to be used as grounds to exclude people from accessing services and goods. There are some difficulties in applying the social model to people with severe developmental disabilities (such as the sons and daughters of participants in this study) whose ability to participate in society maybe restricted due to their disabilities and for whom self-advocacy is impossible (Petry, Maes, & Vlaskamp, 2005).
The Ethical Model proposed by Vehmas (2004) argued that neither the traditional medical model with its emphasis on individual impairments nor the social model with its emphasis on social constructions of disability adequately capture the ethical considerations of living with a disability. As an alternative, he proposed an ethical model of disability in which the “well-being of the marginalized groups of society ought to be seen as an essential indicator of the flourishing of the whole society” (Vehmas, 2004 p. 220). According to this model a society has an obligation to provide support to people who are not able to support themselves.

Models can only ever hope to provide a broad representation of people’s experiences. The models described here have waxed and waned within the disability field and probably a combination of models comes closest to the actual experiences of parents at the news of the birth of a child with a disability. However, diagnosis is just the beginning; taking home the child with a disability and re-ordering their lives to meet the needs of both the child and the rest of the family is an ongoing challenge for parents.

As stated previously, most children and many adults with intellectual disabilities are cared for in their parental homes with varying degrees of formal (services) and informal support through extended family, friends, neighbours, other families of a child with a disability (Gordon, 1999). However for some parents, as described by the Expert model, the feelings of inadequacy and hopelessness in coping with having a child with a disability within their family coupled with the reactions of professionals (and to some extent, other family members or friends) which may reinforce their superior knowledge and expertise may, in fact undermine the family’s ability to continue caring for their child at home.

Blacher (1994) described the out-of-home placement of a child with a disability as a non-normative event which is traumatic for all members of the family. Bruns (2000) talked about the ‘seed having been planted’ in parent’s minds to consider out-of-home placement from a very early stage in the child’s life. Bruns (2000) proposed that as the
realities and stresses of physically and emotionally providing support for the child ‘mount up’, the consideration of out-of-home placement may reassert itself.

2.1.3. History of stress and burden of having a child with a disability

There are various reasons why family members may have relinquished the care of their son or daughter with a disability to an institution, however there is a body of literature which highlights major stressors at different age phases and transitions which may precipitate placement into out-of-home care (Heller, 1993; Turnbull et al., 1993). Seltzer et al., (1994) wrote about ‘premature launching’ of children with intellectual disabilities from their family home to alternative residential care. They cited a number of key factors associated with out-of-home placement for children including:

- age - with the greatest risk of out-of-home placement occurring between the ages of 6-12 and 19-21 which coincide with transition points in the child’s life such as beginning and ending school;
- severity of intellectual disability - with greater levels of intellectual disability more likely to result in out-of-home placement;
- presence of behaviour and physical problems - the more socially unacceptable or different the child’s behaviour and/or appearance is, the more likely out-of-home placement will occur;
- inability of the parents to meet the chronic daily needs of the child - due to financial stresses and/or a lack of support.

The stressors related to caring for the child may become too much for the family to bear when they combine with other family stressors to produce a crisis. One resolution to the crisis may involve the removal of the child with a disability from the family home. There are, therefore, many emotions, issues and concerns raised by both the initial relinquishment of the child with a disability and, in the current situation under study, their move back to community, but not family based care.
Cummins (2001) raised the point that the impetus for care in the community as inherently superior to institutional care is based upon the impact on the person with the disability, (i.e. that they will experience a better quality of life, more contact with the community and more opportunities when they move from an institution to live in the community). However, Cummins (2001) suggested that the impact of care-giving on the family (e.g. the family may actually experience a decline in their quality of life, become more isolated from their community and have their opportunities restricted due to the limitations imposed on them in caring for their child with a disability), is overlooked in the deinstitutionalisation process. In looking at the literature available on families, there is very little which addresses this particular set of circumstances from the family members'/significant others’ perspective.

Knox et al., (1995) pointed out that all families are subject to varying demands and stresses during their life cycle. Some of these demands are normative or expected and as such, are ‘part and parcel’ of having and raising children. The birth of a first child fundamentally changes the way in which the family unit operates with impact in social, economic and emotional terms. Likewise, the ‘launching’ of the youngest family member into independent life, with the subsequent return of the parents to coupledom without dependent children is a critical point for the family. However, Knox et al., (1995) pointed out that other demands on the family that are catastrophic or unexpected are “often accompanied by a sense of helplessness, disruption or loss” (p. 12). The birth of a child with a disability, or an accident resulting in disability might be seen as a potential catastrophic stressor. Again, as Knox et al., (1995, p. 12) stated “It [having a child with a disability] is usually an unanticipated event with little previous experience and time to prepare: there are few sources of guidance and little understanding by those both outside and sometimes within the family. As well the crisis does not end. In general, the disability is life-long”.

Many studies have discussed the negative impact of the diagnosis of disability upon the family. Cummins (2001) provided a useful review of the quality of life of people caring for a relative with a severe disability within their family. According to Cummins,
reviewers have compiled a list of negative effects of caring for a person with a severe
disability including: reduced social and leisure activities; financial problems; lack of
acceptance and assistance from other family members; increased stress and depression;
and a negative impact on family functioning. Ainge (1995) added to this list, the
emotional cost of lifelong sorrow and grief, anxiety, fear, guilt and blame with resulting
higher than normal difficulties in relationships between mothers and fathers.

Stainton and Besser (1998) stated that research prior to the 1980’s was almost universal
in its belief that parents having a child with an intellectual disability inevitably
experienced ‘chronic sorrow’ as a natural response to the birth of the child with a
disability and parents who spoke about the positive impacts were frequently dismissed
as ‘being in denial’ or attempting to alleviate their guilt. As previously mentioned,
Bruns (2000) highlighted the particular stresses which families with children with
complex medical needs face such as the daily physical care required, medication and
pain management issues and financial burdens. Kearney and Griffin (2001, p. 583)
proposed that many, including the nursing profession, still view having a child with a
developmental disability in terms of “tragedy, burden and pain”. Bruns (2000)
suggested that these burdens may represent ‘triggering events’ leading to out-of-home
placement for these children.

Additionally, Kahana, Biegel and Wykle discussed the impact of the physical
maturation of the person with a disability, especially the onset of puberty, on the ability
of the parents (often the mother) to provide hands on care (e.g. bathing, toileting,
dressing etc.) which may precipitate the move to out-of-home care. Blacher (1994)
identified a number of variables which may increase the likelihood of a child with a
disability being placed in out of home care including behaviour problems, medical
difficulties, severe or profound intellectual disability and a diagnosis of autism.
However, as Blacher (1994) pointed out there is rarely one discrete event precipitating
placement of a child with a disability, rather making the decision is usually cumulative
and protracted, sometimes taking years to complete.
2.1.4. Positives of having a child with a disability

In more recent years, a smaller body of work has explored the perceived positives of caring for a person with a severe disability. Cummins’ (2001) review highlighted the research in this area stating that the positives are often linked to, or are the outcomes of, successful coping strategies. Cummins proposed that the positives reported in the literature are closely linked with the philosophy of normalization (that a person with a disability is ‘better off’ living with and being cared for by their family) and economic rationalism (institutions are much more costly to run than providing often minimal support to families) and that the real needs and the lower subjective quality of life of the family are not taken into account. This links with Cummins’ (2001) comments reported earlier in this chapter on the impact of care giving on the family.

Bradley et al., (1992) however reported that families have spoken about positive transformational outcomes from parenting a child with a disability such as becoming more self confident, compassionate, making a difference for others and gaining a more ‘authentic’ view of what is important in their lives and in life in general. Developing this theme, Wilgosh and Fleming (2000) reported that parents in this situation become ‘good copers’ and learn how to use and develop local networks and services. Wilgosh and Fleming (2000) also suggested that personal traits such as patience, determination and cultivating a positive outlook on life assisted parents to cope.

Krauss and Giele (1987) identified both internal and external influences upon a family which will affect their ability to cope and how they perceive having a child with a disability. Internal factors include the personality or education of the parents and external factors include the economy and financial support.

Scorgie and Sobsey (2000) in an article which discussed the transformational outcomes associated with parenting children who have disabilities, reported that parents say there are significant positive changes in their lives as a result of having a child with a
disability. They particularly mentioned personal growth, improved relations with others and changes in philosophical or spiritual values as positives.

Likewise, Stainton and Besser (1998) reported on the findings of a qualitative study on the positive impacts of children with intellectual disabilities on their families. They identified nine core themes: source of joy and happiness; increased sense of purpose and priorities; expanded personal and social networks and community involvement; increased spirituality; sources of family unity and closeness; increased tolerance and understanding; personal growth and strength; positive impacts on others/community.

Kearney and Griffin (2001) discussed the tensions which parents of children with disabilities reported experiencing between the joy inherent in having a child and the sorrow of lost opportunities for their child. They reported parents speaking of “confusing and conflicting emotions, information and advice; ambiguous prognoses…of not knowing what to expect and sometimes of simply not knowing what to do” (Kearney & Griffin, 2001, p. 587). However from their interviews with the parents they concluded that “their experience [of being the parent of a child with a disability] was strengthening. They constructed meaning and developed new strengthening” (Kearney & Griffin, 2001, p. 588).

Scorgie and Sobsey (2000) believed controversially that there is little actual data supporting the view that having a child with a significant disability resulted in negative consequences such as stress and grief but rather that the focus on this within the literature is more to do with the assumptions of the researchers than the experiences of the parents. Supporting this view, Ainge (1995) reviewed a body of work and in particular cited a study by Kazak (1987) which investigated parents of children with intellectual disability, children with physical disability and children without disability and concluded that there were “fewer differences between families with and without a disabled child….than previous literature, clinical experience, and common sense have often suggested” (Ainge, 1995, p. 144). Ainge (1995) suggested that one possible reason for the inconsistency in findings related to the impact of having a child with a
disability is that children with intellectual disabilities have been viewed as a homogenous group in terms of their impact on their parents. However, Ainge (1995, p. 176) concluded that “although there is evidence that a child with a severe intellectual disability requires more intensive care than a child with less severe disability, including more expenditure, level of disability is not an accurate predictor of parental well-being”.

Grant and Whittell (2000) considered the coping strategies of families with children with disabilities. They reported that coping was differentiated according to gender with women seen as the main care givers within the family and displaying more self-belief and confidence in their interactions with their disabled ‘child’ than their male partners. Life stage was also a differentiating point with parents of school-aged and young adults showing greater confidence in their caring abilities and strategies than parents with pre-schoolers and parents who were older carers showing greater resignation and acceptance of their role (Llewellyn et al., 2003). Finally, family structure was important with lone carers relying more on cognitive coping strategies which joint family carers used only in circumstances when ‘all else failed’ and experienced particular difficulties in balancing work and other commitments (Llewellyn et al., 2003).

2.1.5. The journey of having a child with a disability

Having a child with a disability within a family is, therefore, in some respects, a very different journey to the one undertaken by families without a disabled member. Yet, in other ways, it reflects the journey that all families take in raising children. In referring back to the life course or life cycle theories, the developmental stages of the family with a disabled family member may often be prolonged or even become ‘stuck’ at a particular developmental point. For example, there are many people with disabilities in their 40s or 50s still living with parents who are in their 70s or 80s (Bigby, 2000; Llewellyn et al., 2003). The family has never progressed therefore, through the stage of all the children moving out of home and the parents being able to re-establish their relationship and lives with an ‘empty nest’ (Llewellyn et al., 2003). Seltzer et al., said that the delay in a person with a disability moving out of the parental home was very
often due primarily to parental preference as well as the limited availability of suitable options within community-based supported accommodation.

Regardless of the extent to which a family with a child with a disability is seen to be coping, Knox et al., (1995) pointed out that all families will require support at some time or another. These may include the same support systems that families with a child without a disability require: reliable childcare, quality medical services which are affordable, and recreational activities. Whilst in recent years there is an increased emphasis on people with disabilities accessing generic, community based services such as those mentioned above, in reality parents often find they are discouraged or excluded from accessing these services due to the service’s perceived inability to meet the needs of the child with a disability perhaps due to physical inaccessibility or inadequate funding or perhaps due to negative community attitudes (often disguised as other more ‘palatable’ reasons) (Knox et al., 1995). According to Knox et al., (1995) and Turnbull et al., (1993) without adequate and appropriate supports, a child with a disability living with their family (supposedly the least restrictive and most ‘normal’ environment), maybe unintentionally imposing a restrictive environment for all family members. The stressors created by these restrictions maybe the catalyst for the out-of-home placement of a child with a disability (Blacher & Baker, 1994).

Out-of-home placement of a child with a disability is usually not the end of the parental relationship with that person. While there are certainly some examples where parents have placed the person in an institution and severed all ties with them, it is more usual for families to have some level of on-going involvement in the life of the person with a disability (Baker & Blacher, 1993; Baker, Blacher, & Pfeiffer, 1996; Blacher, Baker, & Feinfield, 1999). Undoubtedly however, the frequency and intensity of the relationship between the family and the person living in out-of-home care may diminish over time. Baker and Blacher (1993, p. 375) reported that “the act of placement itself, or even anticipating it, may result in lessened attachment for some families”. Baker and Blacher (1993) argued that a key component of families maintaining contact in this situation was the extent to which the organisation facilitated familial involvement.
The parents who were involved in this study have relinquished the care of their son or daughter with a disability at some point earlier in their life cycle and, arguably, have been able to re-establish a more ‘normal’ family life with other children and/or other facets to their lives. All of the parents interviewed in the current study had maintained contact with their son or daughter and continued to act in a parental role with them. The devolution of the institution was a challenge to their established life to a lesser or greater extent depending on whether the family member with a disability was returning to live with them or to live in supported accommodation in the community.

Blacher (1994) provided a warning that once a child has been placed in out-of-home care, and parents have therefore experienced relief from their care, it is difficult for them to resume the care of their child on a full-time basis. One of the key questions to be answered by the current research was how the devolution of the institution managed by Taradale impacted upon the lives of some of the family members of the people with disabilities who had been living there.

The process of the devolution of Taradale required family members to engage or re-engage with their son or daughter with a disability and with the organisation. From my previous work (Griffin & Dew 2000), I hypothesised that engagement would result in empowerment for these families. The second part of this literature review examines the literature around empowerment and disability with particular reference to families.

### 2.2. Empowerment of Families

There are many definitions of empowerment. The simplest definition was provided by Turnbull and Turnbull (2001, p. 40) as “the ability to get what one wants and needs”. On the other hand, Case (2000, p. 278) described the complexity of empowering families.
The family is highlighted as a system of interlocking social relationships which impact upon how that family copes with their child and what strengths they can draw upon. Each family has a unique adaptation style and differing needs. Professionals must account for these in their interventions and in determining what help the parent needs in becoming a partner.

Empowerment can occur at three levels: systemic, societal and personal (Cocks & Cockram, 1997). It is personal empowerment of significant others and empowerment of the family unit that is most relevant to this study. The impact of empowerment within the disability field is relatively recent and it is useful to consider where this concept originated.

### 2.2.1. History of Empowerment

Dempsey (2002) associated the rise of empowerment with the black rights movement in the USA in the 1960s; however, it did not really become recognized within the disability field until the 1980s and 1990s, again driven by the United States. Empowerment is closely linked to advocacy and these concepts are now widely used in recognition that services may be delivered in ways that promote, rather than restrict, personal growth. This represented a change from the expert model and the medical model discussed earlier in this chapter, in which the professionals (medical and non-medical) were perceived as experts providing information on which parents should act. The empowerment model recognised that parents knew at least as much, if not more about their own child, and that the best support provided to families occurred in a partnership between the family and professionals (Barnes, 1997).

Singer and Powers attributed the rise of the family support movement to a ‘grass roots’ movement by parents of people with disabilities in the 1980s in the USA to respond to the pressures faced by them. According to Singer and Powers the pressures on families were due to high divorce rates, economic stagnation, women being more engaged in the
work-force, and the geographic mobility of families and immigration which resulted in the breakdown or weakening of the help traditionally provided by the extended family. These pressures challenged the ability of all families to cope with raising children, but provided additional challenges to families with a child with a disability. Singers and Powers (1993) pointed out that the growth in family support movements subsequently impacted on legislation, policy and services to people with disabilities throughout the Western world. There was an acknowledgement that families provided the bulk of the care and support to people with developmental disabilities and required support in order to continue to do this. This acknowledgment did not come easily with family support movements needing to fight against the ingrained traditional models of caring for families which Singer and Powers called residualism. They described this approach as society recognizing it needed to provide a ‘safety net’ for a small residual number of families unable to perform their traditional functions. The response to this was to set up services with strict eligibility criteria along with regulatory bureaucracies to ensure that only people who fitted these criteria received the assistance. Along with residualism there was also a tradition within family support towards professional control and ‘fitting’ families into programs. This assistance usually occurred at the point that families were ‘in crisis’ as they were then deemed needy enough to require professional intervention and a program.

The medical model (referred to earlier in this chapter) influenced the way professionals working with people with disabilities viewed them and their families. The person with a disability was described in medical terms: requiring a diagnosis, having pathology or a disease, needing treatment and with hope of a cure (Case, 2000). And their families were seen to require training and assistance (provided by professionals) in order to know how to raise their child. Families were frequently seen as ‘irrational’ or ‘unrealistic’ due to their distress at having a child with a disability. This model, as shown earlier in this chapter, is questionable and became unpalatable to many family members. Due to the efforts of parents, a new model of family support has emerged based on empowerment.
2.2.2. Models of Empowerment

Dunst, Trivette and Deal (1988) provided a three-pronged definition of empowerment. According to their model, in order to be empowered, a person needs:

1) access and control over the resources they require;
2) decision-making and problem-solving abilities;
3) the ability to interact and negotiate with others to procure the necessary resources.

Dunst, Trivette and Deal (1988) acknowledged that this approach is limited as it does not take into account the conditions that influence people’s behaviour at the time that they are seeking assistance. As an extension to this model, they offered a social systems perspective with three additional conditions:

1) the recognition that people are already competent or have the capacity to become competent (a proactive stance);
2) a perceived lack of competence on the part of the person is not due to deficits in the person but rather to the failure of social systems to create opportunities for them to display their competencies (enabling experiences);
3) a need to attribute change as resulting from personal actions in order for them to have a sense of control in their own lives and family (empowerment).

Therefore, underlying the interactions that occur between professionals and families is the principle that, more than the actual meeting of families needs, empowerment comes from the way in which those needs are met. Dunst, Trivette and Deal (1988) used the term ‘enabling model of helping’ by which they meant opportunities are created for the family members to acquire or display their competencies. Gordon (1999) suggested that support to families should be provided in ways which promote family participation, choice and self-determination through listening and acting on what families tell professionals about what will enable a family to care for their child with a disability.
within the boundaries of their family values and lifestyle. This view is consistent with Dunst, Trivette and Deal’s (1988) ‘enabling model of helping’.

Also in keeping with this definition, Singer and Powers described the model of family support as promoting resilience in families so that their ability to cope with new stressors is strengthened. They listed three essential elements of resilience: 1) flexible meaningfulness - the ability to accommodate the birth of child with a disability into your life; 2) balanced coping – the ability to make goals and develop strategies to achieve these; and 3) flexible interdependence through social support and collective action (e.g. self help groups and political advocacy groups). Singer and Powers expressed this concept as: “families can experience periods of intense stress, learn from the experience and emerge stronger”.

Demonstrating this notion of empowerment, a study by Knox et al., (2000) elicited the views of a group of 68 family members of children with disabilities in South Western Sydney by asking what they needed to live a satisfying life. The parents indicated that having input into decisions relating to them and their child with a disability was crucial. They identified two aspects of service provision that promoted shared decision-making. The first was being seen as equal partners and not as ‘consumers’ so that they knew the possible options available to them and were able to choose those that best fitted with their family values and lifestyle. “They wanted to be an integral part of a decision making team” (p. 22). This related well to the views expressed by Gordon (1999) regarding professionals listening to families. It also fitted with what Dunst, Trivette and Deal (1988), said about parents wanting professionals to acknowledge and accommodate their skills. However, as reported in Knox et al’s., (1995) study, most parents did not experience empowering relationships with professionals and those that did felt that they had needed to ‘be pushy’ to receive recognition. The second aspect Knox et al., (1995) identified was that professionals need to be sensitive to the way families feel; again their study revealed that the opposite was too often the case. The families involved in the study advocated the need for “a model of family support underpinned by the family empowerment philosophy” (p. 25). The family systems
theory discussed earlier in this chapter acknowledges that the child with a disability is intrinsically part of their family and as such, the family and not just the child becomes the client of an organisation providing them with support.

2.2.3. Empowerment in the current work

The involvement of and consultation with the significant others of the children and adults who moved out of the institution managed by Taradale had been advocated by both the government body overseeing the devolution (DADHC) and the organisation itself. Early in the planning for devolution, strategies were put in place by the organisation to facilitate this involvement including the publication of a regular newsletter providing significant others with information and opportunities to comment on the process; significant others’ representation on committees, planning meetings and as board members; the appointment of an independent Family Liaison Worker to support and assist significant others through the process and a policy of ‘open door’ contact with the Chief Executive Officer of the organisation and other key staff members.

Were these strategies effective in engaging significant others in the devolution process and in decision making about the life if their son/daughter? Did their engagement in the process lead to feelings of empowerment for significant others affected by this devolution? These questions will be answered in Chapter 7 of this thesis.

2.3. Chapter Summary

A family environment is the most appropriate place for a child with or without a disability to grow up in. Within any family there are a number of normative age-related or developmental influences on the way families are constructed. In addition a family with a child with a disability may experience a number of non-normative or unusual influences. There has been a history of literature that presumes that all families will experience stress and burden from having a member with a disability. However, in more
recent years, research has highlighted the perceived positives of having a child with a disability in terms of personal growth and the ordering of priorities within the family, along with the impact of developing effective coping strategies. For those families who, for whatever reason find themselves unable to continue to care for their child with a disability at home, an out-of-home placement may result. This has been the experience of the significant others interviewed in the current research. Both the person with a disability and their significant others experienced another transition in their life, the movement of the person from institutional to community-based care.

The major focus of this research was to explore whether and how the move was empowering for the significant others. The second part of this chapter explored the history of empowerment in general with its roots in the American Civil Rights movement translated into advocacy movements for people with disabilities. An emerging trend towards engaging significant others as partners in the care provided to their son/daughter with a disability emerged along with a number of models of empowerment. These models shared some common principles. They advocated harnessing the family’s in-depth knowledge of their son or daughter through collaboration and negotiation in order to promote a sense of control over their own lives. However, these models were geared towards the interactions between professionals and family members who had their ‘child’ with a disability living with them. The relationship is quite different where the person with a disability is in out-of-home care and particularly where the person has a severe developmental disability which precludes them fully participating in decision making on their own account. In this case, the significant others have already relinquished much of the power of decision making to the organisation providing accommodation support to their son/daughter. In the current study, the process of devolution engaged the significant others in decision making regarding their son/daughter’s future however, did it empower them? This question forms the basis of the development of the Empowering Partnerships model described in Chapter 7 of this thesis. In order to explain how this model was derived, it is necessary to explain in Chapters 3 and 4 the methodology and methods used in this study and then to present the results in Chapters 5 and 6.
Chapter 3
Research Design

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3.1. Theoretical Background

The theoretical background or methodology underpins the choice and use of particular methods or tools used to gather data for research (Babbie, 1989; Crotty, 1998).

My aim in the current study was to examine the impact of devolution on the significant others of people with severe, multiple disabilities who were moving out of an institution and into community based accommodation. As discussed previously, the majority of other studies into deinstitutionalisation have examined the outcomes (skill development, community access, quality of life etc.) for the people with disabilities themselves using a mixture of quantitative and qualitative methods. However, in the current study, it was the views, perceptions and concerns of significant others I wished to capture. These
perspectives do not lend themselves to ‘tools’ which ‘measure’ them. It would have been possible to measure the number of times significant others saw their son or daughter with a disability pre and post devolution. Data were previously collected in this way in the evaluation of the Hall for Children (Griffin & Dew, 2000). However, a measure such as this, while providing useful information, would not describe the nuances and complexity of the interactions between the significant other, their son or daughter and Taradale. Therefore, I considered methods which enabled me to gather rich, descriptive data from the significant others. I then needed to use these data to provide meaningful interpretations of the significant others’ perceptions. The overall aim was to generate a model of family empowerment which might be usefully applied to other deinstitutionalisations to further enhance the role of significant others within this process, and contribute to further research in the area.

The study was based on a symbolic interactionist perspective (Blumer, 1969) which was originally developed from the work of George Herbert Mead (Mead, 1934). Within this tradition, I used a grounded theory method to gather and analyse the data for the study.

### 3.1.1. Symbolic Interactionism

Symbolic interactionism, according to Blumer (1969, p. 79) draws on “the fact that human beings interpret or ‘define’ each other’s actions instead of merely reacting to each other’s actions…human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the meaning of one another’s actions”. Charmaz and Lofland (2003, p. 2) added that symbolic interactionism is “best understood as a ‘perspective’ rather than as a ‘theory’….a point of departure for investigating the world”.

Symbolic interactionism has its roots in social psychology where the ‘mind’ and ‘self’ were viewed as social products which lead an individual to structure the external world by their perceptions and interpretations of what they conceive the world to be (Benzies & Allen, 2001; Mead, 1934). This is particularly relevant to the current study where it
is the individual perceptions of the effect of devolution on their sons and daughters with disabilities and on their own life which was sought from the perspective of the significant others interviewed. The unique perspective of the ‘self’ of each significant other interviewed in this study sheds light on how a major event such as the devolution played out from their perspective. Their perspective is of particular significance as devolution has the potential to fundamentally change the lives of both the person with the disability and their significant others.

The strongest influence for the symbolic interactionists was the early 20th century pragmatists including James, Dewey, Cooley and Mead (The ‘Chicago School’ of Symbolic Interactionists) who held the view that the meaning of objects is due to the meaning ascribed to them rather than the objects themselves (Blumer, 1969). Blumer (1969) described three premises of symbolic interactionism.

The first premise is that rather than just reacting to internal or external occurrences on some instinctual basis, people act towards things or objects based on the meanings they ascribe to these. ‘Objects’ in this context are defined as including physical objects, people, types of people, the activities of other people, situations, institutions and abstract objects such as moral principles, philosophies and ideas. People interpret meaning and learn social habits.

The second premise is that social interaction between people leads to social products or relationships. The meaning that a thing has for a person “grows out of the ways in which other persons act toward the person with regard to the thing” (Blumer, 1969 p. 4).

The third premise is that through a process of verbal and nonverbal communication between each other, people modify the meanings they attach to things so that people know that the ‘thing’ has meaning and know how to handle that meaning. These three premises are the basis of the interpretive process which is thus a formative process whereby meanings are used or revised to guide and form action.

*Empowering Partnerships*
3.1.2. Goffman’s Influence

Erving Goffman (1971) modified aspects of the symbolic interactionist perspective further by referring to a dramaturgical model whereby people take on social roles just as actors perform a role in the theatre in order to present themselves in the best possible light (Grbich, 1999). The language used to describe the people Goffman studied at an institution in Washington DC in his groundbreaking work ‘Asylums’ is relevant to the current study. As Becker (2003, p. 662) explained “His [Goffman’s] detailed and comprehensive descriptions make it impossible to ignore the continued existence of these organized, socially accepted activities and may have, on occasion, helped to instigate attempts at their reform”. Goffman’s work with people with mental illnesses influenced much of the later work which occurred in institutions for people with intellectual disabilities. This work may, as Becker (2003) pointed out, by putting the spotlight on what was happening within these institutions, have been instrumental in bringing about their closure.

3.1.3. Social Groupings

In discussing the contemporary role of symbolic interactionism in sociology, Maines (2003, p. 6) argued that “interactionism represents good science” because people, as a species, are conscious, think, communicate and act collectively. Interactionists, according to Maines (2003) apply these facts to guide their work by studying human conduct as they interact, negotiate and operate within their social groupings. The parents of people with developmental disabilities may be categorised, by the broader society in which they live, as a ‘social group’ as they share a common experience. Within this ‘social grouping’ a ‘sub-group’ of parents of people with disabilities who live in institutions may be identified and within this group, parents of people who have been through the process of deinstitutionalisation may form a third social group. Being identified by society, and identifying oneself, as belonging to these social groups will impact upon how both society and the individual view themselves.
For all of the reasons described above, a symbolic interactionist approach to studying the process of the devolution for this social group is an appropriate one to take.

Crotty (1998, p. 42) defined the symbolic interactionist approach in the following way:

> All knowledge and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings, and their world, and developed and transmitted within an essentially social context.

Therefore, truth or meaning comes into existence in and out of our engagement with the realities in the world. People construct meaning according to their knowledge of and experience in the world. For example, the structures, rules and regulations within an organisation such as Taradale were not pre-existing. They were developed and changed by the interactions of the individuals utilising them as service users, parents and staff. Many of the rules were not written down but were rather ‘understandings’ amongst members and they were constantly negotiated and changed. Symbolic interactionism is one example, albeit a foundational one, of the broader interpretive or inductivist approach.

### 3.1.4. Inductivism

According to inductivism, theory is generated from or is the outcome of the research. Inductivism involves iteration in which the researcher weaves back and forward between data and theory (Bryman, 2001; Charmaz, 2000). The analysis of the initial set of data may reveal that further data is needed to establish the conditions in which a theory will and will not hold. Interpretivism tends to be aligned with qualitative research methods which emerged within the post-positivist or post-modern period (Charmaz, 2000).
3.2. Qualitative Research

Creswell (1998, p. 73) lists five assumptions that he believes are central to, and guide the design of all good qualitative studies. These five assumptions are the:

1) multiple nature of reality;
2) close relationship of the researcher to that being researched;
3) value-laden aspect of inquiry;
4) personal approach to writing the narrative;
5) emerging inductive methodology of the process of the research.

These five assumptions can be applied to the current research to demonstrate why a qualitative approach to the study was the most appropriate one.

1) The *multiple nature of reality* in the current study is evident in the differing perceptions of the closure and relocation of the children and young adults from the institution managed by Taradale of their significant others. Each significant other carries with them their personal experience of having a child with a disability, caring for that child and, at some point, relinquishing that child to institutional care. This history will impact upon their belief of what the future should or could hold for their son or daughter. Each significant other has different knowledge and experience of ‘community living’ for people with disabilities and so will view future options for their ‘child’ differently. Multiple realities also do not favour one reality over another.

2) The *close relationship of the researcher to that being researched* is evident in the over 20 years experience I have had working with people with disabilities and their significant others. Much of that time has related to the deinstitutionalisation of people with disabilities and so I have an in-depth and long-standing knowledge of the process underpinning the current devolution. I have been involved previously in talking to significant others...
regarding the closure of other institutions. However, I also acknowledge that each person will view the closure and movement of their son or daughter differently due to their own previous experiences. When conducting in-depth interviews with significant others about such a life-changing event as this, the researcher becomes, to some extent, emotionally involved and interested in the experiences of the significant other and the person with a disability.

3) The value laden aspect of the inquiry. The closure of the institution managed by Taradale, which had been the home of the people with disabilities who lived there for most of their lives in many cases, was undoubtedly a value laden occurrence. Indeed, a number of participants in this research had long-standing involvement in the management of the organisation. They have felt torn between the government imperative of closing the congregate setting and the loss of their child’s home with its associated memories and their investment in time and money in the organisation. The researcher also brought values to the research – a belief in the closure of institutions for people with disabilities and the involvement of significant others in this process. The values of the researcher also influenced the choice of topic, method used and expectation of this study.

4) I have sought within this thesis to provide a voice to the significant others who I interviewed by utilising a personal approach in writing their stories. I spent considerable time with participants in discussion of personal and often emotionally charged topics. I sought to provide a voice to the significant others who I interviewed by the use of their own words to illustrate themes as well as through a synthesis of their shared viewpoints.

5) Qualitative research facilitates emerging, inductive methodology as part of the process of conducting and reporting the research. Qualitative research methods, including the use of an emergent interviewing technique, allow the researcher to be creative and open in the way in which the research is reported. Qualitative research methods allow more flexibility than scientific/positivist ‘method and results’ formats of research reporting.
Within this thesis, particularly in the results and discussion chapters, I lead the reader through the process of the research using the participant's own voices to the development of a model of empowering relationships.

3.2.1. Choice of qualitative methods

Having decided upon the use of qualitative research methodology as the most appropriate one to apply in the current study, I then needed to determine which of a number of qualitative research methods to use. Denzin and Lincoln (1998, p. 14) described this as the choice of “a flexible set of guidelines that connects theoretical paradigms to strategies of inquiry and methods for collecting empirical material”.

There are four main traditions in qualitative research (Denzin & Lincoln, 2000):

1) Phenomenology may be best used if the subject of the research is to examine a deep, underlying reason for a person to act in a particular way, or to believe a particular thing.
2) Ethnography may be used if the study is an essentially cultural or values based one.
3) Case study may be used where the study relates to a particular person or clearly defined group.
4) Grounded theory may be the most appropriate approach if the subject is of interest to a researcher but the researcher has no clear theory as to why the subject under study is occurring.

Each of these strategies comes with its own literature, history and preferred methods for putting the strategy into action. Any or some combination of these traditions may be used in a qualitative research study (Creswell, 1998). Deciding upon which tradition best suits the needs of the particular study involves the personal preference of the researcher and the topic under investigation. However, the choice goes beyond a mere preference. The choice of method should be informed by a close examination of the underlying approach of each method so that the method/s which best suits the subject of the research is selected (Bryman, 2001; Denzin & Lincoln, 2000).
The choice of a grounded theory method for the current research supports an emerging inductive methodology in the process of the research. A description of grounded theory and an explanation of its use within the current research follow.

3.3. Grounded Theory

Grounded theory was developed by Barney Glaser and Anselm Strauss in the 1960s and its underpinnings are found in symbolic interactionism (as previously discussed) and particularly the Chicago School of Sociology.

Grounded theory is an analytic inductive technique whereby the researcher uses a rigorous method to work from observed instances to develop a law, model or theory (Grbich, 1999; A. Strauss & Corbin, 1990). It is a theory-generating methodology whereby data are analysed, named and used to generate theory (Glaser, 1992; A. Strauss & Corbin, 1998). Data collection and interpretation in grounded theory focus on what is happening within the individual, and between individuals or groups of individuals in particular contexts. This then feeds into another ‘round’ of data collection, analysis and further theory generation until ‘saturation’ is reached. Saturation means that no further themes are generated from the data.

Strauss and Corbin (1990, p. 23) described the grounded theory process in the following way “one does not begin with a theory, then prove it. Rather one begins with an idea of study and what is relevant to that area is allowed to emerge”. In other words, the researcher begins with a ‘blank slate’ and builds the theory up from the data in an attempt to understand the meaning of concepts, things, events and situations from the perspective of the research participant. In the current study, while I had previously existing knowledge about devolution, I had limited knowledge about how the devolution impacted on the lives of significant others of people with severe, multiple developmental disabilities.
While Strauss and Corbin (1998) identified a process to be employed in applying grounded theory, they also acknowledged the importance of the researcher being a creative and critical thinker incorporating both flexibility and openness in their application of the method. Glaser (1992) also stated that grounded theory entailed a creative process which allowed the researcher considerable licence in its application.

That said, grounded theory uses a number of interactive, concurrent steps of data-gathering, inductive reasoning, hypothesis formation, further purposeful data-gathering and logical deductive reasoning to generate explanations of complex behaviour. The desired outcome of a grounded theory study is a substantive theory or model (i.e. a theory or model which resonates for a defined area) that offers an explanation of interactive processes in particular contexts.

### 3.3.1. Grounded Theory Tools

In order to adopt a grounded theory approach to research Ezzy (2002), Bryman (2001) and Grbich (1999) identified certain ‘tools’ that a researcher will use:

- **Theoretical sampling** – the process of data collection for generating theory whereby the researcher jointly collects, codes and analyses her data and decides what data to collect next and where to find them, in order to develop her theory as it emerges;

- **Coding** – is the key process in grounded theory. The data are broken down into component parts that are given names. Coding begins soon after the collection of initial data and the emerging codes are grounded in theory with different types or levels of theory recognised;

- **Theoretical saturation** – relates to two phases in grounded theory: the coding of the data where the researcher reaches a point where there is no further point in reviewing her data to see how well they fit with her concepts or categories and the collection of data where the researcher reaches a point where new data are no longer illuminating the concept which has been developed;
• Constant comparison – a process of maintaining a close connection between data and conceptualisation so that the theoretical elaboration of that category can begin to emerge. The researcher needs to be sensitive to contrasts between the categories that are emerging.

3.3.2. Model of Grounded Theory

Bryman (2001, p. 394) has attempted to represent the process of grounded theory within a model. This is a difficult thing to do given the fluid nature of grounded theory and the movement backwards and forwards at different points in the process, however the model provides a reasonable representation of how grounded theory is applied to an area of study.

![Grounded Theory Processes and Outcomes](image)

**Figure 1 Grounded Theory Processes and Outcomes (Bryman 2001 p. 394)**
The model shows the inter-relationship between the gathering of data (through theoretical sampling and the testing of the research problem – steps 1-3 on the model), its coding and the generation of concepts and categories based upon the data (steps 4-7). The data are tested and added to through the collection of new data (steps 8-10) in order to generate substantive and, possibly, formal theory (steps 11-12). The dual direction arrows indicate that the process is fluid and developing.

### 3.3.3. Outcomes of Grounded Theory

Glaser and Strauss, and Strauss and Corbin (1998) identified a number of outcomes of grounded theory. These outcomes may be explained by relating them to Bryman’s (2001) model. Concepts (labelled 4a on Bryman’s model) are the ‘building blocks of theory’, and are the labels given to discrete phenomena through open coding. Categories (labelled 5a on Bryman’s model), in contrast, may subsume two or more concepts which have been elaborated to represent a real-world phenomena. The initial hunches about the relationships between concepts are known as hypotheses (labelled 7a on Bryman’s model). Categories are at a higher level of abstraction than concepts and a category may become a core category around which other categories pivot. A category will have properties or attributes associated with it. Major categories will emerge which will incorporate a number of categories. From all of this, a theory or a set of well-developed categories that form a theoretical framework explaining a phenomenon will be generated (11a and 12a on Bryman’s model).

### 3.3.4. Grounded Theory in this study

Grounded theory is the method of choice for this study for a number of reasons:

- Grounded theory allows the researcher to gain insights and generate theory about the experience under study. In this case the impact of devolution on significant others and whether they were empowered by this process.
• Grounded theory is an ideal method to use for this type of study as it is “best used for small scale, everyday life situations where little previous research has occurred and where processes, relationships, meanings and adaptations are the focus” (Grbich, 1999 p. 173).

• Grounded theory is useful when there is limited information on a topic or on particular aspects of a topic, and when there are aspects of the subject area or phenomenon which need to be re-examined. Few studies have investigated the process of deinstitutionalisation from the viewpoint of significant others. Most other studies of deinstitutionalisation have concentrated on the effect and outcomes on the person with a disability.

• Grounded theory is useful when concepts have not been fully identified. In the current study the nature of re-engagement and empowerment of significant others have not been fully described.

I have used grounded theory methods to analyse data collected from the significant others of people with severe, multiple disabilities undergoing devolution from institutional to community based accommodation.

3.4. Chapter Summary

I had a background in Sociology and a work history of over 20 years working with people with disabilities and their significant others. I had done previous research utilising qualitative research methods which yielded the sort of rich, descriptive data I was seeking in this study. It seemed natural therefore, to turn to qualitative methodologies for this study.

However, choosing the most appropriate method to apply to the research entailed a process of learning about, weighing up and deciding upon the methodology which would best suit both my own style of research and support my research aim of discovering the meanings attached by significant others to their engagement and involvement in a devolution.
Symbolic interactionism with its focus on meaningful realities based on interactions between people emerged as the most suitable approach for this study. An inductive approach would enable me to generate a theory or a model from the research. Utilising qualitative research methods and particularly the use of grounded theory would enable me to gather the data and extract from them the full meaning and complexity which I was seeking. These methods also allow flexibility and creativity in their application which was a further attraction for the current research.

Relating back to Creswell’s (1998) five central design features of ‘good’ qualitative studies, this study attempted to discover, using Symbolic Interactionism and Grounded Theory, the multiple reality of deinstitutionalisation as experienced by the significant others of those leaving the institution. The adoption of a grounded theory approach and the very nature of the research where individual experiences and feelings are recounted by individuals, through in-depth interviews, meant that the methodology would emerge as the research proceeded.

In Chapter 4, I describe the application of grounded theory methods and procedures. In Chapter 5, I present results from the study through a discussion of the application of the methodology. Chapter 6 presents the major categories to emerge from the analysis using participants’ voices and reflections from the literature. Chapter 7 explains the development of a model of empowering partnerships which may be applied to similar situations of devolution of people with disabilities to facilitate the empowerment of significant others.

This approach is in line with Strauss and Corbin’s (1990, p. 24) summary “the purpose of grounded theory method is, of course, to build theory that is faithful to and illuminates the area under study”.
Chapter 4
Application of Methods

Contents of Chapter 4:

4.1. Recruitment of participants to the study
   4.1.1. Ethics approval
   4.1.2. ‘Significant others’
   4.1.3. Theoretical sampling
   4.1.4. Sample size
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4.2. The Participants
   4.2.1. Profiles of person with a disability and their ‘significant other’
4.3. Data collection methods
   4.3.1. Establishing rapport
   4.3.2. Background information
   4.3.3. Interview guides
   4.3.4. Questions asked
4.4. Chapter Summary

4.1. Recruitment of participants to the study

There were thirty eight people with disabilities living at the institution managed by Taradale at the time of the commencement of this study. Each person had at least one person who was a significant other in their lives and who was a potential participant in this study.
4.1.1. Ethics Approval

Prior to the commencement of the study, the necessary ethics approval from the University of Western Sydney was obtained (a copy of the ethics approval, number HE 2000/090 is attached at Appendix 1). The ethics application required me to provide information about how I would recruit participants and how I would ensure that participants were not disadvantaged or unduly inconvenienced by participating in the study. There was also an assurance to participants that they could withdraw from the study at any time. Due to the potential distress which may be caused to participants by discussing personal aspects of their lives and the lives of their children with disabilities, I was also required to ensure that such occurrences would be sensitively handled and that participants would have access to a suitably qualified counsellor if required.

An information sheet and consent form to be sent to potential participants was prepared with the ethics application and copies of these are included at Appendix 2. The consent and support of the NSW Department of Ageing, Disability and Home Care (DADHC) and the Board of Directors of Taradale was also obtained prior to the study commencing.

4.1.2. Significant others

In determining who the significant others of each person with a disability was, I relied upon the knowledge of the organisation, and the data bases of those listed as significant others for each of the thirty eight residents at Taradale held by the NSW Department of Ageing, Disability and Home Care (DADHC). These significant others were the people both Taradale and DADHC liaised with and involved in the decision making regarding each person living at Taradale and as such they were the most appropriate people for me to contact regarding interviews.
4.1.3. Theoretical sampling

The criteria for inclusion, (i.e. being the significant other of a person with a disability living at Taradale) resulted in a purposeful sampling procedure which was inline with the theoretical persuasion of the study; symbolic interactionism and the Grounded Theory approach. Purposeful or theoretical sampling, according to Llewellyn, Sullivan and Minichiello (2004, p. 226) “relies on identifying a particular criterion that applies to the sample group and then sampling for specific instances of that criterion”.

In order to maintain the privacy of significant others, DADHC posted out information sheets and consent forms, on my behalf, to the significant others of the thirty eight residents living at Taradale. By contacting people in this way, their privacy was ensured and the onus of contact with the researcher was left with the potential participants. The names of the significant others of the people living at Taradale at the time were therefore unknown to me. This method meant that the sample of participants was self-selected by contacting the researcher and included those who felt strongly about the issues of devolution and wished to share their views through this research. It was particularly interesting to note that those who volunteered as participants were predominately fathers, which is unusual in research in the disability area (Beckman, 1991; Schultz et al., 1992). More will be said about this in the discussion (Chapter 7) of this thesis.

The information sheets asked significant others if they would be prepared to participate in a series of in-depth interviews. At this stage I was uncertain about how often I may need to interview people. As the research progressed it became apparent that for some participants only one interview was required and for others two interviews were requested. The reasons for this selection are detailed below. In this study, the first interviews are called initial interviews, and the second interviews are called follow-up interviews.
Initial interviews were conducted with five people and follow-up interviews were conducted with three of these people (all fathers). Theoretical sampling was utilised to select three fathers for a repeat interview based on the analysis of the initial interview data. Strauss and Corbin (1998, p. 202) state that theoretical sampling may be used in this way to “choose those avenues of sampling that can bring about the greatest theoretical return”. The predominate themes to emerge from the first interviews indicated that level of engagement was a major issue to be explored in the second round of interviews. What was meant by level of engagement?

In this study, level of engagement was defined as the level of current or anticipated contact between the significant other and their disabled son/daughter. Contact was defined by how often they saw or inquired about their son/daughter.

In addition to contact, the initial interviews also revealed that some significant others were more emotionally involved in the devolution at both a personal level (with their son/daughter) and at an organisational level (with Taradale). Emotional involvement was defined as their concern for and overview of their son/daughter’s life. This included the extent to which the significant other knew about, was concerned about and was actively involved in their son/daughter’s current and future life.

Participants were asked about both contact and involvement at the initial interviews. Both these factors: contact and emotional involvement, were used to determine the current and anticipated level of engagement between the significant others and their sons/daughters.

Level of engagement was used as a basis for inclusion in the follow-up interviews because the content and direction of these interviews: summarising, reflecting and describing the devolution process for themselves and their son/daughter, necessitated them having both contact and emotional involvement with their son/daughter and with the organisation.
One of the initial participants who was not re-interviewed, Doreen was spoken to on the telephone prior to follow-up interviews being arranged. Doreen acknowledged that she was currently having limited contact with Darryn and Taradale as her daughter had recently had a baby and she was engaged in helping her. Doreen herself felt that she would have little to add to the information provided at her initial interview.

The other initial participant who was not re-interviewed, Ray had in his initial interview revealed little emotional involvement in his son, Richard’s life. Ray had repeatedly said that he was happy to go along with whatever the staff at Taradale thought was best for Ray. He was not able at the initial interview to provide information about his son’s current lifestyle or about what was planned for his son in the future. In applying theoretical sampling to select participants for a follow-up interview a decision was made that Ray’s level of engagement with his son both in terms of contact and emotional involvement would not provide “the greatest theoretical return” (Strauss & Corbin, 1998, p. 202).

The three fathers who were included in follow-up interviews had a higher level of engagement (contact and emotional involvement) with their son/daughter and with Taradale than Doreen and Ray who were interviewed initially but not asked for a follow-up interview.

4.1.4. Sample size

There was a small response to the invitation to participate in the study. This may have been because ‘significant others’ were already committing considerable amounts of time to the devolution process and felt unable or unwilling to take on an additional commitment. Minichiello, Madison, Hays and Parmenter (2004) used the term ‘volunteer’ participants to describe people who agree to be interviewed for research purposes. They warn that people in this situation may “bring a private agenda to the
interview” and “may have experiences that were different from those who did not volunteer” (Minichiello et al., 2004, p. 430). Whilst these warnings of value-laden views are valid, ‘volunteer’ participants also bring with them an enthusiasm and commitment to the interview.

Moreover, for the purposes of a qualitative study such as this one, a large sample is not crucial to the design of the study or to its outcomes. Llewellyn et al, (2004 p. 231) stated that it is “not uncommon for qualitative research reports to rely on small samples” and that “this is not necessarily a bad thing”. A study such as this one is not looking for generalisation, but rather theoretical sampling.

4.1.5. The sample

The following significant others responded to the initial request to participate in the study by returning the signed consent forms and providing their contact details:

- Five (5) family members (four (4) fathers and one (1) mother);
- One (1) legal guardian;
- One (1) foster parent;

I contacted these people by telephone to arrange a convenient day and time to conduct a face-to-face, individual interview. Five of these seven people were subsequently interviewed:

- Four (4) fathers of three (3) male and one (1) female residents of Taradale ranging in ages from 5 yrs to 20 years old who had been living at Taradale for between 4 and 12 years;
- One (1) guardian of a male aged 27 years who had been living at Taradale for 26 years;

The other two people who consented to participate were not able to be interviewed due to changes in their personal circumstances. The initial interviews with these five participants lasted from between one and two hours and were conducted mostly in the...
participant’s own home, or in the case of one family member, in an interview room at Taradale.

**4.2. The Participants**

In order to present the participants in this study, I have allocated the significant others and their son or daughter living at the institution managed by Taradale with pseudonyms (Table 1 below).

<table>
<thead>
<tr>
<th>Person with a Disability (PWD)</th>
<th>Significant Other</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>Max #</td>
<td></td>
</tr>
<tr>
<td>Darryn</td>
<td>Doreen *</td>
<td></td>
</tr>
<tr>
<td>Bob</td>
<td>Bill #</td>
<td></td>
</tr>
<tr>
<td>Richard</td>
<td>Ray *</td>
<td></td>
</tr>
<tr>
<td>Thomas</td>
<td>Timothy #</td>
<td></td>
</tr>
</tbody>
</table>

# interviewed twice: initial interview and follow-up interview.

* interviewed once: initial interview.

**4.2.1. Profiles of Person with a Disability and their ‘significant other’**

Descriptive information about each of the significant others interviewed for this study and about their son/daughter with a disability is provided here so that the reader comes to know them. More descriptive information is available about the three fathers who were interviewed twice and their son/daughter. Information about these three is provided in the table format. Less information is presented about the two people who were interviewed only once at the initial interview and their son/daughter. Information about them is provided in the text.
<table>
<thead>
<tr>
<th>Mary (PWD)</th>
<th>Max (Father)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 18 years old at the time of the initial interview.</td>
<td>• Aged mid-40s.</td>
</tr>
<tr>
<td>• Lived at the institution managed by Taradale since she was 10 years old;</td>
<td>• Divorced from Mary’s Mother but recently re-married with step children;</td>
</tr>
<tr>
<td>• Lived at home with parents prior to this.</td>
<td>• Mary’s mother lives interstate so has less contact with Mary than Max.</td>
</tr>
<tr>
<td>• One brother aged 10 years old at the time of the initial interview.</td>
<td>• Self employed small businessman;</td>
</tr>
<tr>
<td>• Wheelchair bound;</td>
<td>• Lives 45 min car trip away from group home.</td>
</tr>
<tr>
<td>• Moderate/severe intellectual disability;</td>
<td>• Bad back meant Max was unable to lift and carry Mary.</td>
</tr>
<tr>
<td>• Able to indicate ‘yes/no’ responses (was able to have some input into choosing her housemates, staff, furniture etc.);</td>
<td></td>
</tr>
<tr>
<td>• Increased problems with physical health (digestion, flexibility, pain) due to lack of exercise and therapy over many years;</td>
<td></td>
</tr>
<tr>
<td>• Deteriorating physical condition means she requires more intervention from support staff as she gets older.</td>
<td></td>
</tr>
</tbody>
</table>
| • 12 months living in a group home with 3 others (at time of follow-up interview); | • Max has become very involved in the group home: assisting with buying furniture, doing odd jobs around the house etc.;%
| • The house has a dog for therapy and security.                           | • Max described Mary’s housemates as like her cousins or adopted brothers.    |
| • Group home staffed with one night staff and 2-3 staff on shift during the day | • Due to his position on the Board of Directors of Taradale, Max is involved in decisions about staffing and funding. |
| • Attends Post-school options programme run by Taradale;                  | • Max sees more of Mary now that she spends more time out in the community: the support staff sometimes drop into Max’s house with Mary when she is going to the movies or a doctor’s appointment. |
Darryn is a 27 year old man who had been living at the institution managed by Taradale since he was 18 months old. Darryn’s parents were not Australian and returned to their own country not long after placing Darryn at the institution. According to his guardian Doreen, they planned to be reunited with Darryn once they were settled however, they were unable to find comparable accommodation for Darryn in their own country and so they decided to leave Darryn in his placement at the institution. At this time, Doreen was employed by Taradale as well as having her own child placed in the institution. Due to Darryn’s complex medical care needs (he suffers from osteoporosis and can experience spontaneous fractures if not seated correctly in his wheelchair) the need arose for someone to be officially designated Darryn’s guardian so that consent for medical and health care procedures could be given. Darryn’s parents nominated Doreen for this role and a successful application was made to the NSW Guardianship Tribunal for this to occur. Doreen has guardianship powers to make decisions about Darryn’s medical needs and his accommodation. Since leaving school, Darryn attends the Post School Options program run by Taradale. At the time of the initial interview, it was planned for Darryn to move into a purpose built house with three other people from the institution.

Doreen is a married woman in her sixties who had four children. One daughter had multiple disabilities and lived at the institution managed by Taradale until her death some years ago. Doreen had been actively involved in the management of Taradale in both voluntary and paid capacities. However, she had recently pulled back from this level of involvement in part to assist her surviving daughter who has started a family of her own. Doreen lives about a 10 minute drive from Darryn’s proposed new accommodation.
### Table 3 Profile of Participant - Bill

<table>
<thead>
<tr>
<th>Bob (PWD)</th>
<th>Bill (Father)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 20 years old at time of initial interview.</td>
<td>• Aged 50s.</td>
</tr>
<tr>
<td>• Lived at the institution managed by Taradale since he was 8 years old; Lived at home with parents prior to this.</td>
<td>• Divorced from Bob’s mother but re-married with children and grandchildren; Bob’s mother also lives locally and has become more involved in his life since his move to the group home and Bill’s illness.</td>
</tr>
<tr>
<td>• Three brothers all younger (19, 17 &amp; 13 yrs at the time of the initial interview).</td>
<td>• Employed full time at the time of initial interview; On sick leave at time of follow-up interview (undergoing cancer treatment); Lives 1 hr car trip away from group home.</td>
</tr>
<tr>
<td>• Decreased mobility while at the institution has left him dependent upon a wheelchair; Complex medical needs due to his epilepsy resulting in him needing one staff member with him at all times; Severe intellectual disability; Poor dental hygiene resulting in weight loss as unable to chew his food; Unable to communicate verbally; Requires a very high level of support.</td>
<td>• Bob’s physical health is a cause of great concern to Bill particularly since his move to the group home; Bill does not believe that Bob’s physical health is adequately monitored or managed in the group home.</td>
</tr>
<tr>
<td>• 15 months living in group home with 2 others (at time of follow-up interview).</td>
<td>• According to Bill there is little interaction between housemates as they are all non-verbal</td>
</tr>
<tr>
<td>• Group home staffed with an awake night shift and two staff at all other times (awake night staff due to possibility of Bob having seizures at night)</td>
<td>• The level and quality of support provided to Bob in the group home is a major concern to Bill.</td>
</tr>
<tr>
<td>• Attends Post-school Options programme run by Taradale.</td>
<td></td>
</tr>
</tbody>
</table>
Richard is a 12 year old boy who had been living at the institution managed by Taradale for 5 years. Prior to this Richard lived at home with his parents, one brother and two sisters. Richard is the eldest child in the family. Ray described Richard as ‘profoundly disabled’, having a heart condition, relying on a wheelchair for mobility and requiring feeding by staff. At the time of the initial interview it was planned for Richard to move into a group home with some other people from Taradale.

Ray is approximately mid-40 and is from a non-English speaking background. Both he and Richard’s mother work full-time. Ray lives a two-hour train trip from the institution and visits Richard once a month. Despite the distance, his preference was for Richard to continue living in the same geographic area as the institution rather than closer to his parental home as he believed the air was better for Richard in that location. Ray commented that Richard’s mother does not come to visit him as she finds this too distressing. Since coming to live at the institution managed by Taradale Richard has only once visited his family home.
**Table 4 Profile of Participant - Timothy**

<table>
<thead>
<tr>
<th>Thomas (PWD)</th>
<th>Timothy (Father)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 10 years old at time of first interview.</td>
<td>• Aged late 30s/early 40s</td>
</tr>
<tr>
<td>• Lived at the institution managed by Taradale since he was 7 years old;</td>
<td>• Divorced from Thomas’ mother but recently re-married;</td>
</tr>
<tr>
<td>• Lived at home with family prior to this.</td>
<td>• Thomas’ mother lives about 3 hours drive away and has limited contact but</td>
</tr>
<tr>
<td></td>
<td>remains involved in decision making;</td>
</tr>
<tr>
<td></td>
<td>• Timothy is unemployed.</td>
</tr>
<tr>
<td>• Two younger brothers and an older step-sister.</td>
<td>• Timothy has recently taken over full time care of his two younger sons;</td>
</tr>
<tr>
<td></td>
<td>• Prior to Thomas’ move they had little contact with him however since the</td>
</tr>
<tr>
<td></td>
<td>move they see him frequently.</td>
</tr>
<tr>
<td>• Wheelchair bound;</td>
<td>• Timothy painted a fairly bleak picture of his son Thomas. He was negative</td>
</tr>
<tr>
<td>• Complex medical care needs including frequent infections as a result of</td>
<td>about how he sees Thomas’ quality of life;</td>
</tr>
<tr>
<td>the nasal tube used for feeding Thomas. These infections and associated</td>
<td>• Timothy told me at the initial interview that had they known how Thomas’</td>
</tr>
<tr>
<td>chest infections have resulted in frequent hospitalisations. The family</td>
<td>life would turn out, he and his then wife may have made the decision not to</td>
</tr>
<tr>
<td>and doctors are currently considering a stomach tube for food as a way</td>
<td>keep Thomas alive as a baby.</td>
</tr>
<tr>
<td>of minimising these infections;</td>
<td>• Severe intellectual disability;</td>
</tr>
<tr>
<td>• Very limited communication skills;</td>
<td>• Receives no physiotherapy or hydro-therapy although father believes he would</td>
</tr>
<tr>
<td>• Requires constant care and attention including during the night.</td>
<td>benefit from these (not funded for);</td>
</tr>
<tr>
<td>• Attends a special class at local public primary school however he misses</td>
<td>• gets very stressed by change;</td>
</tr>
<tr>
<td>a lot of school due to his ill-health.</td>
<td>• Requires constant care and attention including during the night.</td>
</tr>
<tr>
<td>• 12 months living with grandmother (Tanya) and step-grandfather (at time</td>
<td>• Decision made to keep Thomas at primary school after the move (despite</td>
</tr>
<tr>
<td>of follow-up interview);</td>
<td>being old enough for high school).</td>
</tr>
<tr>
<td>• Some respite care provided to grandmother.</td>
<td>• Timothy lives 10 minutes by car from his mother (Tanya’s) house where Thomas</td>
</tr>
<tr>
<td>• Grandmother diagnosed and treated for breast cancer in the 6 months prior</td>
<td>now lives.</td>
</tr>
<tr>
<td>to the follow-up interview.</td>
<td>• Timothy was very concerned about his mother’s physical health and her</td>
</tr>
<tr>
<td></td>
<td>ability to continue caring for Thomas.</td>
</tr>
</tbody>
</table>
4.3. Data collection methods

The method of choice for this study was Grounded Theory utilising in-depth interviews in order to collect data. Some participants were interviewed in-person twice. The initial interviews occurred in the middle of 2001 prior to any person with a disability moving out of the institution managed by Taradale. The follow-up interview was conducted 18 months later, by which time all the people with a disability related to the participants had been living in their community-based accommodation for approximately 12 to 15 months. The elapse of time between the two interviews was critical to the design of the study in order to allow for the significant others to experience the reality of the change in accommodation for their son or daughter, for them to see how the organisation had responded to the change and for significant others to be able to reflect on the impact of the move.

I have worked in the field of disability for the past 23 years and during much of this time I have had direct and indirect involvement in the deinstitutionalisation of people with disabilities. Over the past 12 years, I have been involved in research. Much of this research has involved in-depth interviews with significant others of people with disabilities. I have developed in-depth interviewing techniques which are described by Minichiello et al., (2004, p. 415) as “the art of…engaging people in open and frank conversations”. In particular the work I have done in conjunction with Dr. Tim Griffin in the evaluation of the closure of the Hall for Children (Griffin & Dew, 2000) highlighted the empowering aspects of significant others being re-engaged with their previously institutionalised children with disabilities. The opportunity to further explore empowerment in the context of deinstitutionalisation presented itself in the devolution of the institution managed by Taradale.
4.3.1. Establishing rapport

Prior to the commencement of each interview, I spend time establishing rapport with each participant through an explanation of the study and my background. Grbich (1999) said that developing rapport with participants was an essential part of the ‘sizing up’ process prior to the interview and allows the researcher to ‘lay her cards on the table’ so the participant knows who they are speaking to including your background and credentials to conduct the research. Glesne and Peshkin (1992, p. 97) stated that developing rapport is important as “generally people will talk more willingly about personal or sensitive issues once they know you”.

4.3.2. Background information

At the beginning of the initial interview I collected background information about each participant and their son or daughter with a disability. This included information about how long the person with a disability had been living at the institution managed by Taradale and where they had lived prior to moving there. There were also a number of questions about the significant others’ situation such as other children, how often the significant other saw the person with a disability and whether the pattern of seeing the person had changed since the announcement of the devolution (see Appendix 3).

Prior to the commencement of the follow-up interview, information was gathered about the current living situation of the person with a disability such as where they were living post devolution, how long ago they moved, the number of people living with them and the number of staff supporting them (see Appendix 4). At both interviews, this information was recorded on a written schedule and formed the basis of information which I could refer to during the interview (e.g. the name of the person with a disability etc.).
4.3.3. Interview guides

Drawing upon research I had previously conducted, particularly the Evaluation of the Closure of the Hall for Children (Griffin & Dew, 2000), and international literature in the area, interview ‘guides’ were developed for use with participants to ensure that similar topics/information were canvassed with each participant at both the initial and the follow-up interviews.

The guide for the initial interview was organised into ‘sections’ based on my previous knowledge of the process of deinstitutionalisation. The sections included questions about the announcement of the devolution, the participant’s involvement in the planning for the devolution, their access to information about the devolution, the level and type of contact and support offered to them, their current involvement in the devolution, and decision making and planning for the future (see Appendix 5). While this served as a guide, in line with grounded theory techniques, I explored in each subsequent participant’s initial interview issues and concerns raised in interviews with previous participants. In this way an exploration of the issues, concerns and themes was emergent with each interview.

According to Strauss and Corbin (1998) while initial questions will start out broad, they will become progressively narrower and more targeted as the research proceeds. This was certainly the case with my research. Just as with the initial interviews, the themes to emerge from the analysis of the first follow-up interview prompted additional questions or lines of inquiry with subsequent follow-up interview participants.

The analysis of the initial interviews clearly indicated that the level of engagement of the significant others at this critical transition time for their son or daughter was a crucial component of their feelings of empowerment. Therefore the follow-up interview guide was informed by the analysis of all the initial interviews and probed issues related to the impact of the devolution on their lives. There was particular
emphasis on changes in their relationship with both their son or daughter and the organisation and coping strategies to deal with these changes.

The guide for the follow-up interview therefore ‘picked up the story’ by inviting the participants to tell what the intervening period since the initial interview had been like for them and for their son or daughter with a disability. In the follow-up interview, they were asked to summarize what had happened during this period and then to talk about the best and worst things to come out of the devolution. They were asked who had helped them through this period. They were asked to reflect on how this devolution was the same or different to their first experiences of placing their child with a disability into out of home care. They were asked to describe the life of their son or daughter with a disability now and they were asked what they thought the future held for both their child and themselves (see Appendix 6).

4.3.4. Questions asked

The guides were deliberately constructed with open questions using a mix of descriptive and probing questions which allowed for the participant to tell their story in their own words (Grbich, 1999; Minichiello et al., 2004). Descriptive questions should spark the participant to provide a ‘stream of information’ on a topic they know a lot about or feel passionately about. Probing questions indicate that the researcher has been listening to what the participant is saying and wishes more information on a specific point. A silence, appropriate facial expression or verbal cue may also encourage the participant to elaborate on a point (Grbich, 1999).

This part of the interview, with the participants’ permission, was audio-taped using a micro personal tape recorder. This ensured that I could concentrate on the content of what the participant was telling me without trying to take notes. The use of a tape recorder facilitated a more relaxed, conversational climate.
From the analysis of the initial interviews, I developed a summary of key points (Appendix 7). I provided each participant who was interviewed at the follow-up interview with a copy of this and asked for their comments on the relevance of these key points to their experience. Each participant told me that this summary reflected their experience as at the time of the initial interview.

4.4. Chapter Summary

Grounded Theory was the chosen method in this study as a systematic way of analysing the rich descriptive data gained from the in-depth interviews conducted with significant others of people with disabilities moving out of the institution managed by Taradale.

Five people were interviewed initially and three people were purposefully sampled for follow-up interviews. The interviews were fully transcribed and the data analysed utilising a grounded theory method which will be described and illustrated, using examples from the data gathered in this study, in the next chapter.
Chapter 5

Results 1: Application of Methodology

5.1. Analysis of the data

5.1.1. Grounded theory analysis
5.1.2. Coding
5.1.3. Open coding
5.1.4. Axial coding
5.1.5. Convergence of major categories

5.2. Development of Major Categories – initial and follow-up interviews

5.3. Chapter Summary

5.1. Analysis of the Data

For both the initial and follow-up interviews, as soon as possible after each individual interview was completed, the audio-tapes were transcribed, with the aid of a Transcriber, into Word documents. The material was transcribed verbatim for both the interviewee and me, the interviewer, with emotional emphasis recorded by way of a note in the transcript (e.g. ‘laugh’ or ‘angry response’) and printed out. An example of a transcript is provided in Appendix 8. As discussed in Chapter 3, grounded theory allows for considerable flexibility and creativity in its application. Strauss and Corbin (1998, p. 120) stated “each person must find a system that works best for him or her”. Therefore, while I have substantially followed the process of grounded theory as proposed by Strauss and Corbin (1998; 1990), there are also times when, in order to extract the most meaning from the data, I have been flexible and creative in my analysis.
5.1.1. Grounded theory analysis

The first interviews conducted were transcribed in their entirety so that, in line with Grounded Theory principles, they could be fully analysed prior to proceeding to the next interviews. This is a form of theoretical sampling which aims to ensure that issues raised in the first round interviews were identified and analysed for categories for each participant and across participants in order to be tested and built upon in subsequent contact with participants. In this way, an issue raised by one participant in the initial interview can be explored with other participants in their follow-up interviews, or an issue raised in the initial interview with one participant can be further explored in the follow-up interview with that participant. Likewise, the follow-up interviews were transcribed in their entirety and analysed using a similar modified grounded theory approach (Glaser, 1992).

5.1.2. Coding

Coding of the data collected is at the heart of Grounded Theory. The literature describing grounded theory uses various terms to describe the coding process. Strauss and Corbin (1998) describe coding as a dynamic and fluid process which entails the microanalysis of data through a series of activities. According to Glaser and Strauss, and Strauss and Corbin (1990; 1998), analysis in grounded theory is composed of three major activities or types of coding. In this thesis, I have simplified the terms used in order to clarify the process of coding. I have used the following terms to describe my application of the grounded theory method. The terms are described in more detail in each section of this chapter:

- **Open Coding**: the process used in the first wave of analysis to develop open codes. This is done by breaking down, examining, comparing and conceptualising the data;

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3 Grounded Theory principles were described in detail in Chapter 3 of this thesis.
• **Axial Coding**: the process whereby open codes are linked to each other to form axial codes. The axial codes are then connected to form categories. Through making connections with the categories they are collapsed to form major categories.

The third type of coding used in grounded theory is

• **Selective coding** – the process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development.

This chapter describes open and axial coding as it was applied to this study. The selective coding process is described in Chapter 7, Discussion.

### 5.1.3. Open coding

Open coding is a process of identifying codes from the central ideas in the data (Strauss & Corbin, 1998). Codes are the labels given to the event, object or action in the data and as such are described by Strauss and Corbin (1998, p. 101) as the “building blocks of theory”. In conducting open coding on the data I employed a paragraph by paragraph analysis of the transcript by giving the major idea contained in each paragraph a name or title (code) which stood for or represented it (Strauss & Corbin, 1998). Coding is an important component of grounded theory as it enables you to group similar events, happenings and ideas under a common heading or classification. The process of coding: abstracting, reducing and relating, allows you to see new possibilities in the data and to classify them.

Strauss and Corbin (1998) identified key questions a researcher must ask themselves in the coding process: who, where, what and how? During the coding process I asked myself questions “who is he talking about?”, “where is this happening?”, “what is the person saying here?”, “how did he do this?” Strauss and Corbin (1998, p. 67) described
the process of asking questions as “the imaginative use of making theoretical comparisons” in order to increase the researcher’s sensitivity to her data. In conducting open coding, I wrote directly onto the printout of the transcript to relate the coding directly to the text. The following is an example of open coding from one the transcripts of an initial interview:

Table 5 Example of open coding from initial interview with Bill

<table>
<thead>
<tr>
<th>Quote from interview transcript</th>
<th>Open Codes for this quote – written in margin of transcript alongside the words</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I don’t mind the group home concept either.”</td>
<td>Positives of group home model</td>
</tr>
<tr>
<td>I think it is a really good deal and I think the kids will benefit from it,</td>
<td>Positives of group home model</td>
</tr>
<tr>
<td>but my greatest fear is, who is going to pay for it? It is a really high cost option</td>
<td>Fear for the future Cost</td>
</tr>
<tr>
<td>and I don’t know whether the government can sustain it”</td>
<td>Distrust of government</td>
</tr>
</tbody>
</table>

The codes were then written up from the transcripts into ‘code notes’ or a type of memo to ensure consistency in applying these codes to subsequent interview transcripts. Throughout the analysis, I was comparing ideas or grouping ideas together under common headings so that similar ideas were given the same name. Once particular ideas in the data were identified I was able to apply the same code to similar ideas and thus reduced the number of codes I had to work with.

The name given to the code is the one that best describes the idea contained within it but is more abstract that the ideas grouped under it. The name has been selected so that it easily triggers for me the idea which will be contained within that code. Some of the names relate to ‘jargon’ or common phrases used within the disability field, which are well known to me. However, care was taken during this process not to ‘overlay’ meanings from the field onto the ideas expressed by the participants. Some of the names for the codes are the actual words or phrases used by the participants and these are known as ‘in vivo’ codes (Glaser, 1978, p. 70).
The process of open coding allows for the development of not only the code names but also the properties and dimensions of the data which will form the basis for making relationships between codes at the axial level with the identification of categories (Strauss & Corbin 1990).

### 5.1.4. Axial coding

The next stage in the grounded theory process is to apply axial coding whereby the data, which have been “fractured” during the open coding process, are put back together in new ways by making connections between the codes (A. Strauss & Corbin, 1990; 1998, p. 124).

In order to make these connections, the open codes must be linked to the context in which they appear in the interview/transcription (what was the interviewee talking about?); to the consequences (what did the interviewee think would happen as a result of this?); to the patterns of interaction (how does what the interviewee is saying link with other views?) and to causes (why is this happening?). In analysing the data at the axial level, I remained aware of the actual words used by participants to describe their experiences while at the same time employing conceptual thinking in order to translate, define and interpret the data (Strauss & Corbin, 1998). It is a complex process in which the researcher must be cognisant of both what participants are talking about and why they describe what is happening in the way they do.

I took each of the open codes I had assigned to the data and developed axial codes from them by grouping together like ideas. In continuing the previous example, the open codes from the extract were developed into axial codes in the following way:
Table 6 Example of categorising from analysis of initial interview with Bill

<table>
<thead>
<tr>
<th>Open Codes</th>
<th>Axial Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positives of the group home model</td>
<td>Models of care</td>
</tr>
<tr>
<td>Fear for the future</td>
<td>Certainty removed</td>
</tr>
<tr>
<td>Cost - on-going</td>
<td>Distrust of government</td>
</tr>
<tr>
<td>Distrust of government</td>
<td>Distrust of government</td>
</tr>
</tbody>
</table>

As illustrated in Table 6, the open codes were analysed to determine the connections between them which led to the identification of the axial codes. The purpose of axial coding is to group the codes in order to form categories. “Categories have conceptual powers because they are able to pull together around them other groups of concepts or subcategories” (Strauss & Corbin 1990, p. 65). The categories which emerge from the data should be ‘saturated’ during the coding process (i.e. no further categories emerge when the data are re-examined). In order to ensure theoretical saturation, I employed constant comparison by reading and re-reading the data until no further categories presented themselves and I was sure that the ascribed categories best described the data. Strauss and Corbin (1998, p. 93) stated that “making comparisons is essential for identifying categories and for their development”.

The process of developing categories from axial codes is illustrated in Table 7 using the previous example:

Table 7 Example of Axial coding from analysis of initial interview with Bill

<table>
<thead>
<tr>
<th>Axial Code</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Models of care</td>
<td>Government involvement</td>
</tr>
<tr>
<td>Certainty removed</td>
<td>Family issues</td>
</tr>
<tr>
<td>Distrust of government</td>
<td>Government involvement</td>
</tr>
<tr>
<td>Distrust of government</td>
<td>Government involvement</td>
</tr>
</tbody>
</table>

Another memo was generated at this stage to describe what was contained within each category. In compiling these memos I was able to ensure consistency in how I was applying the categories within each transcript and across transcripts. From the current example.
Table 8 Example of memo from analysis of initial interview with Bill

<table>
<thead>
<tr>
<th>Category</th>
<th>Memo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government involvement</td>
<td>Cost</td>
</tr>
<tr>
<td></td>
<td>Distrust</td>
</tr>
<tr>
<td></td>
<td>Lack of options</td>
</tr>
<tr>
<td></td>
<td>Models of care</td>
</tr>
<tr>
<td>Family issues</td>
<td>Commitment/reciprocity</td>
</tr>
<tr>
<td></td>
<td>Distance/involvement in the process</td>
</tr>
<tr>
<td></td>
<td>Moving on from having child at home</td>
</tr>
<tr>
<td></td>
<td>Removal of certainty</td>
</tr>
<tr>
<td></td>
<td>Life choices</td>
</tr>
</tbody>
</table>

In applying the axial coding process, I identified for Bill (the current example), six categories which are presented below along with their memo notes.

Table 9 Example of categories from analysis of initial interview with Bill

<table>
<thead>
<tr>
<th>Categories</th>
<th>Memo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisational issues</td>
<td>Commitment</td>
</tr>
<tr>
<td></td>
<td>Reciprocity</td>
</tr>
<tr>
<td></td>
<td>Pride</td>
</tr>
<tr>
<td></td>
<td>Support</td>
</tr>
<tr>
<td></td>
<td>Information sharing</td>
</tr>
<tr>
<td></td>
<td>Future development</td>
</tr>
<tr>
<td>Government involvement</td>
<td>Cost</td>
</tr>
<tr>
<td></td>
<td>Bigger picture (other people with disabilities)</td>
</tr>
<tr>
<td></td>
<td>Distrust</td>
</tr>
<tr>
<td>Care issues for son</td>
<td>Ageing</td>
</tr>
<tr>
<td></td>
<td>Future</td>
</tr>
<tr>
<td>Family issues</td>
<td>Timing</td>
</tr>
<tr>
<td></td>
<td>Planning</td>
</tr>
<tr>
<td></td>
<td>Future</td>
</tr>
<tr>
<td>Reality</td>
<td>This is how it is</td>
</tr>
<tr>
<td></td>
<td>Reconciled</td>
</tr>
<tr>
<td>Staff issues</td>
<td>Staff roles</td>
</tr>
<tr>
<td></td>
<td>Care issues for son</td>
</tr>
<tr>
<td></td>
<td>Training</td>
</tr>
</tbody>
</table>

This process of open and axial coding to develop categories was completed for each participant after their initial interviews. Analysis of the data occurs not just at an individual level but requires the researcher to compare the categories generated from the
data for each individual across the range of all participants in the study. I therefore engaged in further analysis by comparing the categories for each individual participant across the five participants in order to generate common categories from each of them. Strauss and Corbin (1998, p. 95) called this systematic comparison: “we are interested not in how many individuals exhibit this concept but rather in how often this concept emerges and what it looks like (i.e., its properties) under varying conditions”. Table 10 demonstrates how comparisons of categories were then made across participants.

I found at this stage of the analysis that there was a high degree of concurrence between the five interviewees about the categories which demonstrated theoretical saturation. Using the process of systematic comparison of the categories generated for each participant, I identified five major categories which defined the initial interviews.
### Table 10 Comparison of categories for the five participants in initial interviews

<table>
<thead>
<tr>
<th></th>
<th>Doreen</th>
<th>Bill</th>
<th>Max</th>
<th>Timothy</th>
<th>Ray</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health/frailty &amp; high support needs of resident</td>
<td>Care issues for son</td>
<td></td>
<td>Future for son</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
<td></td>
<td>Living options for daughter</td>
<td></td>
<td></td>
<td>Expectations for son</td>
</tr>
<tr>
<td>Government involvement</td>
<td>Government involvement</td>
<td>Government involvement</td>
<td>Relationship with DADHC (negative)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compatibility of residents</td>
<td>Trust/pride in organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication with Taradale</td>
<td>Organisational issues</td>
<td></td>
<td>Relationship with Taradale (negative)</td>
<td></td>
<td>Contact with and support for Taradale</td>
</tr>
<tr>
<td>Personal input of guardian</td>
<td>Family issues</td>
<td>Family issues</td>
<td>Family issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Building/group home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long term viability &amp; sustainability of changes</td>
<td>Reality</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staffing issues/considerations</td>
<td>Staff issues</td>
<td>Staff issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident’s ability to communicate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In applying systematic comparison to the categories identified through the process of axial coding on the initial interviews for each participant (as presented in Table 10), five major categories (presented in Table 11) were developed. These major categories are an amalgam of the categories identified for each participant through the application of axial coding. Table 11 shows how the categories grounded in the data and extracted through the application of axial coding from the initial interviews with the five participants informed the development of the major categories. The categories identified from Bill’s initial interview (see Table 10) are presented in bold type in Table 11 to demonstrate how the categories from each participant’s transcript contributed towards the development of the five major categories which represented how the participants saw the devolution of Taradale at this initial stage.

Table 11 Development of major categories (initial interviews)

<table>
<thead>
<tr>
<th>Categories from initial interviews with five participants</th>
<th>Major Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Communication with Taradale;</td>
<td>1) Relationship of significant other with Taradale</td>
</tr>
<tr>
<td>• Personal input of guardian;</td>
<td></td>
</tr>
<tr>
<td>• <strong>Organisational issues:</strong></td>
<td></td>
</tr>
<tr>
<td>• Trust/pride in organisation</td>
<td></td>
</tr>
<tr>
<td>• Relationship with Taradale;</td>
<td></td>
</tr>
<tr>
<td>• Contact with and support for Taradale</td>
<td></td>
</tr>
<tr>
<td>• <strong>Government involvement</strong> (3 participants);</td>
<td>2) Government Involvement</td>
</tr>
<tr>
<td>• Long term viability &amp; sustainability of changes;</td>
<td></td>
</tr>
<tr>
<td>• Relationship with DADHC</td>
<td></td>
</tr>
<tr>
<td>• <strong>Physical health/frailty and high support needs of resident;</strong></td>
<td>3) Issues related to their son/daughter</td>
</tr>
<tr>
<td>• Quality of life of resident;</td>
<td></td>
</tr>
<tr>
<td>• Compatibility of residents;</td>
<td></td>
</tr>
<tr>
<td>• Resident’s ability to communicate;</td>
<td></td>
</tr>
<tr>
<td>• <strong>Care issues for son:</strong></td>
<td></td>
</tr>
<tr>
<td>• Living options for daughter;</td>
<td></td>
</tr>
<tr>
<td>• Future for son;</td>
<td></td>
</tr>
<tr>
<td>• Expectations for son.</td>
<td></td>
</tr>
<tr>
<td>• Personal input of guardian;</td>
<td></td>
</tr>
<tr>
<td>• <strong>Family issues</strong> (3 participants).</td>
<td>4) Family Issues</td>
</tr>
<tr>
<td>• Staffing issues/considerations;</td>
<td></td>
</tr>
<tr>
<td>• <strong>Staff issues</strong> (2 participants).</td>
<td>5) Staff issues</td>
</tr>
<tr>
<td>• Future for daughter;</td>
<td></td>
</tr>
<tr>
<td>• Expectations for son.</td>
<td></td>
</tr>
</tbody>
</table>
The application of Grounded Theory principles using the process of asking questions and making theoretical comparisons consistently and systematically during analysis (Strauss & Corbin, 1998), led to the identification of five major categories from the initial interviews. As presented in Table 11, these major categories demonstrated that participants were predominately positive and supportive of Taradale but negative or suspicious of government’s role in the devolution especially the cost and the long-term commitment to continue funding. Significant others also voiced their concerns about their son’s/daughter’s adaptation to community living due particularly to their complex care needs resulting from the level of their disability, medical frailty and limited communication skills. This major category was linked to staff issues with concerns about the numbers, qualifications, commitment and availability of staff to work in the community placements as compared to the perceived stability and commitment of the staff employed in the institutional setting. These major categories were placed within the context of what was happening in the life of the significant other at the time of the initial interviews.

Within the major category Family Issues, the data revealed that the devolution of the institution managed by Taradale reawakened feelings related to the initial out-of-home placement of their son or daughter in an institution while at the same time threatening the stability of the lives they had established for themselves since their ‘child’s’ institutionalisation. Fundamental to all this was their stated on-going commitment to ensure the best for their son or daughter with a disability.

As described previously, the follow-up interviews with three participants sought to ‘pick up the story’ and test whether engagement in their son/daughter’s life through the devolution of the institution managed by Taradale was an empowering experience for them.
5.1.5. Convergence of major categories

The analysis of the transcripts of the follow-up interviews was conducted in the same way as previously described. The grounded theory techniques of open and axial coding were applied to the follow-up interview data for each interview participant in order to develop categories. At this stage there was no attempt made by me to overlay the emerging categories from the follow-up interviews with the five major categories to emerge from the initial interviews. However, once the follow-up interviews had been analysed to the level of categories for each of the three participants, a comparison was made between the emerging follow-up interview categories and the initial interview major categories.

Browne and Sullivan (1999, p. 598) described this process as “refining categories using an analytical mode” to look for meanings, conditions, interactions, strategies, structural influences, and consequences. According to Browne and Sullivan (1999, p. 599) “Actions, interactions and strategies lead to identifiable consequences and those consequences influence subsequent actions and interactions that occur…throughout this process we continue to go back to the data to obtain more and more information”.

As table 12 (over) shows, there was a high degree of concurrence between the major categories which emerged from the analysis of both the initial and follow-up interviews. However, in referring back to the data for each participant, it was evident that the content described in each category varied from the initial to the follow-up interviews. This difference in categories was reflected in the major categories with a shift in emphasis (some things were more or less important from one interview time to the other) and content (new issues had emerged) for participants between the two interviews. Therefore, a reinterpretation of participants’ anticipated outcomes of the devolution (as expressed at their initial interviews) in relation to their actual experiences of it (as told to me in the follow-up interviews) was required. In table 12 the major categories are represented in **bold** type and the categories within each major category are represented as dot points in normal type.
Table 12 Comparison of Categories and Major Categories: Initial Interviews to Follow-up interviews

<table>
<thead>
<tr>
<th>Categories &amp; Major categories to emerge from analysis of initial interviews</th>
<th>Categories &amp; Major categories to emerge from analysis of follow up interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The relationship between significant others and Taradale</strong></td>
<td><strong>The relationship between significant others and Taradale: from support to disgruntlement</strong></td>
</tr>
<tr>
<td>• Information;</td>
<td>• Communication problems;</td>
</tr>
<tr>
<td>• Communication;</td>
<td>• Responsiveness;</td>
</tr>
<tr>
<td>• Responsiveness;</td>
<td>• Family Support Worker;</td>
</tr>
<tr>
<td>• Family Support Worker.</td>
<td>• Appropriateness of housing;</td>
</tr>
<tr>
<td></td>
<td>• Financial costs.</td>
</tr>
<tr>
<td><strong>The quality of life of their sons/daughters</strong></td>
<td><strong>The quality of life of their sons/daughters: What’s better? What’s worse?</strong></td>
</tr>
<tr>
<td>• Standard of care;</td>
<td>What’s better:</td>
</tr>
<tr>
<td>• Provision of health care;</td>
<td>• Community access;</td>
</tr>
<tr>
<td>• Compatibility and companionship in living arrangement;</td>
<td>• Lifestyle;</td>
</tr>
<tr>
<td>• Contact with past friends;</td>
<td>• Staff ratios;</td>
</tr>
<tr>
<td>• Level of family contact;</td>
<td>• Mobility;</td>
</tr>
<tr>
<td>• Financial costs;</td>
<td>• Knowing their family.</td>
</tr>
<tr>
<td>• Overall benefits to living in the community.</td>
<td>What’s worse:</td>
</tr>
<tr>
<td></td>
<td>• Health;</td>
</tr>
<tr>
<td></td>
<td>• Isolation;</td>
</tr>
<tr>
<td></td>
<td>• Additional costs.</td>
</tr>
</tbody>
</table>
### Table 12 continued: Comparison of Categories & Major Categories: Initial Interview to Follow up Interviews

<table>
<thead>
<tr>
<th>Initial Interviews</th>
<th>Follow-up Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Meeting Families Needs</strong></td>
<td><strong>Meeting Families Needs: Regrets with reality</strong></td>
</tr>
<tr>
<td>- Re-awakening of guilt over initial out-of-home placement;</td>
<td>- Re-awakening of guilt over initial out-of-home placement;</td>
</tr>
<tr>
<td>- Competing demands;</td>
<td>- Competing demands;</td>
</tr>
<tr>
<td>- Level of involvement with Taradale;</td>
<td>- Level of involvement with Taradale;</td>
</tr>
<tr>
<td>- Concerns about the future.</td>
<td>- Diminishing communication with Taradale;</td>
</tr>
<tr>
<td></td>
<td>- Concerns about the future.</td>
</tr>
<tr>
<td><strong>Quality of Staff Support</strong></td>
<td>**Quality of Staff Support: Uncertainty about quality and</td>
</tr>
<tr>
<td>- Finding suitable people;</td>
<td>quantity of staff**</td>
</tr>
<tr>
<td>- Training, supervision and isolation;</td>
<td>- Finding suitable people;</td>
</tr>
<tr>
<td>- Staffing levels and ratios;</td>
<td>- Training, supervision and isolation;</td>
</tr>
<tr>
<td>- Diverse roles;</td>
<td>- Staffing levels and ratios;</td>
</tr>
<tr>
<td>- Empathy and care.</td>
<td>- Diverse roles;</td>
</tr>
<tr>
<td></td>
<td>- Empathy and care.</td>
</tr>
<tr>
<td><strong>Government’s Role in the Devolution</strong></td>
<td><strong>Government’s Role in the Devolution: Government always</strong></td>
</tr>
<tr>
<td>- Original Transition Plan;</td>
<td>wins**</td>
</tr>
<tr>
<td>- Government’s ongoing involvement.</td>
<td>(One father only)</td>
</tr>
<tr>
<td></td>
<td>- From his perspective as a Board Member of Taradale</td>
</tr>
<tr>
<td></td>
<td>- For the other people interviewed, their focus has shifted</td>
</tr>
<tr>
<td></td>
<td>from government to Taradale.</td>
</tr>
</tbody>
</table>
5.2. Development of Major Categories – initial and follow-up interviews

Once I had identified the major categories displayed in Table 12, I returned to the data to further refine my understanding of what my participants were telling me about what devolution had been like for them. The five initial major categories described what devolution meant to the participants prior to their son/daughter actually moving out of the institution. Analysis of the follow-up interviews revealed that these major categories (with the exception of the role of government) were still relevant for participants. However, the emphasis and content of these major categories had changed to capture their experience of their sons/daughters living in their new, community-based accommodation. From the data analysis and through the application of conceptual thinking, I worked towards the development of major categories which would describe the process of devolution from the viewpoint of the participants in this study drawing upon their initial and follow-up interviews. Strauss (1987, p. 29) described this process as “stepping away into conceptualisation”. This is a difficult, but necessary process, in order to develop a theoretical understanding which will lead to a theory or model representing the area studied. I again employed the cornerstones of grounded theory in order to do this: I asked questions of the data and I systematically compared what participants told me at the initial interview with what they were telling me at the follow-up interview. In conducting this analytical work I sought to capture what it was about the devolution that was most important to the participants. How could I best represent what they told me about this transition in their lives which would help others to understand what it was like for them? This further conceptualisation of the data resulted in collapsing the number of major categories I was working with and to the emergence of three major categories. Table 13 shows the development of the major categories to emerge from the follow-up interviews from the major categories identified from the initial interviews. This process ensured that the initial major categories were incorporated into the follow-up major categories so that the final three major categories represented both the initial and follow-up interviews.
Table 13: Development of final major categories

<table>
<thead>
<tr>
<th>Initial major categories</th>
<th>Final major categories (developed from incorporation of major categories for initial and follow-up interviews)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The relationship between family members and Taradale</td>
<td>1. Getting it Right</td>
</tr>
<tr>
<td>2. Quality of staff support</td>
<td></td>
</tr>
<tr>
<td>3. The quality of life of their sons/daughters</td>
<td>2. Parents Forever</td>
</tr>
<tr>
<td>4. Meeting families needs</td>
<td>3. Changing lives</td>
</tr>
<tr>
<td>5. Government’s role in devolution</td>
<td>Not included – not seen as relevant by participants in follow-up interviews.</td>
</tr>
</tbody>
</table>

The three final major categories are:

1) Getting it Right;
2) Parents Forever;

These three major categories are described and illustrated in Chapter 6 of this thesis.

5.3. Chapter Summary

Grounded theory was the method of choice in this study. I applied grounded theory methodology by conducting open and axial coding on the transcripts of the individual interviews until categories were identified and theoretical saturation was reached. Grounded theory allows for flexibility and creativity in its application which is essential in order to extract from the raw data a sense of what it is that participants are saying about their experiences. The process of grounded theory is dynamic and unfolding. As such, open and axial coding are a process not sequential steps in analysis. The researcher moves backwards and forwards between open and axial coding throughout the process. The purpose of the open and axial components of the coding process is to develop categories which describe the experiences of the participants in the study.
Categories can be identified at a number of levels. In this chapter I have described the development of categories and major categories.

Five major categories emerged from the analysis of the initial interview data collected in this study. The follow-up interviews were conducted with three participants and their data were treated in the same way as the process described above. “Stepping away into conceptualisation” (A. Strauss, 1987, p. 29) led to the development of three major categories which described the process of devolution from the viewpoint of the participants.

In Chapter 6, the Results II chapter, the major categories and associated categories (identified through the axial coding process) are described and discussed in detail.
Chapter 6
Results II: Themes, Voices and Literature

Contents of Chapter 6:

6.1. Major Categories

6.2. Getting it Right
   6.2.1. Provision of information pre-devolution
   6.2.2. Communication problems post-devolution
   6.2.3. Responsiveness to problems & concerns
   6.2.4. Family Support Worker
   6.2.5. Appropriateness of housing
   6.2.6. Financial costs
   6.2.7. Quality of staff support
   6.2.8. Overall benefits of living in the community
   6.2.9. Reflections from the literature
   6.2.10. Major category summary

6.3. Parents Forever
   6.3.1. Re-awakening guilt over the initial out-of-home placement
   6.3.2. Standard of care
   6.3.3. Provision of health care
   6.3.4. Compatibility and companionship in living arrangement
   6.3.5. Contact with past friends
   6.3.6. Level of family contact
   6.3.7. Reflections from the literature
   6.3.8. Major category summary

6.4. Changing Lives
   6.4.1. Competing demands
   6.4.2. Level of involvement in management of Taradale
   6.4.3. Diminishing communication with Taradale
   6.4.4. Concerns about the future
6.4.5. Reflections from the literature

6.4.6. Major category summary

6.5. Chapter summary

This chapter describes the results of the analysis of the interviews conducted initially with five participants and follow-up interviews with three participants. All participants were identified by DADHC and Taradale as significant others of people who moved from Taradale into community-based accommodation. The results are presented using direct quotes from the transcripts of the interviews, discussion of the data and drawing upon international literature relating to the major categories.

This chapter describes and illustrates the three major categories which emerged, using Grounded Theory methods of applying analysis to refine the categories or “stepping away into conceptualisation” as described by Strauss (1987). These three major categories resulted from incorporating the five major categories identified at the initial interviews with the analysis of the data collected at the follow-up interviews. Each major category contains a number of categories which are derived from the axial coding process which ground the major categories in the data (see table 14).

Table 14 identifies the major categories and categories which will be described in this chapter.
### Table 14 Major categories and Categories

<table>
<thead>
<tr>
<th>Major Category</th>
<th>Category</th>
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<tbody>
<tr>
<td>1. Getting it Right</td>
<td>• Provision of information pre-devolution;</td>
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<tr>
<td></td>
<td>• Communication problems post-devolution;</td>
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<tr>
<td></td>
<td>• Responsiveness to problems and concerns;</td>
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<td></td>
<td>• Family Support Worker;</td>
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<td>• Appropriateness of housing;</td>
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<td></td>
<td>• Financial costs;</td>
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<td></td>
<td>• Quality of staff support.</td>
</tr>
<tr>
<td>2. Parents Forever</td>
<td>• Re-awakening guilt over the initial out-of-home placement;</td>
</tr>
<tr>
<td></td>
<td>• Standard of care;</td>
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<td></td>
<td>• Provision of health care;</td>
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<td></td>
<td>• Level of family contact.</td>
</tr>
<tr>
<td>3. Changing Lives</td>
<td>• Competing demands;</td>
</tr>
<tr>
<td></td>
<td>• Level of involvement in management of Taradale;</td>
</tr>
<tr>
<td></td>
<td>• Diminishing communication with Taradale;</td>
</tr>
<tr>
<td></td>
<td>• Concerns about the future</td>
</tr>
</tbody>
</table>

Throughout the description of the results I have used excerpts from participants’ interviews both initially and at the follow-up interviews in order to further demonstrate the shift in participants’ thinking between the two interviews as it was expressed in the participants’ own words, using the pseudonyms allocated earlier. These comparative quotes are presented within boxes. Other quotes which demonstrate the category but are not comparative are presented within the text and written in italics.

Within each major category I introduce some literature which places the major category within a broader context. Some of this literature has already been reviewed earlier in this thesis. There is also some new literature introduced to elucidate a specific major category or category.
At the end of each category, I present a summary of the major category by tying together the content of the categories and the literature relating to the major category. At the end of the chapter is a summary of the three major categories.

6.1. Major Categories

The devolution of Taradale marked a major transition in both the lives of the people with disabilities who made the move, and their significant others who planned, worried about, and supported them through the move.

As described in Chapter 5, three major categories emerged from the grounded theory analysis of the interviews.

1) Getting it Right
2) Parents Forever
3) Changing Lives

Initial interviews were conducted with five participants and follow-up interviews, 18 months after the initial interviews, were conducted with three participants. Initial interviews occurred prior to any of the people moving from Taradale and the follow-up interviews occurred 18 months later, after all the people had moved. The initial interviews established the high level of engagement of participants with their son or daughter with a disability and with Taradale. The follow-up interviews explored how a high level of engagement impacted upon participants’ feelings of empowerment throughout the devolution process. As mentioned previously, there was a high degree of commonality in the major categories which emerged from the analysis of the data collected at the initial interviews. These major categories were targeted in the follow-up interviews in order to provide me with a deeper understanding of what the devolution meant to the participants and how this impacted upon their lives. In most studies of deinstitutionalisation, initial resistance by significant others turns to acceptance (Booth et al., 1990; Griffin & Dew, 2000). However, the reverse was described by some participants in this study. This point will be discussed in Chapter 7.
6.2. Getting it Right

**Initial interview:** “With Taradale and the services they currently provide, they are probably the leader in the field in NSW, if not in Australia” (comment made by Bill).

**Follow-up interview:** “It’s all involved about looking after the kids in that situation, and if we can’t do that, well then someone else can do it better. So yes, we seriously considered other services, we’re that pissed off with Taradale” (comment made by Bill).

Believing that Taradale was *getting it right* for their sons and daughters with disabilities was very important to the participants in this study. They described their sons/daughters as vulnerable people due to the severity and complexity of their disabilities. They believed that their sons/daughters needed specialised care to ensure their quality of life. Did Taradale *get it right*?

At the initial interviews, participants spoke in glowing terms about Taradale. There was an evident sense of pride in the organisation, and trust and support for the organisation’s on-going involvement with their son/daughter. Participants reported feeling more comfortable with the devolution because of the organisation’s continued involvement in providing a service to their son/daughter and they were keen to see the organisation grow and prosper after the devolution so that this involvement would be assured. They felt that Taradale, pre-devolution, was by and large *getting it right* in providing support to their son/daughter.

At the follow-up interview, 18 months later, some participants were less complimentary about the organisation and expressed concerns about its ability to *get it right* and provide the best possible care to their son or daughter.

Within this major category a number of categories were identified which defined the importance of ‘getting it right’ to the participants. The categories are:
6.2.1. The provision of information pre-devolution;
6.2.2. Communication problems post-devolution;
6.2.3 Responsiveness to problems & concerns;
6.2.4. Family Support Worker;
6.2.5. Appropriateness of housing;
6.2.6. Financial costs;
6.2.7. Quality of staff support;
6.2.8. Overall benefits of living in the community.

Each of these categories will now be discussed using participants’ own voices and a synthesis of their combined voices.

6.2.1. Provision of information pre-devolution

At the initial interviews, all but one participant reported receiving frequent and useful contact from Taradale regarding the devolution. This contact occurred via a regular newsletter sent out to all significant others, which included information about what was happening at each stage of the planning for the devolution and also included information about staff members who could be contacted if further information was required. Max spoke about the importance of this communication for him

“I work seven days a week now so it’s very hard for me now to focus on lots of little bits and pieces. I rely on Taradale to get it right. So while the information is being disseminated, I don’t have time to absorb it all. I give it the once over to see if there is anything important, but if there was anything important they [Taradale] will have contacted me” (comment by Max at initial interview).

Ray, who was interviewed once, was from a non-English speaking background (NESB) and he reported that
“Sometimes I don’t have a good command of English, of reading English. And so I sometimes feel that I am not so up-to-date” (comment by Ray at initial interview).

Doreen suggested that the newsletters should include

“A spot for the parents to say what they think” (comment by Doreen at initial interview).

All participants reported contact by Taradale at the initial interviews also occurred via telephone calls and Ray relied upon this more personal contact in order to receive information. Doreen thought it would be good to have more opportunities for significant others to meet together in person so that support could be provided and questions answered.

Overall, participants at the initial interview felt that they were consulted about what was happening and that there were opportunities for them to have input into the devolution process if they wished.

6.2.2. Communication problems post-devolution

At the follow-up interviews, participants reported some difficulties in communication with Taradale and they attributed this to problems within the organisation itself, which they said revealed flaws in the new system or management structures. As they described it, the organisation had previously operated as a small, contained, centralised model with a known and static population to care for within a purpose-built environment. Through years of providing an accommodation service to people with severe, multiple disabilities, the organisation had been able to adapt to and accommodate changes and fluctuations in staffing and other operational demands. Its systems were tried and tested. They may not have been ideal, but they were seen to work.
At the follow-up interviews, the three participants described the organisation since the devolution as needing to manage a decentralised system. This they saw characterised by a growth in staff numbers, and accompanying operational budget, with the added complexity of managing a number of geographically spread community based group homes.

Bill, whose son Bob had moved into a group home, and experienced significant health problems since the move, felt that the organisation did not listen to his concerns and did not act to rectify the problems

“Our concerns have fallen on deaf ears” (comment by Bill at follow-up interview).

The comments from Bill at the initial interview and then at the follow-up interview, demonstrate this shift:

**Initial interview:** “I think most people have confidence in [names senior staff member] which is part of Taradale, you know? It is more of a personal relationship that I think people build up with the person doing the job”.

**Follow-up interview:** “I think things started to run down a bit because there wasn’t that one person directly looking at the whole operation … it’s got that big…”

### 6.2.3. Responsiveness to Problems & Concerns

The problems in communication with Taradale which emerged between the initial and follow-up interviews were evident when participants talked about how Taradale responded to any problems or concerns they raised post-move. They identified that Taradale had undergone considerable change in its structure, operations and funding during the three years taken to complete the devolution. The organisation was
experiencing pressure from government to cut costs while still providing a service to clients. There was also pressure to conduct additional fund-raising to meet the shortfall.

“Funding levels to the houses are a major concern. Especially when the government says we have to be self-funded. You think well how on earth can we be self-funding except through donations and that’s at the whim of someone saying ‘yes’ or ‘no’” (comment by Max at follow-up interview).

Timothy was the one participant who had expressed his dissatisfaction with Taradale at both the initial interview and the follow-up interviews. At the initial interview, Timothy spoke about Taradale and the Department of Ageing, Disability and Home Care (DADHC, the NSW government department which was overseeing and funding the devolution of Taradale) as one and the same and reported his involvement with them as “a constant battle”. He had been initially supportive of the idea of the devolution but felt that the bureaucracy involved in planning for Thomas’ return to the community had made the exercise overly complex and costly. However at the initial interview Timothy, despite his concerns regarding the devolution process, supported Taradale for the care provided to Thomas. His view of this had changed by the follow-up interview. These comments from the two interviews with Timothy demonstrate this change

| Initial interview: “Taradale was the better care for him, the best care for him. I want to keep Thomas in the same quality that he’s got now and obviously the care around the clock....and someone caring for him all the time”.
| Follow-up interview: “It was never explained [by Taradale] how it was with Thomas. At the moment he’s been very ill, he’s being nasal fed at the moment because he just doesn’t want to eat. And this is all new, but it’s come up now that this happened all the time at Taradale. If information was given by Taradale from the beginning of an exact detail, as close as you could to Thomas’ normal routine, he probably wouldn’t have gone to Tanya [grandmother]. It’s as simple as that.” |
The three participants who were interviewed a second time reported feeling abandoned by the organisation once the move had occurred. In particular Timothy, father of Thomas who had moved to live with his grandmother (Tanya), reported that the organisation had offered very little additional assistance since she had been diagnosed and treated for cancer:

“I don’t hold any faith in Taradale, in what they say at all……Taradale just don’t seem to care; it doesn’t seem to matter [to them]…….They [Taradale] short change her every which way they can and they know that she wanted him [Thomas] regardless and they play to that” (comment by Timothy at follow-up interview).

The participants were realistic that there were bound to be ‘teething problems’ but they were disappointed that the issues had extended beyond the anticipated 3-6 month settling in period.

The views expressed by Bill at the initial and follow-up interviews revealed his views that the organisation did not appear to have learnt from observing other examples of deinstitutionalisation despite his having identified this as a strategy in the initial interview:

**Initial interview:** “[Names senior managers] have experience, they have made contacts from visiting other places that have started the process [of devolution] or have been through the process – trying to avoid the pitfalls”

**Follow-up interview:** “on the surface, once all this started [devolution], everything was hunky dory, everything was going along fine, then certain elements have dropped out over the last 6 months…….Some of the key staff have lost what they’re there for. They’re there for the well-being of our kids. Nothing else. Anything else is immaterial. I just don’t think it gets through”.

Empowering Partnerships

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6.2.4. Family Support Worker

A Family Support Worker (FSW) was appointed by DADHC to assist significant others through the devolution and, if required, to act as an independent liaison between the significant other, DADHC and Taradale.

This model was based on the very successful appointment of two Family Support Workers in The Hall for Children closure. In that case, as reported on by Griffin and Dew (2000, p. 119), the “role of the FSWs has been vital in ensuring that families of Hall for Children consumers have been informed and supported throughout the process of the closure and move to the new accommodation” and the report of the evaluation recommended that “this role should be included in all future similar relocations and devolutions of people with disabilities”.

Mirfin-Veitch et al. also highlighted the importance of ‘independent service coordination’ which was set up during the closure of the Templeton Centre “as a resource or support for families as they negotiated their way through the process of deinstitutionalisation”.

However, in the case of Taradale, it was left up to the significant others to make contact with the Family Support Worker, with the result that some people who would have benefited from the support (and said they were open to receive it) did not feel confident initiating the contact. In the study of Taradale, the participants had not had any personal contact from the FSW (they had received written information of her availability) and the role appeared to have a lower priority when compared to the support provided to family members in the Hall closure. This is possibly because Taradale was working closely with the government to effect the devolution and possibly because significant others were perceived as being less antagonistic than was the case with the Hall closure.
When Bill was asked at the initial interview about whether he had made contact with the FSW his response was

“No. Why? What’s she going to do for me? I think it just gives the Department [DADHC] a nice, warm, fuzzy feeling that they are doing something right in monitoring the process, I suppose” (comment by Bill at initial interview).

At the time of the second interview, Bill had enlisted the help of the FSW to conduct an independent review of the group home in which his son Bob was living due to concerns about the management and operation of the group home. More will be said about this later.

6.2.5. Appropriateness of housing

The accommodation into which people moved required renovations and adaptations to meet the people’s complex care needs and mobility problems. Although Taradale was not directly responsible for house renovations (an outside organisation had been contracted by DADHC to coordinate the purchase and renovation of properties) participants still saw Taradale as ultimately responsible for the completion of these tasks.

At the initial interviews participants identified problems in getting renovations completed in a timely and competent fashion

“They’re a bit haphazard, finishing things off properly, project managing things…it’s like, uncoordinated is the best way to describe it” (comment by Max at initial interview).

However, during the follow-up interviews, by which time most people had been living in their new accommodation for at least one year, the participants gave specifics about
major problems with the housing. Houses were reported as being too small to accommodate wheelchairs and the other equipment required for the care of the residents

“You try to put three of them in the lounge room and then you can’t get through the place” (comment by Bill at follow-up interview).

Pathways, driveways and in one case a room in a house, did not conform to slope requirements for wheelchairs resulting in problems for people using these spaces.

“I mean the undercover parking’s got a slope on it of about 4 or 5 degrees”. “The back room’s got big slopes in it that makes it totally useless to put kids on in wheelchairs, they just run away” (comment by Bill at follow-up interview).

6.2.6. Financial Costs

Participants expressed concerns about the additional costs associated with community living as they felt it was more expensive to live in the community than it was to live in an institution.

“[in the institution], you’ve got a large building, administration costs are fairly reasonable and the children are well looked after…then there’s a shift in political demand requiring a huge expenditure of money but there’s no money being put towards the administration of the group homes” (comment by Max at follow-up interview).

The participants felt that their son or daughter was asked to pay for more goods and services themselves where these would previously have been provided by the organisation. Timothy, for example, felt that his mother, Tanya was paying for things
out of her own pocket, which he felt should have been provided by Taradale, in order to support Thomas in her home

“She’s [Tanya] frightened to tell them ‘that this is wrong, it’s broken, it needs to be replaced’, so there’s no upkeep. I can see the financial burden of even running the air-conditioning all the time for my mum…she’s watching her pennies now” (comment by Timothy at follow-up interview).

6.2.7. Quality of staff support

**Initial interview:** “It’s the security in knowing that you’ve got good staff and you’ve got enough there to see what is going on…. I’ve seen it in some group homes…the staff changed as often as you change your underwear” (comment by Bill).

**Follow-up interview:** “We find that the standard of care is good but the supervision of the people giving the care is lacking” (comment by Bill).

The quality of staff support was identified by all participants at both the initial and follow-up interviews of critical importance to getting it right.

At the initial interviews, participants mentioned that many of the current staff at Taradale were fearful for their jobs when the announcement of the devolution was made, and Timothy at the initial interviews felt that staff were “pushing the group home model” (over return of the child to their family home) in order to ensure the staff’s ongoing employment.

However, according to participants, the fears of the staff in this regard were reportedly largely allayed by the open attitude of the organisation and its assurances to staff that more would be employed by the organisation rather than fewer due to the decentralized nature of the service delivery with a group home model.
“The feedback from staff [at the institution] is that they are all edgy because they think they are going to lose their job. So part of the process is feeding back information to the staff saying ‘hey, you guys we need more staff and more qualified staff’. So they are starting TAFE courses” (comment from Bill at initial interview).

According to the management at Taradale, current staff was provided with the opportunity to upgrade their skills via access to a TAFE course on Disability Support held at the local TAFE. However, at the follow-up interviews, participants reported difficulties in finding, training and keeping staff at both the group home level and at the private home level.

“We have a serious problem when we can’t keep the staff looking after our children” (comment by Bill at follow-up interview).

From my knowledge of the geographic area where the group homes established from the devolution of Taradale are located, there are now a number of organisations providing group home accommodation to people with developmental disabilities. Participants reported that these organisations are competing for a limited pool of trained and untrained staff.

“One of the biggest problems is trying to find trained staff…not just nurses but just general carers….there are just not enough people in the training coming through as you can imagine” (comment by Bill at follow-up interview).

So, while Taradale are funding people to complete the TAFE Disability Workers course, it would appear from the participants that they are then competing to retain staff who, once trained, can reportedly earn more working for DADHC than for a non-government provider. The category of quality of staff support can be further broken down into a number of points.
Finding Suitable Support People

Participants talked about staff having the ‘right sort’ of attitude as the most important criterion for employing staff, alongside the requirement of having some medically trained staff members to oversee the physical care of the residents. For those residents going into group homes, a balance of staff skills including some with medical training (due to the high support needs and frail health of many of the residents) was seen to be very important. Bill expressed his concerns about this at his follow-up interview

“The people up the top are not looking down and seeing exactly what’s going on. I believe they [staff] all think they’re doing the right thing – all care taken but no responsibility” (comment by Bill at follow-up interview).

Participants compared the institutional setting of Taradale where there were a number of staff rostered on duty at one time (with a mix of more senior/experienced and possibly health care trained personnel working alongside more junior/inexperienced and untrained staff), to the group home environment where there are two or three staff on at a time (with often inexperienced and untrained people on duty together). Participants felt that the responsibility placed on these staff to competently care for people with severe, multiple disabilities was too much and that the residents’ health suffered as a result. As Bill expressed at his follow-up interview

“We have concerns about his medical care. And I have some really serious concerns about their [staff] ability to look after the rest of the kids. If they can’t do it for one, how are they doing it for the rest?” (comment by Bill at follow-up interview).

Timothy, the father of Thomas who is living with his grandmother (Tanya) reported that she has had difficulty finding suitable people to relieve her and assist in Thomas’ care due to his complex medical needs
“Mum’s finding it hard to get the right people to watch him” (comment by Timothy at follow-up interview).

This resulted in Taradale paying Tanya additional money to cover some of the hours which would have been filled by another person providing respite for Tanya. Tanya’s ill-health was cause for concern in this case as she was required to do more herself with less ‘time off’.

**Training, Supervision and Isolation of Staff**

At the initial interviews, participants expressed concerns that individual group homes scattered throughout the geographic area serviced by Taradale would result in isolation for both residents and staff. They feared that a lack of supervision and support for staff may result in lower quality care for residents. The institutional setting was seen to provide a measure of security against abuses to residents as there were always other people around to see what was happening. There was less concern expressed about this issue at the follow-up interviews and some participants reported that staff was attempting to overcome the relative isolation of the group homes by organising social events between them.

However, the issue of perceived lack of training and supervision for direct care staff working in the community setting was a focus for participants’ concerns at the follow-up interviews

“We’ve given them minimal training and we haven’t provided the supervision to make sure that everything’s done properly” (comment by Bill at follow-up interview).

The supervision of staff was perceived by the participants as more difficult to do in the group home setting due to the decentralised nature of the workplace. They saw
supervision lacking at the group home due to the limited experience of group home managers and at the organisation level due to a ‘credibility gap’ between what they, as significant others, saw happening in the houses and what the middle and senior management of Taradale believed was happening.

“It just seems that the middle level management are unable to supervise properly” (comment by Bill at follow-up interview).

There was a perception of a lack of accountability within the chain of management

“I’ve even had some of the middle level management lie to me, in front of their immediate superiors and they haven’t picked it up and corrected it. We’ve got a public service mentality in a lot of the middle level and upper level managers that forget what they’re doing there” (comment by Bill at follow-up interview).

Bill also expressed his concerns about the education and skills of some of the staff being employed to work in the group homes

“They’ve employed people, some people there are illiterate, you get the bottom end of the scale for people…..they’ve just come into it because it’s a job” (comment by Bill at follow-up interview).

However, Bill acknowledged that a lack of literacy skills, while making it difficult for the staff member/s to complete some of their administrative duties, in itself was not as important as attitude

“Some of these people provide excellent hands-on care and have unbelievable empathy with the kids” (comment by Bill at follow-up interview).
Staffing Levels and Ratios

The concerns expressed by participants at the initial interviews about maintaining staffing levels was born out in the follow-up interviews with reports of inadequate numbers of staff available to fill all shifts and problems with recruiting casual staff members. Participants’ knowledge of these issues demonstrates their level of involvement in the group homes where their sons/daughters are living.

These quotes from two different fathers from the initial and follow-up interviews demonstrated the concerns held by participants prior to the devolution and the reality after the devolution:

**Initial interview:** “How many people are there who are going to be available out there with the qualifications that we want to look after our kids? Can we staff all those positions or is it going to be a short staffed situation? (comment by Max).

**Follow-up interview:** “I’ve got the manager of the accommodation service saying ‘we’ll **endeavour** to fill the shifts’ and I’m saying ‘you’ve got this all wrong fella, you **will** fill all the shifts… there is no room to manoeuvre in this situation….straight away, we’ve got the wrong attitude’” (comment by Bill).

According to participants, problems in filling shifts resulted in some group homes being staffed below their optimal level at times with a decreased staff to client ratio and an increased responsibility for those staff who were on duty. These factors reportedly combined to produce a negative impact on the health care and general quality of life of the residents and a curtailment of community access due to reduced staff levels.

“**It’s just when there’s only one [staff member] on with three kids there, it’s very difficult and it’s just trying to get through to some of these people that that’s not what you do, you don’t let that happen. That’s why we’ve got two staff members on**” (comment by Bill at follow-up interview).
Diverse Roles

The diverse roles staff would be required to fulfil within a group home was also seen by some family members to be potentially problematic. Within the institution different people performed distinct roles – cooking, cleaning, maintenance, personal hygiene, administration of medication and so on. However, within the group home, one category of staff would fulfil all these roles.

The comments of Max and Bill at the initial and the follow-up interviews demonstrate this concern:

**Initial interview:** “When you are hiring people to do things then you have a whole range of issues like can each home be maintained in the way that is intended?” (comment by Max).

**Follow-up interview:** “Houses shouldn’t be dirty... the cupboards should be clean, the clothes should be ironed and neat, they should be given the right medication, they should have the correct health care for them and have it monitored. I don’t see any of that” (comment by Bill).

Empathy and Care

All the participants interviewed initially stated that the staff within the institutional setting at Taradale knew the residents well, understood their needs, were able to communicate with them and in many cases had relationships with the residents built up over many years. This was seen as a positive which might not be transported to the community settings. At the follow-up interviews the fathers were reporting that, for the main part they were happy with the quality of the *hands-on* carers.
As Bill told it at the two separate interviews:

**Initial interview:** “He’s been in Taradale more than half his life now and frankly; the environment of up there was like a big home anyway”.

**Follow-up interview:** “The carers in the house are trying to do what they think is the right thing, and I mean they’re really very helpful, most of them, they’re really helpful with the kids and they put the extra effort in”.

As mentioned previously, participants identified the positives of smaller numbers of residents together (within a group home setting) facilitating more one-to-one time with staff and hopefully the development of close relationships. Taradale had always fostered a concept of ‘special friends’ between staff and residents. At the initial interviews parents expressed their hope that Taradale staff would be able to choose to work in the houses of the resident whose special friend they were, thus maintaining this close relationship. This was not raised at the follow-up interviews.

### 6.2.8. Overall Benefits of Living in the Community

At the initial interviews, participants identified the possible positives to community placement in terms of quality of life measures: they saw the separation of children from adults as very important for both age groups; they saw positives in residents having their own space and more individual time due to the smaller staff to resident ratios; and they hoped for greater social interactions and community access with more opportunities for choice making.

In the follow-up interviews all the participants acknowledged that they were seeing benefits for their ‘child’ from living in the community. One of the main benefits was seen as the increase in community access with for example, people going shopping, to movies, to cafes. The lifestyle was seen to be more relaxed, less institutional

“She just dropped in [to father’s house] for coffee and cake on her way
through to the movies or on her way through to a doctor’s appointment, she can come in. If she wants to sleep in she can, if she doesn’t want to get up, if she’s not feeling too well, she can” (comment by Max at follow-up interview).

In line with participants’ expectations at the initial interviews, at the follow-up interview, participants reported that the improved staff:client ratios (2 staff for 3 or 4 clients) had translated into more individual time

“He has benefited from being in the house and having a 2:3 ratio, where before it was like 1:7 or 8” (comment by Bill at follow-up interview).

So, their hopes regarding an improved quality of life appear to have been fulfilled for people in their new community based settings.

An example of this is the comments made by Bill:

**Initial interview:** “[name] is in a wheelchair, he has no speech, he has no communication, he can’t do anything for himself so what sort of skills can you give him? Access skills?”

**Follow-up interview:** “His access to doing other things [has improved], not being stuck in Taradale day in, day out with very few other activities. It’s allowed the opening up of that, to get out into the community and start enjoying a lot more things.”

### 6.2.9. Reflections from the Literature

Strong significant other support, and a belief that they were getting it right, for an organisation providing care to a son/daughter with a disability is a feature of studies of deinstitutionalisation and is reported on in previous research, (Griffin & Dew, 2000;
Mirfin-Veitch et al., 1998, 2000). Another feature of these studies is that the majority of significant others do not initially support deinstitutionalisation (whereas the participants in this study were supportive of the devolution of the institution from the beginning).

The evaluation of the closure of The Hall for Children (Griffin & Dew, 2000) reported strong parental support for the management and staff at the Hall despite condemnation, by a government report for providing substandard care to the residents (Community Services Commission, 1997).

Mirfin-Veitch et al., (1998; 2000) reported, from the viewpoint of the family members, on the closure of the Templeton Centre near Christchurch, New Zealand. As with the Hall for Children evaluation, Mirfin-Veitch et al., (1998) found that prior to the move most families were supportive of the Templeton Centre as a “home for life” (p. 12) for their family member with a disability and saw the announcement of the closure as an indication that they had “done the wrong thing in the past” (p. 105) by placing their son/daughter at Templeton in the first place.

Funnell (2002) recounted the experiences of a number of families of people with disabilities who moved from the Challinor Centre in Brisbane, Australia. 4 Funnell identified what she termed “a changed consciousness” (p. 79) whereby family members’ previous acceptance of the institution as the most appropriate place for the person with a disability to live was firstly challenged, and then changed, by the closure of the institution and the movement of their family member into community based accommodation.

In an earlier study, Tuvesson and Ericsson (1996) studied the closure of a large institution in the county of Skaraborg in Sweden, and stated that “when relatives are informed that the institution will be closed it is not uncommon that the reaction is one of

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4 The impact of the deinstitutionalisation of Challinor Centre on the people with disabilities themselves is reported on by Young et al (2000; 2001)
anxiety, even anger and aggression” (p. 201) due their concerns about change and their desire for things to stay the same as they were.

Tabatabainia (2003) reported on families views of deinstitutionalisation prior to the closure of an institution in Queensland, Australia which he called the ‘Zafar institution’ (not its real name). He identified a number of reasons why family members reported being opposed to deinstitutionalisation: concerns about adverse impacts on family members themselves and on the person with a disability and the view that the institution was providing very good services to the person.

These previous studies provide a background against which the views of the current study’s family members can be examined. It appears to be common for family members to be supportive of the institution in which their family member is living and to be fearful and sometimes antagonistic towards the closure of the institution and the move of their family member with a disability into alternative accommodation.

The family members who were participants in this study were supportive of the institution and at least initially, largely supportive of the devolution process. They believed that Taradale in its institutional guise was getting it right for their sons and daughters and they expected that this would translate to the community settings.

In relation to the issues of quality of staff support, participants concerns about staff are consistent with research into staff turnover in residential settings for people with disabilities. Shaddock, Hill and van Limbeek (1998) identified burnout, job turnover, absenteeism and low morale as common features of staff working in various types of residential facilities for people with intellectual disabilities. Likewise, Hatton et al., (2001) acknowledged that high levels of staff turnover are a major problem in services for people with intellectual disability and they identified four factors primarily associated with turnover: low work satisfaction, high job strain, younger staff age and easier subjective labour conditions, and two additional factors as indicative of intended turnover: lack of commitment to the organisation and lack of staff support.
Dempsey and Arthur (2002) studied the factors that were likely to mitigate against staff turnover and discovered the nature of the interaction with clients, client’s families and other staff as the main factors in a person’s decision to remain working in community residential settings for people with severe disability. The more positive this interaction, the more likely the staff member was to remain in their job. They also found that staff who felt supported by supervisors and colleagues and received training and attention to their professional development were more likely to remain working in that setting.

The problems identified in the literature are consistent with concerns raised by participants in this study relating to recruiting, training and retaining staff to work with their sons/daughters in their new community settings.

### 6.2.10. Major Category Summary

*Getting it right* for participants in this study included having regular, ongoing, open and respectful communication with Taradale. It also meant sharing values and working towards common goals particularly in the areas of appropriateness of housing, costs, staff support and the overall benefits of living in the community for their sons/daughters with disabilities. While participants were optimistic at the initial interviews that Taradale would be able to get these things right, by the follow-up interviews, some participants believed that Taradale was not *getting it right*.

Taradale was respected within the disability field as an organisation that provided high quality care to the people living there and so the initial feeling by participants that Taradale was *getting it right* was consistent with the wider view. The difference in this study, when compared with the other studies cited, is that some of the participants, over the course of the devolution, experienced a turnaround whereby they were initially supportive of the organisation and the devolution but became critical of both post devolution, expressing this at their follow-up interviews.
As the participants described it at the follow-up interview, they were now uncertain about the future for their sons/daughters. So, between the two interview times there had been a shift in thinking on the part of participants from support for Taradale to expressions of unhappiness with the way the devolution had played out and a concern that Taradale was not getting it right for their son/daughter or for them as the significant others. The mechanisms for information, communication and support which had been put in place by Taradale prior to the devolution appeared to have broken down for at least two of the three participants interviewed at the follow-up interviews and this appeared to have contributed to ongoing concerns and problems. For these two participants, there was a perceived lack of respect on the part of Taradale towards them and their role in their son’s lives.

Staffing issues were important to the participants at both the initial and follow-up interviews. Some of the concerns participants expressed prior to the move relating to adequate staff numbers, training and supervision have been born out by their experiences expressed at the follow-up interviews. At the follow-up interviews participants discussed the need for a balance between the right sort of staff attitudes and their skills, especially when they are supporting people with severe, multiple disabilities and often complex medical problems. While the ‘right’ attitude was seen as crucial, participants also believed that staff with some degree of skill in ensuring people with complex medical needs and limited communication skills received appropriate health care was equally important.

At the follow-up interviews, participants also expressed concerns about whether Taradale had sufficiently adapted its managerial systems to be able to adequately supervise staff working in decentralised settings. This issue of management was, for participants, a crucial factor. They acknowledged staff constraints but felt that the oversight and support of management towards direct care staff was critical and often lacking.
This major category demonstrated the need for significant others and Taradale to have shared values and common goals for the person with a disability with a need to adopt an individualised approach to providing that support.

The importance of *getting it right* for their sons/daughters was indicative of the second major category to emerge from the analysis of the interviews – parents are *parents forever*.
6.3. Parents Forever

Initial interview: “Trying to look after your kid the best you can, it’s a bit of a problem if you know your child is totally dependent on other people for their care and once you die who’s going to be the caregiver?” (comment by Bill).

Follow-up interview: “When he first went to Taradale, I suppose [you feel] that no one can look after your kid as well as you can….I thought it [devolution] would have been a lot better…there’s certain elements in this move and the growing of the company that shouldn’t be happening” (comment by Bill).

Some participants described Taradale as ‘a home away from home’ for their ‘child’ however this in no way replaced the importance of the person to their natural family. Although many of the day-to-day concerns about providing for the person were abdicated to the staff at Taradale, concerns about the person’s overall welfare and long term care were ever present for their significant others. Parents are parents forever.

At no point did participants indicate that they would not continue to advocate for their son or daughter or to be part of their lives in their new settings. As Baker and Blacher (1993, p. 368) stated “placement out of the home need not mean placement out of the family. Families can play a critical factor in enhancing the quality of life for a son or daughter with mental retardation who is living out of the natural home”.

At the initial interviews, participants discussed their lifelong involvement and commitment to their family member with a disability. A change in accommodation such as this devolution, removed some of the certainty regarding the person’s future and caused participants to become stressed about their and their family member’s long term prospects.
At the time of the devolution of Taradale, deinstitutionalisation of people with developmental disabilities had been occurring in Australia for over 20 years. The participants involved in this devolution told me that they were aware of other organisations which had devolved or closed and had heard other family member’s experiences of deinstitutionalisation. They were aware of both the positives and the negatives attributed to deinstitutionalisation. They had previous examples against which to measure their own experiences.

At the initial interviews, participants spoke about the poor physical health, frailty and high support needs and limited verbal skills of their sons/daughters. This necessitated special equipment and housing, medical intervention and increasing levels of care over time due to physical degeneration, including the need for pain management and palliative care. This quote from the initial interview with Doreen highlights Darryn’s frailty and lack of verbal communication skills

“His wheelchair is very flexible, it can tilt because he can’t bend his legs very well and he needs to change his position in the wheelchair. He has osteoporosis so badly that he can have spontaneous fractures just from not being placed correctly [in his wheelchair]. If he is unhappy with his seating or his body has aches and pains, he’ll pull at his clothes or chew his clothes. They’re the signals that people know when something is wrong.” (comment by Doreen at initial interview).

Some participants also discussed issues related to the ageing of residents with implications for an increased level and intensity of support able to be provided to their son/daughter as they got older. Bill expressed his concerns for Bob’s future at the initial interview in this way

“All I can see at the moment is Bob growing old. I don’t know what his life expectancy is but I imagine he is going to get into his 40’s. I think the standard of care for him in the future will probably go down purely because of the
funding constraints. I don’t relish the thought of looking that far down because I don’t like what I see. The greatest fear I have is the funding, the ongoing funding. I’ve looked at the numbers and I know how much it’s going to cost.”

(comment by Bill at initial interview).

The quality of life of their sons/daughters with disabilities was raised as a major issue of concern by all the participants interviewed both initially and at follow-up. Quality of life\(^5\) is a difficult concept to define. However for the participants interviewed in this research the standard and type of care provided to their severely disabled son/daughter were very important. There were a number of categories which describe the major category parents forever:

6.3.1. Re-awakening guilt over the initial out-of-home placement;
6.3.2. Standard of care;
6.3.3. Provision of health care;
6.3.4. Compatibility and companionship in the living arrangement;
6.3.5. Contact with past friends;
6.3.6. Level of family contact.

Each of these categories will now be discussed using participants’ own voices and a synthesis of their combined voices.

6.3.1. Re-awakening of guilt over the initial out-of-home placement

For participants whose ‘child’ with a disability had been living at Taradale for many years, the devolution re-awakened their feelings of guilt and distress felt when the ‘child’ had been originally placed into out of home care. Two quotes, one from Bill’s

\(^5\) There is a body of literature examining the concept of quality of life for people with disabilities and it is out of the scope of this thesis to examine this literature in detail. Reference is made to Bramston, Bruggerman and Pretty (2002); Gardner, Nudler and Chapman (1997); McVilly and Rawlinson (1998); Schalock (1993; 2004).
initial interview and one from Max’s follow-up interview articulate well the feelings which out-of-home placement aroused for them

**Initial Interview with Bill:** “If you have your child [with a disability] for awhile at home and then you don’t have that child there, all of sudden you go ‘how the hell did I cope full time?’ and you get on with your life. A lot of families don’t not care about their child but they find it very hard to go back. You go through cycles and you can’t judge anyone for what part of the cycle they are in”

**Follow-up interview with Max:** “I think all parents did go through a bit of grieving again [with devolution] because you were given the opportunity of taking that child back home and when you’re offered you think ‘well maybe I should’ and then you feel guilty because your life has changed while that child was away and you have excluded that child from your daily life”.

This category highlights the need for organisations to adopt an individualised approach towards significant others so that they gain an understanding of the reasons why they may have placed their child into out-of-home care initially and how deinstitutionalisation may cause their feelings about that initial placement to resurface. An understanding of the pressures on the significant others will hopefully mean that staff treat the family members with respect.

### 6.3.2. Standard of Care

Participants reported at the initial interviews that they felt that the institutional setting at Taradale provided good quality care in response to the high support needs of their sons/daughters. However they expressed concerns at that time about the ability of community based accommodation (either in group homes or in family homes) to sustain this and, at least for one of the participant’s interviewed, these fears may have been born out.
These comments made by Bill at the two separate interviews show the shift in his views about the care provided to his son in the two different settings:

**Initial interview**: “What’s wrong with Taradale the way it is? The standard of care up there is second to none”

**Follow-up interview** [talking about the care provided at the group home]: “Wrong medication, not filling shifts, medical team that’s giving him suppositories when he doesn’t need them, that are not reviewing bowel charts that are not following up on wheelchair. It just reeks of incompetence”

At the initial interviews, participants felt that within the institutional setting at Taradale, the residents were made to feel special and were given affection and love by the staff members.

“...it’s the social frivolity that goes on [there] at different times. The fun and games and interaction with lots of different staff members” (comment by Doreen at initial interview).

They hoped that this would be continued in the community settings. At the follow-up interviews, there was a general feeling that staff were caring and interested in the resident’s best interests tempered by a concern about the training and supervision provided to staff particularly in relation to the high support needs of their son/daughter.

**6.3.3. Provision of Health Care**

Central to their son/daughter’s high support needs was the issue of meeting their health care needs. This proved to be a major issue for two of the participants at the follow-up interviews. There was a perception by these participants that deterioration in their sons’ health was, at least partly, caused by the move and a subsequent decline in health care provision and monitoring.
“We’re just not happy with the medical care that’s there to support the staff…… we don’t know what they’re doing, but they’re not looking after the medical needs of our son” (comment by Bill at follow-up interview).

This was a major issue for these participants as they told me at the initial interviews about their concerns related to their children’s severe disabilities and associated health problems which made them particularly vulnerable to ill-health.

“I’d say he’s going down hill, I can see him slowly cutting off, for whatever reason” (comment by Timothy at initial interview).

The focus on health care by Bill from the initial to the follow-up interview demonstrated what he saw as deterioration in the provision of health care to his son, Bob. At the initial interview Bill reported general age-related deterioration in Bob’s condition. At the follow-up interview Bill reported on a specific problem which he felt was avoidable given appropriate health care:

**Initial interview:** “His physical condition is going backwards; he was really healthy and happy and mobile, was learning to feed himself when he was 10. At 20 he’s in a wheelchair and cannot feed himself or get around. So his skill levels are going backwards. All you can do with Bob is make him comfortable”.

**Follow-up interview:** “In the middle of last year, Bob’s weight was right down, he was about half the weight he should have been and they [staff at group home] were saying ‘Well, we need to consider feeding him through the stomach’. His mother stepped in and said ‘Have you looked in his mouth?’ He’s got ulcers everywhere, his teeth are rotten. He can’t eat because it’s too painful”.

Given the complex care needs of their sons and daughters it is not surprising that participant’s felt the need to be vigilant in relation to the health care provided to them. This category demonstrates the need for an individualised approach so that the complex health care needs of each individual are understood and incorporated into their care.
plan. This will impact upon the training and numbers of staff employed to support those with the most complex health care needs.

6.3.4. Compatibility and Companionship in Living Arrangements

In the current research, some participants expressed the view at the initial interviews that their son/daughter would miss their old home and friends and the fun and busy-ness of the Taradale setting. The relative isolation of some of the venues chosen for group homes was also of concern to some participants with houses located some distance from shops, parks and public transport. It was felt that it would be necessary for staff to facilitate contact between group homes and also to ensure that residents participated in activities in the community. There was a feeling expressed at the follow-up interviews that this contact was occurring.

Also at the initial interviews, significant others of those moving into group homes spoke about the importance of compatibility amongst residents with a focus on friends being housed together and networking occurring amongst houses.

“I think we’ve been very careful about choosing who goes with whom and I’m happy with the group we’ve got going into Darryn’s house, his friends, they are his closest friends, the longest friends he’s had” (comment by Doreen prior to the move at initial interview).

They also acknowledged a need for a review of accommodation as time went on in order to suit people’s changing needs.

“I think this is only one part of a longer term situation...because things will always change, kids get older, their needs change, they might get better, they might get worse” (comment by Max at initial interview).
At the follow-up interviews, the participants believed that their sons/daughters did miss the companionship which they experienced with the group of residents who lived at Taradale however they were reported as having contact with other ex-Taradale residents living in group homes nearby.

This excerpt from the initial and follow-up interviews with Max demonstrates his initial concerns about residents being split up and the way in which this has been managed since the move.

**Initial interview:** “I mean one of the main things we are worried about is that we could have the children split up ....because it actually is an extended family”

**Follow-up interview:** “Yea, the kids have sleep-overs at different houses, they have parties and visitations and then there’s the house staff themselves. It’s in their best interests not to be isolated either”.

### 6.3.5. Contact with Past Friends

Despite this contact, living with fewer people, or living alone with grandparents, was seen to be isolating and participant’s believed this resulted in a reduction in social contacts.

Timothy reflected on this change for his son, Thomas who is now living at home with his grandmother:

**Initial interview:** “there was an older boy up there [at the institution] and Thomas used to be next to him all the time and I used to talk to him and say, ‘look after Thomas for me when I'm gone’ and he used to laugh, I couldn’t tell whether he knew what I was saying or not but Thomas was always around him”.

**Follow-up interview:** “Thomas likes having other people around but it just can’t be happening much in a house that’s just a normal household where he can’t do anything at all for himself”.

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Thomas had not, since his move to his grandmother’s house, seen anyone who he had previously been living with at Taradale.

6.3.6. Level of Family Contact

An advantage of the move for Thomas, however, is that he had increased contact with extended family members: brothers, aunts and cousins. These quotes from Timothy’s initial and follow-up interviews demonstrate the increase in contact with his immediate family which has occurred for Thomas as a result of his move.

| Initial interview: | “We don’t see a great deal of him at all. Every now and then we go up. But it’s really difficult being at [the institution at Taradale] when you’ve got a six and a seven year old and you have got Thomas in a wheelchair. As a single parent where do you go? They have a room up there but how long can you sit in a room with a six and seven year old who want to go and play, who are starting to fight? Where’s the quality time for Thomas?” |
| Follow up interview: | “They [other sons] spend their weekends [at grandmothers], they play around him, they walk over and talk to him…..he follows, he watches, someone will fall over or hit something, he’ll laugh. I’m happy that they understand about Thomas. They get a bit upset about how he is…they can see his deterioration” |

Contact with significant others for most people living at Taradale was high prior to the devolution and participants reported that this level was maintained, and in some cases such as Thomas’, was increased post-move. Facilitating good communication between the organisation and the significant others is essential to them maintaining contact and feeling comfortable in visiting their son/daughter (Blacher et al., 1999).
6.3.7. Reflections from the Literature

The level of anxiety engendered in the significant others interviewed in other studies of deinstitutionalisation highlights the on-going commitment and concern which family members of people with intellectual disabilities continue to hold for the life-time of their ‘child’ with a disability.

Blacher, Baker and Feinfield (1999) stated that it was feasible that parents who placed their son or daughter with a disability in out-of-home care might perceive benefits (e.g. reduced stress, ability to make other life plans and be engaged in other activities) to this placement but also “continue to worry about their child and feel a constant sense of responsibility” (p.463). They concluded that “placement out of home has not meant a lessening of ties to the family” (p. 464) in the families they interviewed. Baker, Blacher and Pfeiffer (1996) commented that the importance of family ties and families fulfilling multiple roles was even greater for people with severe intellectual disabilities as they often have limited social networks outside of their families.

Griffin and Dew (2000) in conducting the evaluation of the closure of The Hall for Children noted the initial anxiety, and indeed antagonism, of many parents towards the closure of the Hall and the move of their ‘child’ with a disability into community-based accommodation. Underlying these feelings was a need for the parents to feel vindicated regarding the initial placement of their child at the Hall. If the Hall was indeed as ‘bad’ as it was painted in the government report by the Community Services Commission (1997) Suffer the Children, which led to its closure, then parents felt guilty and responsible for having placed their child in that situation. For many parents this was untenable.

Griffin and Dew (2000) also reported on parent’s perceptions of the health care and medication for their sons/daughters who moved out of The Hall for Children. We reported that for a small number of people with complex medical conditions (mainly epilepsy) the move to community-based accommodation had resulted in an increased
number of emergency hospital admissions and problems in the day-to-day management of their condition, particularly the administration of anti-convulsant medications.

According to Griffin and Dew (2000), at the twelve-month follow-up interviews “parents commented that, whilst it had taken time and training for staff to become familiar with the consumers’ specific needs in this area [health care, diet and medication], they were now managing this well” (p. 82). The report recommended in this area that on-going staff training and the utilisation of appropriate health care professionals was essential to ensure that people’s health care needs were being met adequately.

Beange, Lennox and Parmenter (1999) reported on the poor health of people with developmental disabilities with premature death common. They cited a study by D. Strauss and Kastner (1996) which indicated that people living in the community had a 72% higher risk of mortality than did those living in institutions which Beange et al., (1999) proposed may have been due to less appropriate health care provided by generic community based settings. Beange et al., (1999) proposed fifteen health targets which they believed would address the health care concerns of people with disabilities wherever they live. Interestingly, in relation to the issues raised by the participants in this research the targets included dental care, nutritional status, chronic constipation, epilepsy treatment, gastro-oesophageal disease and helicobacter pylori infection, medication review and regular comprehensive health reviews by a medical practitioner.

Petry, Maes and Vlaskamp (2005) conducted a study which examined how parents and direct support staff operationalised the basic domains of quality of life (as they appear in theoretical models) for people with profound disabilities. Seventy-six parents and direct support staff of people with profound disabilities were interviewed. The results showed that the domains of physical well-being and social well-being were the most frequently mentioned by respondents. According to Petry et al., (2005, pp. 38-39)
The importance attributed to physical well-being can be explained by the specific physical and motor limitations of people with profound multiple disabilities. The significance of social well-being may be a consequence of the extreme dependence and the idiosyncratic way of communicating with people with profound multiple disabilities. Long-standing affective relationships and good communication are of great importance for this target group.

The study by Petry et al., (2005) provides confirmation of the importance placed by the participants in this study on the aspects of physical well-being and social well-being for their sons/daughters with severe multiple disabilities. This study also identified family bonds as very important to the social well-being of people with profound multiple disabilities as the parents remain “the most constant figures in the life of their child” (Petry et al., 2005, p. 41).

An increase in family contact is one of the positives identified in many of the previous studies of deinstitutionalisation. Griffin and Dew (2000, p. 74) reported that the “re-engagement and empowerment of parents/family members with the ex-Hall residents has been one of the major benefits of the relocation of consumers throughout NSW”. Likewise, Mirfin-Veitch et al., stated that “it is clear that the positive involvement of family results in enhanced outcomes for people with intellectual disabilities themselves”. They also stated that deinstitutionalisation has “been a catalyst for rekindling or reconnecting of family relationships” (p. 25). Tuvesson and Ericsson (1996) also reported that deinstitutionalisation provided an opportunity for family members to develop completely new types of relationships with the person with a disability in a more informal situation (a home environment) than was possible in the institution.

However, Funnell (2002) warned that while the strengthening of family ties for those people who were deinstitutionalised was an important goal, it was difficult to achieve and would require significant commitment on the part of service providers.
The bulk of studies into deinstitutionalisation have considered its impact on the quality of life of the people with disabilities themselves and so there is considerable evidence to support the views of the participants of this study in relation to increased community access, higher staff ratios and improved quality of life. According to Griffin and Dew (2000) the quality of life of ex-Hall residents was seen by all stakeholders interviewed to have increased considerably with their move to community-based accommodation. The evaluation found people had more opportunities for choice making, more individuality, and had developed social and living skills. Likewise, Young and Ashman (2004) reported from Queensland on increased levels of adaptive behaviour, choice-making, and objective life quality and stable levels of maladaptive behaviour over 24 months of community living.

From an international perspective, Emerson and Hatton (1996), reviewed studies in the UK and Ireland and found that deinstitutionalisation had led to increased choice and a better material standard of living alongside a wider acceptance in the community. And from a retrospective point of view, O’Brien, Thesing, Tuck and Capie (2001) reported on the findings of a New Zealand study of the deinstitutionalisation of 54 people who moved from a psychiatric hospital into community residential homes during 1988. They interviewed staff and family members and discovered an “overwhelmingly positive” (p. 77) response by these informants on the effect of community living for the people who had moved, with reported increases in social and adaptive skills.

However, the importance of family in the lives of people with disabilities is best summed up by Spreat and Conroy (2002, p. 208) who commented that “perhaps the greatest quality assurance mechanism that can support community placement is a high level of family involvement”.

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6.3.8. Category Summary

The participants in the current study perceived themselves as parents forever to their son/daughter with a disability. As mentioned previously, they were aware, prior to the move, of the likely benefits of community living and there was an expectation that they would see these benefits for their sons and daughters. This expectation was however tempered by their concerns about the level of disability of their ‘children’ and whether they would benefit from community living in the same way other less disabled people had. They were mostly satisfied that these positives were occurring.

However, their main area of concern at both the initial and follow-up interviews remained the level and quality of health care received by their sons/daughters who have severe, multiple disabilities and poor general health. Taradale, in its institutional guise, had been set up on a medical model and employed a mix of staff who, through their training and experience, were well placed to provide high level medical/health care. The move to community-based group homes and family homes resulted in, from the family members’ perspectives, less of a focus on medical/health care while providing greater opportunities for choice, participation and individualisation.

The organisation had set up a ‘medical support team’ which provided health care advice to the residents of all the group homes administered by Taradale. Bill, in particular was unhappy with the expertise and knowledge demonstrated by the medical support team members in relation to the care provided to Bob. In general, participants felt there needed to be more health care support particularly for those residents with complex medical care needs. The concerns about the long term health and well-being of their sons/daughters were indicative of participant’s view of themselves as parents forever.

This major category also highlights the importance of an individualised approach to ensure that people are compatible with their house-mates and have opportunities to maintain contact with past friends and extended family. The third major category to emerge from the analysis was the changing lives of significant others.
6.4. Changing Lives

**Initial Interview:** “So then my mum came up with the idea, she said well instead of the kids [siblings] having to move from here, why doesn’t Thomas go and live with her?” (comment by Timothy)

**Follow-up Interview:** “I’ve got mum going through her cancer and she’s settling down with what’s going on with Thomas and trying not to cause too much of a hiccup with him. I think it’s so unfair.” (comment by Timothy)

Devolution does not happen overnight. Years typically elapse between the time of the initial announcement of the devolution and the actual move into new accommodation. This is because devolution is a complex process requiring much discussion, planning and an array of practical tasks (house purchasing, modifications, outfitting, staff selection, training etc.). Over the course of those years, things will change in the lives of all involved in the process.

In this study, all of the participants were undergoing or had undergone changes in their lives which impacted upon their relationship with their son or daughter with a disability. The three participants who were interviewed twice were all divorced and all had remarried with increased demands on their time and ability to be involved in the organisation and the life of their son or daughter with a disability.

Despite this they had all remained actively involved in their sons/daughter’s lives. All three participants at the follow-up interviews were experiencing ill health either personally or with a close family member. One participant who was interviewed initially had become a grandmother and was caught up in assisting her daughter with the demands of a new baby. None of this is unusual as people’s lives are complex and constantly changing. However, these participants were also facing deinstitutionalisation of the facility which their son or daughter had called home and the prospect of them moving into new, community based accommodation. This change coupled with all the
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other changes, increased the participants’ stress and concerns about what might happen in the future for themselves and their son/daughter with a disability.

At his initial interview, Bill described the change in his life brought about by the announcement of the devolution of Taradale in this way

“Yea, you’re just getting things sorted out [in your own life] because you think that child [with a disability] is going to be there [in the institution] for life and all of a sudden out comes the mat and you are into the unknown again”
(comment by Bill at initial interview)

The issues which are identified in this major category are compatible with Family Systems Theory (discussed in the Family Literature section, Chapter 2 of this thesis) which identified how external influences impact on the way in which a family operates. Also important in this theme is self efficacy, a person’s sense of control over events (Bandura, 1989); and resilience, a person’s ability to cope with adversity (Rutter, 1985). These two concepts will be further explored in Chapter 7, Discussion.

Within this major category a number of categories where identified which describe the impact of the devolution on the participants themselves:

6.4.1. Competing demands;
6.4.2. Level of involvement in the management of Taradale;
6.4.3. Diminishing communication with Taradale;
6.4.4. Concerns about the future.

Each of these categories will now be discussed using participants’ own voices and a synthesis of their combined voices.
6.4.1. Competing Demands

At the initial interviews, participants discussed competing issues such as poor health, which resulted in a need to ‘pull back’ from more intensive involvement with both their ‘child’ and the organisation, and the pressures of work, including running a business and meeting the needs of other family members.

“I’m getting older and I’m having an operation on my shoulder, then I’ll have to have physiotherapy and that means I’m not going to be able to pick her up and bring her home and she wants to come back here but I just can’t do it”

(comment by Max at initial interview)

The relationship with the siblings of the disabled person was particularly mentioned by a few of the participants. For example, Timothy’s initial plans for bringing Thomas home to live from Taradale, as part of the devolution, had to be modified due to the negative views about this of Thomas’ younger siblings.

“So it was all happening [Thomas returning to live with Timothy] and then there were a few hassles with the kids. Nothing was working. I think the kids were thinking he [Thomas] was coming back to the point that they wouldn’t even join up sport again this year because they thought they couldn’t do it with Thomas here” (comment by Timothy at initial interview).

One participant mentioned distance and the constraints this placed on their ability to visit their son/daughter regularly and maintain a high level of input. Three of the five participants initially interviewed were divorced and mentioned complex arrangements for giving consent, in conjunction with the other parent, for aspects of their son/daughter’s lives.

“They [DADHC and Taradale] were pitting me and [ex-wife] against each other, telling her information and then telling me something different. They
wouldn’t accept it when I said that she had told me it was fine, whatever I said goes. They had to get confirmation from her” (comment by Timothy at initial interview).

All these issues had to be weighed up and considered alongside the needs of the family member with a disability.

### 6.4.2. Level of Involvement in the Management of Taradale

Some of the participants interviewed initially were very involved in the running of Taradale as past or present Board members, sub-committee members or participants in social activities. This situation had changed for Max and Bill at the follow-up interviews with Bill distancing himself due to his dissatisfaction with the organisation.

The change in Bill’s views can be seen from the following quotes:

**Initial interview:** “it [being a Board member] is the only way that I can put something back in rather than taking all the time”.

**Follow-up interview:** “I took 3 months leave out of the Board because I'm that cranky. I'm just trying to hold it at arms length and get through this review”.

Max, on the other hand, had joined the Board in the intervening 18 months and the change for him is reflected in these quotes from the two interviews:

**Initial interview:** “I work seven days a week now….so while the information [about the devolution] is being disseminated, I don’t have time to absorb it, I give it the once over to see if there is anything important….. but I am relying on Taradale to get it right”.

**Follow-up interview:** “I needed to give something back [by joining the Board] to the home that was helping Mary. Also there were things I didn’t understand and I had only heard through other parents who were on the Board, but some of the older parents whose children were dying or had died, they had left the Board. We’ve now got a Board that is 50:50 parents and local community people….they have no idea what it is like to have a handicapped child…they don’t understand the motivation behind it”.

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Doreen, who had been very involved with the organisation over many years, stated at the initial interview that the devolution was an opportunity to “move on” and distance herself from the day to day running of the organisation. Timothy and Ray had limited contact with the management of the organisation when they were initially interviewed.

Bill and Timothy expressed at the follow-up interviews that the move was not what they thought it would be. They felt let down by the organisation.

“They [Taradale] withheld all the vital information that you really needed to make an informed decision about Thomas’ care” (comment by Timothy at follow-up interview).

6.4.3. Diminishing Communication with Taradale

Timothy and Bill, at their follow-up interviews reported that communication between themselves and Taradale was very poor

“Nothing ever gets done, it never gets followed through and I'm finding it reeks of public service mentality……This one [current CEO of Taradale] was put in to run a business, so she relies on information back from her management staff and can’t separate fact from fiction” (comment by Bill at follow-up interview).

Bill was so unhappy about the management of the group home where his son, Bob was living that he and his ex-wife instigated an independent review of the group home in an effort to address the problems they saw there.

“We have a person doing an independent review of the service at the moment…we'll see what happens from that, that will take a little bit of time but I figure the organisation needs a bit of a shake up because
they’re just not meeting a lot of the basic needs” (comment by Bill at follow-up interview).

That review had just commenced at the time of my follow-up interview. Bill indicated that the call for a review resulted from his frustration in attempting to address the problems with both the group home and organisation’s management

“Bob’s mother put in quite a few letters, the answers she got back from [Taradale] would appear to be OK, they didn’t answer everything, but then nothing was ever done” (comment by Bill at follow-up interview).

6.4.4. Concerns for the Future

All those interviewed both initially and at the follow-up interviews expressed concerns about the future for their son/daughter. There was a perception that the new placement would not be as secure as the previous placement at Taradale. This may be due to the process of change itself (if they have been ‘forced’ to change once, they may be ‘forced’ to do so again). As Max put it at his follow-up interview

“It’s no wonder that so many parents say, look we’ll take our children home because we’re worried about the level of service you’re going to provide in the future” (comment by Max at follow-up interview).

Concerns for the future may be due to the heightened political awareness of the significant others as a result of the devolution (more aware of government policies and responses). As Doreen said at her initial interview

“Some of the philosophies of some of the people [in government] are now being broadcast everywhere and I don’t believe it [small group homes] is the only way and I will never change that thought” (comment by Doreen at initial interview).
Concerns for the future may also be a response based on ageing of the significant others and that of their son/daughter. Bill expressed his concerns about his son Bob’s ageing at the initial interview

“I mean [Bob’s] regressing, he’s going backwards. He has lost the skills that he had when he was four and five years old. His skill base is decreasing. All you can do is make him comfortable” (comment by Bill at initial interview).

Timothy, whose son, Thomas is living with his grandmother (Tanya), is very concerned about the future placement of Thomas due to Tanya’s recent diagnosis and treatment for cancer. At the follow-up interview, Timothy expressed doubts that his mother would be able to provide the necessary level of care for Thomas in the long term. Whilst Timothy had verbal assurances from Taradale that Thomas would be able to move into a group home if anything happened to Tanya, he was concerned that this assurance had not be given in writing and feared that the organisation may try to renege on this

“It’s the only place he can go………so one day they’ll probably find
Thomas up there on their doorstep. The best resolution for
Taradale is if Thomas passes away. Out of sight, out of mind then”
(comment by Timothy at follow-up interview).

Timothy expressed negative views of his ‘child’ with a disability at the initial interview

“Thomas has no worth to give anyone except for to show people how lucky they can be” and “we were given the decision after he was born about living or dying and we didn’t realize, it wasn’t put to us properly but really we consider that he probably would have been better off if he died not long after birth. All this would have been gone, over and done with, the sorrow, finished. But as it is now it is a constant drag on, it’s a constant” (comment by Timothy at initial interview).
6.4.5. Reflections from the Literature

Feelings of stress and uncertainty during deinstitutionalisation are consistent with the findings of other studies of devolution in which families views have been sought.

Mirfin-Veitch et al. (2000) noted that all families of people who lived at the Templeton Centre were concerned about the resettlement of their family member with a disability. A particular concern was the impact of the deinstitutionalisation on the families’ own lives. Some older parents in Mirfin-Veitch et al’s (2000) study expressed concerns about the possibility of their son or daughter coming back to live with them despite this not being an option in this resettlement.

Likewise, Tabatabainia (2003) noted the similar concerns amongst the family members he interviewed pre-deinstitutionalisation. He described parental feelings of “anger, fear and confusion” (p. 250) in regard to the anticipated announcement of the closure of the institution.

These examples are indicative of a lack of sense of control felt by significant others during the process of deinstitutionalisation and are reflected in the views of participants in this study. Self efficacy is defined by Bandura (1989) as related to a sense of control over events which affect our lives. Self efficacy has been identified by Nolan, Grant and Keady (1996) as an important component in families’ feelings of empowerment (refer to Figure 3 Self efficacy and outcome beliefs in Chapter 7). People who believe they have greater control over what is happening in their lives will experience high self efficacy and conversely those who feel they have little or no control will experience low self efficacy. Dunst et al., (1988) also referred to sense of control in their social systems perspective of empowerment discussed in the Empowerment literature review (Chapter 2) section of this thesis. According to Dunst et al., (1988) family members needed to be able to see changes occurring for their family member with a disability as a result of their personal actions in order for them to feel a sense of control in their own lives and that of their son/daughter.
How people deal with disruption in their lives may also depend on their resilience. Resilience is defined by Hardy, Concarto and Gill (2004) as a person’s ability to cope with adversity. Rutter (1985) argued that in order to be resilient it was important to have an ability to form some sort of action, and to make a plan when something went wrong, drawing upon a sense of self-esteem and self-confidence and a belief in your self-efficacy. The ability to deal with change and adaptation depends on a repertoire of social problem-solving approaches. Rutter (1985) suggested that having a sense of self-esteem and self-efficacy assists people to cope with adversity and problems in their lives. He saw this not so much as a fixed personality trait but rather something that changed according to the circumstances. Singers and Powers (1993) referred to in the empowerment literature section of this thesis (Chapter 2) believed that a model of family support would promote resilience in families so that their ability to cope with new stresses would be strengthened.

Along with their concerns about their ability to cope with how deinstitutionalisation would impact on their lives, significant others also expressed concerns for their son/daughter’s future. The ‘ageing in place’ of people with disabilities has become a major issue of concern to families (who are ageing themselves), service providers (who are often struggling to assist people to age in place) and policy makers (who recognize that, along with the general population, there are many ‘baby boomers’ with disabilities who are going to require specialist care in the next 10-20 years). Dew and Griffin (2002) compiled a good practice sourcebook with national and international examples of ageing in place strategies for people with disabilities. The interest in such a resource demonstrates this issue as one of increasing importance within the disability sector. How Taradale, and other organisations, deal with the issue of increasing care needs over time is a critical one impacting on resident’s quality of life and family’s sense of control over the future.
6.4.6. Major Category Summary

The Family Systems Model and Transactional Models which were discussed in the Family Literature section of Chapter 2 of this thesis, propose that no person operates in isolation from the other members of their family. This is evident from the reports of the participants in this research and relates to this major category of changing lives. The decisions they were required to make regarding their son/daughter with a disability were implicitly bound to the needs and circumstances of themselves, their partners, and their other children. The devolution disrupted the status quo which had existed in having their ‘child’ placed at Taradale and caused them to question what the future would look like for both themselves and their family member with a disability.

While these feelings are not uncommon in examples of deinstitutionalisation (as discussed earlier in this section), what is unusual is the longer term negative response of two of the three participants at the follow-up interviews. A breakdown in communication and the relationship between Taradale and these participants occurred at a time when they needed their relationship to be working well. There were certainly other stressors, events and changes occurring in these father’s lives (e.g. ill health and re-marriage). Feelings of self-efficacy with a sense that they have some control over the results of these changes has been an important component of people adapting to and displaying resilience to major changes in their lives. A process which is committed to an individualised approach and based on mutual respect in order to make deinstitutionalisation work for the person with a disability needs to take into account that readjustments will need to be made in the relationship between the organisation and the family members to account for their changing lives.
6.5. Chapter Summary

As described in Chapter 5, five major categories emerged from the initial interviews which described the views of the family members interviewed of the devolution of Taradale:

1) the relationship of the family members with Taradale;
2) the quality of life of their sons/daughters;
3) meeting families needs;
4) quality of staff support;
5) the government role in the devolution.

In identifying these major categories, the analysis of the initial interviews painted a picture of a devolution which, from the viewpoint of all but one participant, was being well managed. While they expressed some concerns about the future, they believed that Taradale was the best organisation to continue to provide their ‘child’ who had a severe disability with support in the future. I approached the follow-up interviews with an expectation that the parents optimism expressed at the initial interviews would, by and large, be born out in the reality of community living.

The follow-up interviews revealed a shift in the views and involvement of all three fathers subsequently interviewed. In analysing the data from the follow-up interviews and incorporating the major categories from the initial interviews, I developed three major categories

1) Getting it Right
2) Parents Forever
3) Changing Lives
The devolution of Taradale meant the movement of their sons and daughters from the perceived security and safety of the institution to community care. This resulted in participants questioning the nature of their relationship with their son/daughter and with Taradale as the organisation providing them with care and support. Was Taradale still getting it right? The devolution was not what the fathers had expected it to be. For Bill and Timothy the changes in their relationship with Taradale were predominately negative and this impacted on their feelings of being in control of the decisions affecting the lives of their sons/daughters. Max experienced an increase in his involvement with the organisation (via Board membership) and he found this a fulfilling experience. His Board membership revealed to him the complexities of dealing with DADHC as the policy maker and funder of disability services in NSW. This, in turn, left him feeling anxious about the long-term prospects for both Taradale and his daughter, Mary.

6.5.1. Dis-engagement and Dis-empowerment

It was evident from the analysis of the data I collected that I was seeing something which has not been represented previously in the literature on deinstitutionalisation. I expected that the participant’s high level of engagement with both the organisation and their son/daughter would be reflective of a sense of empowerment. Indeed the initial interviews indicated that this was the case. However, a change had occurred by the time of the follow-up interview and the feelings, which I have termed disengagement and disempowerment, of family members who had previously been engaged and empowered in their relationship with Taradale was a surprising and disconcerting discovery. Using grounded theory principles of open and axial coding of the initial and follow-up interview data and then applying a process of “stepping away into conceptualisation” (A. Strauss, 1987, p.29), I identified three major categories which related to feelings of empowerment or disempowerment within the devolution context.
The first major category I described as *getting it right*. This study shows that unless an organisation aims to *get it right* for the person with a disability and their significant others devolution may be a disempowering experience. As identified by the participants, *getting it right* includes the provision of timely and accurate information pre-devolution; good on-going communication with the organisation post-devolution with mechanisms for responding to significant other’s concerns, queries and problems promptly and effectively; the provision of an independent person who can advocate for significant others throughout the process; housing which is appropriate to the person with a disability’s needs; reasonable financial costs which are sustainable in the long term; quality staff who are recruited, trained and retained with the needs of the individual people as the primary factor; and finally proof that there are overall benefits of living in the community for the individual.

The second major category related to the experience of family members in placing their ‘child’ with a disability in out-of-home care. When they place their child in out-of-home care they abdicate the day to day care of their son/daughter however, they still perceive themselves to be *parents forever*. The process of devolution re-awakened feelings of guilt over the initial out-of-home placement of their son or daughter. For significant others to feel comfortable about devolution they needed assurance that the standard of care provided to their son or daughter would be of a consistently high quality and responsive to their needs over time. This was particularly so due to the severe level of disability of their sons/daughter coupled with their multiple, complex care needs. Besides physical care needs, the participants also wanted their sons/daughters to have their emotional needs catered to with compatibility of house-mates, contact with past friends and maintenance of family contact as important components of their sons/daughter’s quality of life.

The third major category explored the impact of *changes in family member’s lives* which necessarily impact on the lives of their sons and daughter’s with a disability who are in out-of-home care. *Changing lives* encompass a number of variables as reported by participants in this study. Significant others have competing demands within their
lives, which they must balance while also maintaining their involvement with the organisation providing support to their son or daughter with a disability. They saw maintaining this involvement as increasingly difficult as the organisation devolved to a decentralised, community based one. This led to a diminishment of their communication with the organisation’s management. Overriding all of this was their concerns for the future, both for themselves, and for their son/daughter with a disability.

An exploration of these major categories resulted in the development of a model of Empowering Partnerships which is designed to provide family members, their son or daughter with a disability and the organisation supporting them with a positive way forward through the process of devolution. The principles underlying the model and the model itself are explored and presented in Chapter 7, Discussion.
Chapter 7
Development of the Model of Empowering Partnerships in Devolution

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7.7. Chapter Summary
7.1. Introduction

The aims of this study were to explore:

- the extent to which significant others are engaged in the process of deinstitutionalisation of their son or daughter with a disability;
- the extent to which the supporting organisation involved significant others in decision-making regarding their son or daughter with a disability;
- whether significant others’ engagement and involvement led to feelings of empowerment for them.

These aims were achieved by analysing the perspectives of the significant others of people with severe, multiple disabilities who were undergoing devolution from an institutional setting to community based living.

Through the procedure of selective coding (A. Strauss & Corbin, 1990, 1998) and by reference to existing models (Dunst et al., 1988; Hornby, 2000; Nolan et al., 1996; Turnbull & Turnbull, 2001), a Model of Empowering Partnerships in Devolution was developed.

Selective coding is defined by Strauss and Corbin (1998, p. 143) as “the process of integrating and refining the theory”. Integration occurs throughout the data analysis as the researcher interacts with the data, is emersed in the data and so, their thoughts about the data evolve. Through the process of open and axial coding, individual and group data are analysed to form category’s which represent a higher form of abstraction from the codes originally identified from the data. As the categories are grounded in the comparison of the data from each participant, they should have relevance to and be applicable to all participants in the study. The interpretive process of selective coding enables the researcher to recognise the relationships within the data which are then
presented as a set of interrelated categories. Strauss and Corbin (1998, p. 145) described this process in this way, “an analyst reduces data from many cases into concepts and sets of relational statements that can be used to explain, in a general sense, what is going on”.

In applying selective coding I related the three major categories presented in Chapter 6, Results II to each other and identified a core category that underpins significant others’ engagement and empowerment in devolution. The core category, i.e. that \textit{devolution may be a disempowering process}, is presented along with its relationship to the three major categories. Empirical data are presented to illustrate this core category and its relationship to the major categories, and relevant literature is discussed. From this, five principles of empowering partnerships are identified and finally a Model of Empowering Partnerships in Devolution is presented and described.

\textbf{7.2. Selective coding}

After collecting and analysing data and developing the three major categories, the next stage in the use of a Grounded Theory method is to integrate these major categories to develop a model or theory. According to Browne and Sullivan (1999, p. 589) “The final goal of analysis, after considering the aspects or pieces of data (codes and categories) is to reconstitute them and merge the ideas developed into a theoretical explanation or description of the study topic”. According to Strauss and Corbin (1990, p. 116) selective coding is the “process of selecting the core category, systematically relating it to the other categories, validating those relationships and filling in categories that need further refinement and development”. The core category is the “central phenomenon around which all the other categories are integrated” (A. Strauss & Corbin, 1990, p. 116). The three major categories which I identified in this study: \textit{getting it right}; \textit{parents forever}; and \textit{changing lives} indicated that for some significant others devolution was a disempowering process. How this conclusion was reached is explained by the story which developed from the data through the selective coding process and which then forms the basis of the emerging model.
7.2.1. The Story

The story is the basis from which the core category develops during analysis and is arrived at by asking a series of questions: “What about this area of study seems most striking? What do I think is the main problem?” (A. Strauss & Corbin, 1990, p. 119).

In this study, there was an initial story (derived from the initial interviews) relating to the five major categories identified at that stage: 1) the relationship of the family members with Taradale; 2) the quality of life of their sons/daughters; 3) meeting families needs; 4) quality of staff support; 5) the government role in the devolution.

The follow-up story (derived from the synthesis of the initial interviews and follow-up interviews) related to the three major categories emergent from the application of grounded theory: 1) getting it right; 2) parents forever; 3) changing lives.

The initial story

The initial story was based on the interviews with five significant others of people with severe, multiple disabilities affected by the devolution of Taradale. The grounded theory analysis of the initial interviews painted a picture of significant others who were very supportive of Taradale in its institutional guise. They had supported Taradale in the submission of the original Transition Plan (which some still viewed as the preferred option) and they now supported Taradale in its plans to devolve to provide community based support to the residents. Significant others believed they had been informed and consulted by Taradale in the period leading up to the moves and described a number of ways in which this happened. These views were described by the major category of “the relationship of the family members with Taradale”.

Despite their faith in the organisation, they expressed concerns about how the devolution would impact upon their sons and daughters who they described as having severe, multiple disabilities and medical frailty with resultant very high support needs. The discussion of these matters was captured by the major category “the quality of life of their sons/daughters”.

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Participants also expressed concerns about how the changes would impact on their own lives. Since the placement of their son/daughter into the institutional setting of Taradale, they had reorganised their lives without the necessity of providing day to day care and support. These issues were contained within the major category “meeting families’ needs”.

Participants were worried about the availability of suitably trained and experienced staff to support their sons/daughters within the community based settings. They identified some potential problems in recruiting, training and maintaining staff compared to the staff arrangements within in the institutional setting. These concerns were expressed within the major category “quality of staff support”.

Participants were also sceptical about the ongoing commitment of government to provide the required level of funding to maintain good quality care and support in the future. Their comments were grouped in the major category “the government role in the devolution”.

The five major categories told the story of a group of significant others who were involved in the lives of their sons/daughters and who reported being engaged by Taradale in the process of the devolution.

7.3. Development of the core category

Once the analysis of the initial interviews was completed, the story was reviewed to select the core category that seemed to be emerging from the data. According to Strauss and Corbin (1990, p. 120) a core category may emerge from the data which is already developed and seems “abstract enough to encompass all that has been described in the story”. In looking at the five major categories to emerge from the initial story it was apparent that engagement was an essential element for all participants. Engagement occurred at two levels, with the organisation and with their son/daughter with a
disability. However at this initial stage of data collection and analysis it was not clear whether engagement was sufficient to lead to feelings of empowerment within the devolution process.

Theoretical sampling of participants was therefore conducted with three participants identified as being the most engaged (from the original sample of five) with both their son/daughter and with Taradale. Strauss and Corbin (1990) call the theoretical sampling which occurs at this stage as discriminate sampling. “In discriminate sampling, a researcher chooses the sites, persons, and documents that will maximize opportunities for verifying the story line, relationships between categories, and for filling in poorly developed categories” (A. Strauss & Corbin, 1990, p. 187).

These three participants were all fathers of people with severe, multiple disabilities. One son and one daughter were moving from the institution of Taradale into group homes in the community which were administered by Taradale. One son was moving from the institution to live with his paternal grandmother in her modified home, with support from Taradale. It is unusual within disability studies to recruit fathers rather than mothers as participants in research. However, of the original sample of five, four were fathers. Why this occurred is unknown however their perspective is likely to be different as a result. Findings of research which considered separately or compared the views of mothers and fathers caring for a child with a disability (Beckman, 1991; Grant & Whittell, 2000; Ricci & Hodapp, 2003; Salovita, Italilla, & Leinonen, 2003; Schultz et al., 1992; Simmerman & Blacher, 2001), showed there were differences between how fathers and mothers viewed their situation. How these differences translate to their experience of deinstitutionalisation would be an interesting area of future research.

The follow-up interviews with these three fathers assisted the further development of the core category and its relationship to the major categories.
7.3.1. The core category

The experience of the three fathers in the follow-up interviews pointed to a core category named **Devolution as a disempowering process**. This study revealed that for some family members the process of devolution is disempowering. What is meant by dis-empowerment? According to Dempsey (1996, p. 3) empowerment includes a “sense of control, self-efficacy, participation, personal action, an understanding of the environment, access to resources and an ability to meet personal needs”. Disempowerment then would mean that at least some of these elements are not present for people (i.e. they do not have a sense of control over what is happening in their lives, they have low self-efficacy with little belief that their participation or personal actions will impact on the outcome). They may have little understanding of the environment in which they are operating along with limited access to resources and an inability to meet their personal needs.

This is not a view which has been widely expressed within the disability literature. Studies of the closure of institutions and the movement of people with developmental disabilities into the community have largely been reported as a positive experience for all concerned. The reported results of international studies of deinstitutionalisation presented in Chapter 1, Introduction of this thesis described increases in adaptive behaviour, community participation and choice making, for people who were placed in the community from institutions (Cummins & Dunt, 1988; Cummins, Polzin & Theobold, 1990a; 1990b; Dunt & Cummins, 1990; Emerson & Hatton, 1996; Griffin & Dew, 2000; Kim, Larson & Lakin, 2001; Mansell & Ericsson, 1996a; 1996b; Young et al., 1998; 2000).

Those few studies which considered the views of family members reported that, after initial opposition to closure of the institution, family members became often ardent supporters of the new community accommodation due mainly to the perceived
improvements in their son or daughter’s quality of life (Griffin & Dew, 2000; Mirfin-Veitch et al., 2002; Tuvesson & Ericsson, 1996). Where some variance to this view was reported it was a minority view which was subsumed in the majority view of satisfaction (Griffin & Dew, 2000).

However, the method used in this study allowed these voices to be heard rather than submerged as in the larger studies. This study revealed that not all significant others involved in devolution will perceive it as a positive experience. This view is presented in the follow-up story.

**The follow-up story**

Three people were theoretically sampled to participate in follow-up interviews 18 months after the initial interviews. They had demonstrated at their initial interviews a high level of engagement with both their son/daughter and with Taradale. The story to emerge from the follow-up interviews differed markedly from the initial story.

The final story to emerge from the analysis revealed that participants were disgruntled with the outcomes of the devolution for their sons/daughter and themselves. The relationship with Taradale had deteriorated for two of the three fathers to the point that they were questioning whether it was the right organisation to provide support to their sons. Within the major category ‘Getting it Right’, communication with Taradale appeared to have broken down to the extent that one person had sought an independent enquiry into the management of the group home his son was living in. The flow of information between Taradale and the significant others was questioned as to its reliability and validity with one participant calling it “misinformation”.

Participants raised concerns about Taradale’s responsiveness to their problems and concerns. They also spoke about problems with appropriate housing, higher individual financial costs and the ability of staff to manage their sons’ complex medical and health care needs.
Within the major category ‘Parents Forever’, participants spoke about how the devolution re-awakened their feelings of guilt at having placed their child with a disability in out-of-home care. They also spoke about the standard of care being provided to their son/daughter in a community setting with the quality of health care of special concern.

Participants did acknowledge an improvement in the lives of their sons/daughters in terms of community access, improved staff:client ratios and personal space. However, in the participants’ eyes, their concerns about physical health largely offset these positives. Issues related to limited contact with past friends from Taradale were raised; however they also reported increased contact with family members.

Within the major category ‘Changing Lives’, participants spoke about the competing demands within their own lives and especially their own or close family member’s ill-health which impacted upon their relationship with and view of Taradale and the support it was providing to their sons/daughter. The change brought about by the devolution of the institution administered by Taradale and their son’s/daughter’s move into community based accommodation resulted in decreased communication with the management of Taradale and concerns about what the future would bring for their sons/daughter.

The significant others interviewed for this study were engaged in the process of deinstitutionalisation. Taradale had policies and procedures in place to involve significant others in decision making. While these strategies were mentioned and acknowledged by participants in the initial interviews (prior to any moves occurring), by the time of the follow-up interviews, approximately 12 months after the people with disabilities had moved, there was concern by some participants about the application and effectiveness of these strategies. It would appear that while the organisation had the best of intentions to include and consult with significant others, the maintenance of these strategies, once the people had moved, was problematic from the viewpoint of some significant others.
7.4. Implications of the Core Category

This study indicates that engagement and involvement are not sufficient to ensure feelings of empowerment. It also points to elements which will enhance empowerment: the need for organisations to get it right; the importance of recognising that parents are forever and accommodation of their changing lives. The implications of each of these major categories on the core category of devolution as a disempowering process will now be discussed in terms of both my own data and the literature. I return to these major categories at this point in order to illustrate their relationship to the core category and as a way of validating, using grounded theory principles, the relationship between the major categories and the model developed in this thesis. Further quotes from the data are used to demonstrate the points made. The section lessons to be learned at the end of the discussion of each major category provides some suggestions for ways in which organisations can reduce the likelihood that devolution is disempowering for significant others. Reworking the three major categories to consider their relationship to the core category and deriving from this the lessons to be learned, has led to the development of a model which will be presented and explained at the end of this chapter.

7.4.1. How do you know if you are getting it right?

The major category Getting it Right included the categories of:

1) provision of information pre-devolution;
2) communication problems post-devolution;
3) responsiveness to problems & concerns;
4) family support worker;
5) appropriateness of housing;
6) financial costs;
7) quality of staff support;
8) overall benefits of living in the community.
The first four (1-4) of these categories relate to the systems which underpin the relationship between the significant others and the organisation. The relationship is based on information sharing, communication and responsiveness to significant other’s concerns when things are not going well.

Categories numbers five to eight (5-8) relate to household arrangements which lead to outcomes for the person with a disability. They include the physical environment of the place the person is living in, how much community living costs and most importantly for participants in this study, the availability and expertise of the staff employed to support their sons/daughter. These elements impact on what the overall benefits of living in the community will be for the person with a disability.

**Relationship Issues**

The first four categories in getting it right relate to the relationship between significant others, the person with a disability and the supporting organisation. Underpinning this relationship is the acceptance of the importance of significant others in the lives of their son/daughter with a severe developmental disability and providing opportunities and encouragement for significant others to be involved. Nolan, Grant, Keady and Lundh (2003, p. 273) refer to the relationship between the person being cared for, the care giver, and the supporting organisation as a “triadic relationship” which recognises the “importance of people’s support networks and how these can shape a person’s support, opportunities, inclusion and quality of life”.

**Importance of significant others**

The literature is clear that people with disabilities, particularly those with severe, multiple developmental disabilities, have better long term outcomes when they have significant others who are actively involved in their lives (Booth et al., 1990; Schwartz & Rabinovitz, 2003). Spret and Conroy (2002, p. 202) stated that “family contact must
be viewed as both beneficial and protective of persons with mental retardation”. This makes good sense for if you are not able to communicate your own needs and desires easily (due to an intellectual disability and/or a communication impairment), you need someone who will advocate and ensure that your needs and desires are prioritised and actioned. That advocate is usually a family member or significant other whose relationship with the person with a disability is of different nature to that of paid staff due to the love between a parent and their child. By recognising and promoting significant other involvement, an organisation undergoing deinstitutionalisation is likely to experience better outcomes with less time and energy expended on dealing with complaints, defending their position, and mediating disputes.

Max, in his follow up interview, talked about what he saw as important facets of his relationship with his daughter

“We have no other family in Australia. We make good decisions and bad decisions in life and sometimes they’re made out of love and sometimes they’re made out of fear for the future. She’s got to move. The decision has been made and so she’s got to move.” (comment by Max at follow-up interview).

Timothy’s decision for Thomas to live with his grandmother (Tanya) was evidence of the commitment he and his ex-wife felt towards Thomas

“Thomas was never going to go into a group home, he was never going to be fostered out. Our rights, me and [Thomas’ mother’s] rights were never going to be taken away from us so that we never had a say over Thomas. There was no way in the world that that was going to happen.” (comment by Timothy at initial interview).

These comments point to the level of commitment of significant others when faced with difficult decisions as a result of the devolution of Taradale.
Involvement of significant others

The government department funding and overseeing this devolution, DADHC and the organisation itself, Taradale, had policies and strategies for including significant others in devolution. However, this study shows that having these policies and strategies on paper is not sufficient. Dempsey (2002) stated that at the macro level of government policy and organisational policies and procedures, empowerment and enabling practices are enshrined as requirements; however at the micro level of interpersonal relationships between staff and families, “the evidence of the uptake of principles of empowerment and help-giving practices is patchy indeed” (p. 7). This statement proved to be important in the context of this work as significant others recounted a breakdown in communication and hence engagement with Taradale post-devolution.

Comments made by Bill at his follow-up interview highlight what happened when significant others become disengaged in the devolution process

“I took three months leave out of the Board because I'm that cranky. I'm just trying to hold it at arms length and get through this review. I'm not hearing the right answers [from Taradale]” (comments by Bill at follow-up interview).

On the other hand, Max’s experience demonstrates how involvement at the Board level may provide significant others with information and a greater understanding of the constraints placed on the organisation

“Parents don’t, unless you’re on the Board, you don’t see those issues [of staff, funding, politics]. What you’re looking at is ‘are the children’s needs being met? Why isn’t there enough therapy? Why isn’t there this or that?’ What needs to be done [by the Board] is important for the financial security of the home which involves our children” (comment by Max at follow-up interview).
Nolan et al., (2003) discussed partnerships in family care for people who come to a care giving role later in life (such as a spouse caring for their partner with dementia or a daughter caring for a parent who has had a stroke) and for life-long carers (such as parents of children/adults with developmental disabilities). In their work, Nolan et al., (2003, pp. 274-275) developed a “senses framework” to “capture the subjective and perceptual dimensions of caring relationships”. The framework included sense of security; belonging; continuity; purpose; achievement; and significance. The underlying principles of Nolan et al’s., (2003) work highlight the importance of a supportive triadic care giving relationship. More will be said about Nolan et al’s., (2003) work in the next section of this chapter looking at models of empowerment.

Household Arrangements

Housing, Costs and Staffing

Getting the household arrangements right is vitally important in providing support to people with disabilities. Significant others linked getting the household arrangements right directly to their sons/daughter’s quality of life. It was evident that significant others wanted to play an active role in finding and advising on housing, knowing about the costs and employing and monitoring staff. Doreen spoke about the knowledge she and her husband had as long term residents living in the area, which they wished to apply to selecting a site and design for Darryn’s purpose built group home

“I’d like to be involved when the place is being built because I’ve lived in [the area] for 32 years and I’m very aware of aspect. My husband is an engineer and he designed [the institutional building of Taradale] with the aspect in mind. It gets the northern sun, it’s cool in summer and warm in winter. It’s a great design. It’s critical for these kids to be able to see outside. Over the years people wanted to put up blinds in certain areas and close off areas and we’d say ‘You can walk to look outside but the children can’t’. So,
I'd really like to be involved in the final floor plans [for the group home]” (comment by Doreen at initial interview).

At his follow-up interview, Max told of the pride and joy he took from helping to set up Mary’s group home

“I went round there [to Mary’s group home] and took round some pictures from my house here, took them up there and stuck them on the wall to make it more like a home. I bought a clock for the wall. All the parents, we all chipped in and volunteered. One person bought the Christmas tree and decorations. The parents of all four kids went out and did something for that house” (comment by Max at follow-up interview).

Staff qualifications, training and supervision were key issues for significant others and this was written about in some depth in Chapter 6, Results II of this thesis. Significant others identified both positives and negatives in relation to the staff employed in the community settings compared to those employed in the institutional setting. The positives related mainly to the much improved staff:client ratios. However, of major concern to significant others in the community settings was what they saw as the lack of training of staff in relation to health care and the difficulties of providing full staff numbers to ensure that their sons/daughter were able to access the community. Staff competency and numbers were particularly relevant given the level of disability of their sons/daughter and their high support needs and health issues. Bill’s comments about the staffing situation highlight his concerns

“I thought it [living in the community] would have been a lot better. I thought it would have been a lot more personalised care and a lot more intense for the kids” (comment by Bill at follow-up interview).
Significant others will be reassured if they can see that their son’s/daughter’s physical care needs are being met through good nutrition, personal cleanliness, high standard of clothing and appearance, good quality housing, environmental cleanliness, and a high level of attention to health care needs. As mentioned previously, the issue of health care needs was of particular importance to participants due to the complex care needs of their sons/daughter. Beange et al., (1999, p. 292) argued that attention to the physical health care needs of people with disabilities is “an essential element in quality of life” which must be addressed if people are to “live decent lives in the community”. Participants in this study would concur with this view.

*Getting it right* is very important for significant others and incorporates a number of elements. What lessons can be learned from what participants told me in this study which will assist organisations supporting people with disabilities to *get it right*?

**Lessons to be Learned**

In order to *get it right* organisations need to:

- Provide accurate, timely and honest information to significant others;
- Create mechanisms for communication at all levels: individual; group; organisation and with the wider disability community;
- Be responsive to the needs of significant others by accommodating changes; being flexible; taking an individual approach and being empathetic;
- Promote opportunities for external support to significant others which is independent, available and accessible;
- Recognise the importance of significant others through creating and promoting opportunities for their involvement in the decisions relating to their sons/daughter’s lives;
- Provide opportunities for significant others to be involved in practical tasks such as house purchases and renovations and the employment of direct care staff;
• Draw on the knowledge, experience and expertise of significant others in a range of areas relating directly to their son/daughter and with reference to their other life experiences;
• Develop equal and empowering relationships between family members, the person with a disability and the accommodation provider (whether institution or community based).

7.4.2. How do you recognise that parents are forever?

The major category *Parents Forever* included the categories of:

1) Re-awakening guilt over the initial out-of-home placement;
2) Standard of care;
3) Provision of health care;
4) Compatibility and comradeship in living arrangement;
5) Contact with past friends;
6) Level of family contact.

The first (1) of these categories demonstrates the **life-long care** which significant others feel towards their sons/daughters even though they may be placed in out-of-home care. The second and third (2-3) categories relate to the how parents/significant others see their **ongoing role** in their child with a disability’s life, in relation to the life stage they are currently in, in order to monitor the service provided to their child. The category of provision of health care was of particular importance to the participants in this study given their sons/daughter’s level of disability and complex health care needs. Categories four, five and six (4, 5 & 6) relate to the **emotional needs** of their sons/daughter evidenced in the enduring bonds with family, friends and compatible living companions.
Life-Long Care

As stated in the Family Literature review chapter of this thesis (Chapter 2), the family is the most enduring social unit in society (Krauss & Giele, 1987). Prior to the placement of their child with a disability into out-of-home care, significant others have given birth to that child, nurtured and loved them and formed a family bond with them. The difficult decision to place a ‘child’ into an out-of-home placement does not mean the end of that relationship. The traditional view of families/significant others experiencing only negative consequences from having a child with a developmental disability is discussed within the Family literature review (Chapter 2) as being challenged by more recent studies which have described perceived benefits from the experience (Scorgie & Sobsey, 2000).

Out-of-home placement

The majority of significant others do not see out-of-home placement for their son/daughter as the first option. Indeed, the majority of people with developmental disabilities live in their family homes at least during their childhood and many into adulthood (Blacher, 1994; Llewellyn et al., 1999).

The decision to place a child with a disability in an out-of-home placement is very often precipitated by the on-going pressures and strains encountered by families who have a child with a disability often coupled with a “triggering event” (Baker & Blacher, 1993; Blacher & Baker, 1994; Blacher et al., 1999). When the family makes the decision to place the child in an out-of-home placement, they may describe the decision as “the hardest and most painful decision in my life” (Mirfin-Veitch et al., 2003 p. 99). Blacher et al., (1999) proposed that placing a child in an out-of-home placement may not diminish the parental attachment to the child; indeed the decision to defer placement for as long as possible is often due to the strength of the attachment.

Participants in this study reported feelings of guilt, hurt and remorse regarding the decision to place the person with a disability in out-of-home care and these feelings
appear to be long-lasting (Blacher et al., 1999) and re-surface when deinstitutionalisation is proposed (Mirfin-Veitch et al., 2003). Significant others facing the situation of placing a child into out-of-home care must ask themselves the fundamental question for a parent: “why can’t we continue to care for our child?” Bill and Max both spoke about how difficult it was to make the initial out-of-home placement decision and how the devolution had led them to question whether they could or should bring their son/daughter back to live in their parental home. At his initial interview, Max spoke about feeling his feelings of guilt

“Because your life has changed while that child was away and you have excluded that child from your daily life” (comment by Max at initial interview).

Max spoke about some of the stresses involved in making the initial decision to place his daughter in an out-of-home placement and how these stresses resurfaced with the devolution

“You are often times forced into choosing things that you wouldn’t have chosen to do because to make ends meet you can’t work and look after the [other] children and a handicapped child on the income of a disability allowance. I’ve thought about having Mary back home but it’s totally impractical. I just couldn’t look after her the way that she needs to be” (comment by Max at follow-up interview).

The attachment which the participants felt towards their son or daughter with a disability was represented by the way in which they saw their lives inextricably linked to that of their son/daughter who had severe, multiple disabilities requiring high levels of care and support to ensure their quality of life. Placement in out-of-home care does not diminish significant others’ feelings of love, care and support for their son/daughter. Their role has changed from one of providing hands-on day-to-day care to one of
support and monitoring of the care provided to their son/daughter. Participants talked about the devolution of the institution at Taradale and their son/daughter’s move into the community as akin to leaving their home.

**Leaving Home**

Institutional living may be perceived by significant others to be a safe option with defined geographic boundaries (often delineated by fences and parkland settings), closed doors and many watchful eyes. Moving out into the community may be likened to a young adult child taking the first step in leaving home. ‘Delayed launching’ is the term used to describe what happens when a person with a disability leaves their family home in mid or late adulthood. This was discussed in the Family Literature section (Chapter 2) of this thesis with reference to Seltzer et al., (1994). However, the term may be equally applied to a person leaving an institution where they may have lived for most of their lives, to live in the community. The feelings of significant others (and often the feelings of staff) of uncertainty, protectiveness, and fears for the future appear to be similar in both circumstances. Additionally, devolution challenges the original placement decision and re-awakens feelings of guilt about out-of-home placement. Do I now bring my child home? And if I do, what will be the ramifications of that decision on the rest of my family? Max talked in his initial interview about how he thought his daughter Mary might view her move.

“*Mary can say yes and no to things. She has a capacity to understand [some things] but she hasn’t got the experience to appreciate the things that we are talking about [the devolution]. She thought initially it [moving to a group home] was all going to be a big holiday camp, like going to the snow for a weekend*” (comment made by Max at initial interview).

The feelings significant others expressed about out-of-home placement and devolution were linked to their on-going role in monitoring the services provided to their sons/daughters.
On-going Role

The major category *Parents forever* relates to the sense of love and responsibility which significant others feel towards their children. The level of support provided by significant others to their children will typically vary in type and intensity over the life course. For significant others of people with severe, multiple disabilities, a high level of support will be required for the life span of the person. Significant others face the double bind of their child chronologically ageing and becoming an adult while at the same time functioning at a level below their chronological age. As an adult, the person would normally no longer be living with their parents; however they still require the level of care typically provided to a child (e.g. assistance with feeding, dressing, bathing, toileting, decision making, communication, money management) (Mansell, Ashman, Macdonald, & Beadle-Brown, 2002). As significant others themselves age or become ill or infirm their ability to provide that support directly may diminish and they will need to rely more on others to assist with this (Llewellyn, Gething, Kendig, & Cant, 2004). However, most significant others (and this role may shift from a parent to a sibling, aunt or good family friend over time as parents become too old, infirm or die) will maintain a monitoring role in the life of the person with a disability, ensuring that they receive the personal care they need.

The monitoring role in a community based setting appears to be different to the role within an institutional setting. Perhaps this is because the community setting is usually a more home-like environment which more closely reflects the significant others’ own daily lives. The community based settings are also usually smaller so significant others may be able to more clearly see what is happening in their son’s/daughter’s life. Much of what happened within the institutional setting may have been hidden from view within the larger, more structured environment. With the smaller setting also comes smaller staff numbers. Significant others are more likely to encounter the same staff when they visit, and are more likely to develop personal relationships with those staff. However, they are less likely to meet middle and senior management who tend not to be
based at the group home level. There may need to be some preparation of significant others to adapt to their changed role in the new environment in order to re-negotiate the new relationships. An independent support person may be useful in providing this preparation.

The on-going role of significant others in the life of their son/daughter with severe, multiple disabilities may be viewed within the context of the family’s life stages.

**Life Stages**

Family Life Cycle Theory, discussed in the Family Literature review section (Chapter 2) of this thesis, described the ‘normal’ stages a family may experience during its life course including the launching or departing of family members in the ‘middle’ family years and the role of the parents subsequently in maintaining the extended family with ongoing support and care (Carter & McGoldrick, 1989). Llewellyn et al, (2004 p. 379) explained the scope of the relationship between older parent caregivers and their adult sons and daughters with intellectual disability in the following way “their parental care giving career does not start and end at a particular stage of their life cycle. It begins with the birth of their child and ends when they themselves die”. This is particularly true when the person with a disability continues to live with their mother and/or father as they become old.

However, parents’ on-going care is also evident when the person with a disability is living in an out-of-home placement. The need for on-going care into adulthood is especially true when the person has a severe intellectual disability which precludes them, despite their chronological age, from taking on many ‘adult’ roles in life (e.g. holding a job, getting married and having children, managing money, purchasing a home etc.). In this situation, as in the case of the people in this study, the parental role continues to operate at the ‘pre-launching’ stage with significant others continuing to play an important role in monitoring and decision making. Max talked about these issues in his follow-up interview
“These children will never have a job, they will never produce anything to put back into the community” (comment by Max at follow-up interview).

There may be a need for significant others to view the move of their son/daughter to community based care as a new phase in their lives and for significant others to ‘move on’ in the way they regard their son/daughter. As a result of this move, significant others may need to look at their role in their son’s/daughter’s lives differently. Their son/daughter will be older than they were when they were originally placed into out-of-home care. The decision to enter community based accommodation will necessarily be a different decision to the original decision to place the person into institutional care. Very often the decision is made for significant others as the decision to close the institution is made by government. Participants in this study expressed concerns about what would happen to their son or daughter as they themselves got older. They identified a need for supports to be monitored and adapted to suit the changing needs of the person. They viewed Taradale as having some long term responsibility for their son or daughter after they died.

The participants represented different stages in the life cycle. Max, Timothy and Ray still had children of school age and so were experiencing the middle years of life with the need to nurture and support dependent children. Doreen and Bill, on the other hand, had grandchildren and were becoming more involved as support people to their adult children. Doreen spoke about what these changes meant to her relationship with Darryn

“The reason I'm seeing him less at the moment is because I've had some grandchildren and I seem to be being grandma and minding babies a bit at the moment. But I keep informed” (comment by Doreen at initial interview).

Additionally, all five participants still had a ‘child’ with a severe, multiple disability whose long term needs would be an ongoing concern to them. Significant others
continue to love, care for and support their son/daughter however they need to re-negotiate their role in their child’s life.

At his initial interview, Bill spoke about how he saw the future for himself and his son Bob

“You go through cycles and you can’t judge anyone for what part of the cycle they are in. There are no other options than group homes for me. I mean I don’t want to burden myself with a child until I am 80. I don’t want him living in the backyard or a purpose built flat beside me. I mean that’s an option, but it’s not an option for me. I don’t want that because I don’t consider that normal. I don’t want my children living with me when I get older so the option for Bob is a group home” (comment by Bill at initial interview).

The need for significant others to monitor service provision is linked with what I have called the emotional needs of their sons/daughters.

**Emotional Needs**

**Maintaining Contact**

As evidence of the strong and enduring bond between significant others and their children, most significant others wish for and maintain ongoing contact with their son or daughter with a disability after out-of-home placement. This is contrary to the advice which many parents report being given by professionals to place their child with a severe disability in an institution, forget them and get on with their own lives (Funnell, 2002; Llewellyn, 2003).

According to Baker et al., (1996) most family members will maintain contact and will attempt to engage in some sort of relationship with the organisation providing care to
their son or daughter. At his initial interview Bill talked about his reasons for joining the Board of Taradale

“I do that [sit on the Board] because it is the only way that I can put something back in rather than taking all the time. It’s cost me absolutely nothing to have Bob up there since he turned 18 and even before then, it was the only way that I could put anything back into the system to ensure that he was looked after” (comment by Bill at initial interview).

Most significant others want the best for their son or daughter, often taking considerable time to find a placement which they think will best suit their ‘child’s’ needs. They may defer placement while awaiting a vacancy at their preferred location. They may seek community based care options for their son or daughter only to discover that such services do not exist in their area or have no vacancies at the time they need the placement. Whatever the background to seeking out-of-home placement, once found, significant others want security and stability from it (Baker et al., 1996).

Home for Life

The participants in this study and those in other studies of deinstitutionalisation (Funnell, 2002; Griffin & Dew, 2000; Mirfin-Veitch et al., 2003) stated they believed that their son or daughter with a disability was permanently placed in the institution in which they were living. The institutional setting was seen as a surrogate home for the person and participants reported it as a safe and secure environment which satisfied their need to have their son or daughter placed in a “home for life”. Once their child was placed there, participants had dedicated themselves to fund raising to ensure that the institution could afford to provide additional services or extra staff over and above what was provided for by government funding. This commitment was very often in addition to busy lives with jobs, other children and extended family. The commitment which participants felt towards Taradale was evident in the initial interviews during which they were fulsome in their praise of the care it provided to their son or daughter.
Comments made by Max at his initial interview highlighted this commitment to Taradale

“Basically once you put your trust into some organisation like Taradale, it’s like a big brother or an extended family. It is an extended family when you come back to it. It’s our children and we’re directly affected by any decision” (comment by Max at initial interview).

Of particular interest in this study was the change that occurred in some participants’ perception of the ability of Taradale to provide the same level of support to their son or daughter in the new community based setting. Bill’s comments at his follow-up interview in relation to the review of the group home his son is living in are indicative of this change in perception

“You’ve got to start questioning everything that’s being done. That’s why we’ve got an independent review. We’ll see what happens from that. That will take a little bit of time but I figure the organisation needs a bit of a shake up because they’re just not meeting a lot of the basic needs” (comment by Bill at follow-up interview).

Participants hoped that their son/daughter would be living with people with whom they were compatible. They hoped that they would be able to maintain contact with past friends from the institution but also have opportunities to make new friendships. Participants also spoke about wanting their son/daughter to have warm, caring, empathetic relationships with the staff providing support to them. And they spoke about wanting their role as the significant other recognised as the most important relationship in their son’s/daughter’s life. Parents Forever incorporates the ways in which significant others view their engagement in their children’s lives. What lessons can be learned from what participants told me in this study which will assist organisations supporting people with disabilities to appreciate the theme of parents forever?
Lessons to be Learned

In order to understand what parents forever means within the context of the relationship between significant others and their son/daughter with a disability, organisations and policy makers need to:

- Recognise the on-going role of significant others in the life of their son/daughter with a disability. This means developing mechanisms and structures which facilitate contact and include the significant other in decisions about their son’s/daughter’s life;
- Understand life cycle issues and provide significant others with assistance to ‘move on’ and adapt to life cycle changes for their son/daughter;
- View deinstitutionalisation as another stage within the context of life-long care provided by significant others to their son/daughter with a disability;
- Understand the background to out-of-home placement and deinstitutionalisation through reference to the extensive literature available about these issues;
- Recognise the emotional needs of significant others and their sons/daughters with disabilities through the maintenance of on-going contact. This will include the identification of the place the person with a disability lives in as their home;
- Provide significant others with preparation for their changing role in the life of their son/daughter in their new living environment.

7.4.3. How do you accommodate changing lives?

The major category Changing Lives included the categories of:

1) Competing demands;
2) Level of involvement in management of Taradale;
3) Diminishing communication with Taradale;
4) Concerns about the future.

The first and fourth (1 & 4) of these categories relate to life changes which have occurred for participants in this study and may be matched by the changes occurring within the organisation. Devolution of an institution typically occurs over a number of years and family members own lives are not standing still during this time. Over the time taken to complete the devolution of Taradale, the significant others had experienced numerous changes in their lives including re-marriage, the birth of grandchildren, and most significantly their own or close family member’s ill-health. These changes resulted in concerns about the future for their sons/daughter with a disability. The second and third (2 & 3) categories relate to maintaining communication with the management of Taradale through opportunities for input.

Life Changes

For Significant Others

As discussed in the Family Literature section, (Chapter 2) of this thesis, within a family without a child with a disability, the usual pattern is for the parental role to change over time as the child grows, becomes more independent and finally leaves home to pursue life as an adult (Carter & McGoldrick, 1989; Knox et al., 1995; Seltzer et al., 1994). Most parents continue to love, support and be involved in the lives of their adult children while re-establishing their own lives independent of their children. However, when the child has a developmental disability, the dimensions of the significant other/child relationship are very different. However, neither the significant other’s nor the child’s life stand still.

People age chronologically, milestones are passed and good and bad events overtake people. For the significant others interviewed in this study, the devolution of Taradale
and the consequent need for increased involvement had come at a time in their own lives where they had anticipated that their son/daughter with a disability was in settled, long term accommodation. The devolution of Taradale required them to re-think the child’s, and their own, future. Bill talked about this in his initial interview

“I don’t relish the thought of looking that far down [the track into the future] because I don’t like what I see. They [government] don’t care how many lives they have disrupted to get their point of view across and get it put into law, but what happens further down the track?” (comment by Bill at initial interview).

Other circumstances had also intervened to make the impending changes in the lives of their sons or daughters with disabilities more unsettling. While these events never happen in isolation, when they occur at the same time as another major event, such as this devolution, they have the potential to seriously disrupt people’s lives and the way people view what is happening in their lives. These changes may have provided a serious additional stress in participants’ lives and may have contributed to their negative attitude towards what was happening for their sons/daughter post-devolution. Timothy spoke about the impact of his mother’s diagnosis and treatment for breast cancer in his follow-up interview

“The only reason I haven’t done anything against Taradale, or said anything is that I’ve got mum going through her cancer and she’s settling down with what’s going on with Thomas and she’s trying not to cause too much of a hiccup. Whereas I just think it’s so unfair” (comment made by Timothy at follow-up interview).

Bill spoke about how his diagnosis with cancer meant that his ex-wife took more of a role in what was happening for their son, Bob
“I purposely stepped out of it. I felt my personality and the way I am [undergoing treatment for cancer] meant I would be forcing issues through and that may not have been the right thing. So I stepped out of that side of it and purposely stayed away from it. But then I find out what’s happened” (comment made by Bill at follow-up interview).

An important component in how people cope with life changes is their sense of control over events. Sense of control, self efficacy and resilience have been discussed in Results II (Chapter 6) of this thesis and will be referred to again below and later in this chapter when looking at models of empowerment.

**For the Organisation**

Organisations also experience difficulty in transitioning from an institutional to a community based service. Managing a service for people with disabilities in community based settings offers particular challenges which are very different to those faced in institutional settings. The significant others participating in this study identified some of these difficulties when they spoke about staff support, issues of multiple roles for staff, lack of direct supervision and isolation for staff working in community settings. Max spoke about his concerns during his initial interview

> “That’s a parent’s role [doing the cooking, providing personal care, providing health care, being a taxi service] and if a parent has got five kids or one kid it doesn’t matter, it’s still their own children. But when you are hiring people to do things then you have a whole range of issues. Like can each home be maintained in the way that is intended?” (comment by Max at initial interview).

At the follow-up interviews, participants also identified the rapid growth of the organisation and the decentralised management systems as causing problems. An organisation must put so much time and effort into planning and executing the
devolution that less time and effort may go into operational details post devolution. This may be particularly the case for an organisation such as Taradale which had no prior experience of managing community based services. Bill talked about the Board’s role in monitoring what was happening post devolution

“No, the Board’s not totally aware of what is happening. I don’t think they have a full understanding of what’s going on. Most of the Board members are business people. There’s only a couple of them that would understand” (comment by Bill at follow-up interview).

Coping with change

Whatever else had happened or would happen in the lives of the participants in this study, they had a common experience in having a child with a severe multiple disability. They had all lived with that child in the family home for some years prior to making the decision to place the child in out-of-home care. They had all ‘got on with’ their lives: having other children, working, divorcing, remarrying, and engaging in recreational and social activities. They displayed resilience through an ability to cope with adversity (Hardy et al., 2004) such as the stress of having a child with a severe disability; making a decision for that child to live in out-of-home care; and coping with the devolution along with all the other events happening in their lives.

The theories of sense of control, self efficacy and resilience are discussed later in this chapter as factors in models of empowerment and as such, they offer some insights into how change (as displayed between the initial and follow-up interviews) affected the significant others interviewed for this study. The fathers who experienced the greatest negative shift in their thinking about Taradale and the support it was providing to their sons were Bill and Timothy. Bill, at the time of the follow up interview was experiencing ill health and undergoing treatment for cancer. Timothy’s mother, Tanya who was providing care for Thomas, was also undergoing treatment for cancer. A life threatening illness such as cancer and its invasive treatment diminishes a person’s sense
of control over what is happening in their life and hence their self efficacy and resilience (Lev, Paul, & Owen, 1999; Nolan et al., 1996; Saegrov & Halding, 2004). The diagnosis and treatment for cancer in these two families may therefore have influenced how the fathers viewed what was happening for their sons, Bob and Thomas. The following comments by Bill illustrate his feelings of lack of control and low self efficacy

“I'm just trying to hold it at arms length”
“I'm angry”
“I'm just not hearing the right answers”
“That’s not the way it should be”
“I don’t know how to address it”
“It gets to me I'm telling you”
“I'm getting very cranky, so that’s why I’ve stepped out of it for a little bit and every time I think about it, I don’t sleep. After tonight’s session, you’ve just brought it all back up again!”
“I want it resolved”
(All comments made by Bill at his follow-up interview)

Comments by Timothy at his follow-up interview also highlight his feelings of lack of control with his mother caring for Thomas while at the same time undergoing treatment for breast cancer

“It’s sort of like all over the place”
“I find it difficult for my mum”
“I just don’t feel there’s a lot of concern from Taradale”
“It just shouldn’t be this way”
“I am keeping a close eye on mum and if it gets any worse [oedema in her arm]. I’ll be putting some sort of a stop to it [caring for Thomas] because I see it’s affecting her health”
(All comments made by Timothy at his follow-up interview).
The impact of a life changing event such as cancer happening concurrently with another life changing event such as deinstitutionalisation provides a subject for interesting and important future study.

Maintaining Communication

Opportunities for input

The pattern of previous contact and control over decisions affecting their son or daughter’s life was also an important component to be considered in this study. Indeed the decision to re-interview Max, Bill and Timothy was based upon their high degree of involvement in the process of the devolution and their child’s life expressed at the initial interview. The extent of involvement of significant others after out-of-home placement varies. Some significant others will maintain a high degree of control with regular input into decisions regarding their child’s life. Others will partly or wholly abdicate this responsibility to the supporting organisation. Others will engage an independent person (guardian or advocate) to assist them in decision making. Baker, Blacher and Pfeiffer (1996) suggested that families determined at the time of first placement the pattern of involvement they would have and they stated that this pattern continued with little change over the ensuing years. In a previous article Baker and Blacher (1993) pointed out that the strongest variable related to family involvement in out-of-home placement facilities was the opportunities the facility provided for family involvement. Facilities which went out of their way to encourage and facilitate family contact resulted in greater family interaction with both their ‘child’ and the facility itself. This was demonstrated in the closure of the Hall for Children (Griffin & Dew, 2000) in which repatriation of the residents to be geographically close to their significant others was a key feature of the devolution and resulted in much higher levels of family engagement than previously found when people were living at the institution. However, the initial interviews of participants in this study indicated that Taradale in its institutional guise
had been very successful in encouraging and facilitating contact with significant others. This was evident in the comments made by Doreen:

“Oh, we get regular letters on what is happening with the changes and initially I joined a group of the parents on a consulting day to decide who would do the assessments and I’ve been over [to Taradale] to talk about his move. I’m very much involved in his day to day programmes so I’ve got the opportunity to ask and they [staff] are very open about everything. There is no problem there at all” (comment by Doreen at initial interview).

At the time of the follow-up interviews however, by which time Taradale was operating in a decentralised, community based model, participants were reporting difficulties in their communication at management level as shown by Bill’s comments:

“We don’t need a policy or procedure to do that [clean the house]. We just need a bit of common sense! There was more monitoring in the conglomerate setting. The CEO [at the time] used to sit in the building at the front door and she would see what was going on every day. Now the operation’s got so big it’s not happening and some of the people we’ve got in those key positions are probably not performing at their best” (comment by Bill at follow-up interview).

Significant other’s opportunities for contact with and input into management and the decisions made by management appeared to have diminished post-devolution.

Changing Lives captures the effects of time on the lives of significant others involved in the process of devolution. What lessons can be learned from what participants told me in this study which will assist organisations supporting people with disabilities to accommodate significant other’s changing lives?
Lessons to be Learned

In order to be responsive to the changing lives of significant others and the impact that this will have on the life of the person with a disability, organisations need to:

- Recognise the changes which may occur within significant others’ lives;
- Adapt to changes in the way significant others are involved and kept informed about what is happening in the organisation and within the life of their son/daughter with a disability;
- Conduct forward planning which includes significant others so that changes which are expected can be planned for;
- Ensure there are independent support mechanisms to provide significant others with an alternative contact and point of reference outside of the organisation;
- Build new strategies within community based services to ensure opportunities for input. This may mean adaptation to existing mechanisms or it may mean the establishment of new mechanisms.

7.4.4. Summary

The lessons learned from the study I conducted with significant others of people with severe, multiple disabilities undergoing deinstitutionalisation highlight the need for organisations to work at developing and maintaining relationships with significant others which promote both their engagement and their empowerment. With reference to the major categories of getting it right; parents forever and changing lives, I asked what lessons could be learnt from considering devolution as a possibly disempowering process? I conducted further thematic analysis on the three major categories in order to ‘tease out’ what principles could be applied to assist organisations to develop and maintain engaging and empowering relationships with people with disabilities and their significant others. Table 15 shows how the five key principles emerged from and are based on the lessons learned from the three major categories. I argue that the application of these five principles will facilitate empowering partnerships between
significant others, people with disabilities and the organisations which provide them with support. The five key principles are:

- Respect;
- Communication;
- Common Goals;
- Shared Values;
- Individualised Approaches.

How the key principles were grounded in the three major categories and lessons learnt is shown in Table 15.
Table 15 Development of Five Principles of Empowering Partnerships from Lessons Learnt

<table>
<thead>
<tr>
<th>Lesson Learnt</th>
<th>Principle</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Major category from which the lesson is drawn is presented in italics in brackets)</td>
<td></td>
</tr>
<tr>
<td>• Promote opportunities for external support to significant others which is independent, available and accessible (<em>Getting it Right</em>);</td>
<td>Respect</td>
</tr>
<tr>
<td>• Recognise the importance of significant others through creating and promoting opportunities for their involvement in the decisions relating to their sons/daughter’s lives (<em>Getting it Right</em>);</td>
<td></td>
</tr>
<tr>
<td>• Provide opportunities for significant others to be involved in practical tasks such as house purchasing and renovations and the employment of direct care staff (<em>Getting it Right</em>);</td>
<td></td>
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<tr>
<td>• Recognise the on-going role of significant others in the life of their son/daughter with a disability and develop mechanisms and structures to facilitate contact and inclusion (<em>Parents Forever</em>);</td>
<td></td>
</tr>
<tr>
<td>• Recognise the emotional needs of significant others and their son/daughter with a disability through maintenance of ongoing contact including the identification of the place the person with a disability lives in as their home (<em>Parents Forever</em>).</td>
<td></td>
</tr>
<tr>
<td>• Provide accurate, timely and honest information to significant others (<em>Getting it Right</em>);</td>
<td>Communication</td>
</tr>
<tr>
<td>• Create mechanisms for communication at all levels – individual, group, organisation, wider disability community (<em>Getting it Right</em>);</td>
<td></td>
</tr>
<tr>
<td>• Ensure there are independent support mechanisms to provide significant others with an alternative contact and point of reference outside of the organisation (<em>Changing Lives</em>).</td>
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</tbody>
</table>
Table 15 continued Development of Five Principles of Empowering Partnerships from Lessons Learnt

<table>
<thead>
<tr>
<th>Lesson Learnt</th>
<th>Principle</th>
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<tbody>
<tr>
<td><strong>Shared Values</strong></td>
<td></td>
</tr>
<tr>
<td>• Draw on the knowledge, experience and expertise of significant others in a range of areas relating directly to their son/daughter and with reference to their other life experiences <em>(Getting it Right)</em>;</td>
<td></td>
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<tr>
<td>• Provide significant others with preparation for their changing role in the life of their son/daughter in their new living environment <em>(Parents Forever)</em>;</td>
<td></td>
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<tr>
<td>• Understand the life cycle issues with assistance to significant others to ‘move on’ and adapt to life cycle changes for their son/daughter with a disability <em>(Parents Forever)</em>;</td>
<td></td>
</tr>
<tr>
<td>• View deinstitutionalisation as another stage within the context of life-long care provided by significant others to their son/daughter with a disability <em>(Parents Forever)</em>;</td>
<td></td>
</tr>
<tr>
<td>• Understand the background to out-of-home placement and deinstitutionalisation through reference to the extensive available literature <em>(Parents Forever)</em>.</td>
<td></td>
</tr>
<tr>
<td>• Develop equal and empowering relationships between family members, the person with a disability and the accommodation provider (whether institution or community based) <em>(Getting it Right)</em>;</td>
<td><strong>Common Goals</strong></td>
</tr>
<tr>
<td>• Build new strategies within community based services to ensure opportunities for input through adaptation of existing or provision of new mechanisms <em>(Changing Lives)</em>.</td>
<td></td>
</tr>
<tr>
<td>• Be responsive to the needs of significant others – accommodate changes, be flexible, individual and empathetic <em>(Getting it Right)</em>;</td>
<td><strong>Individualised Approaches</strong></td>
</tr>
<tr>
<td>• Recognise that changes may occur within significant others’ lives <em>(Changing Lives)</em>;</td>
<td></td>
</tr>
<tr>
<td>• Adapt to changes in the way significant others are involved and kept informed about what is happening in organisations and within the lives of their sons/daughters with disabilities <em>(Changing Lives)</em>;</td>
<td></td>
</tr>
<tr>
<td>• Conduct forward planning which includes significant others so that changes which are expected can be anticipated <em>(Changing Lives)</em>.</td>
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</table>
Before describing these key principles I examine the models of empowerment found in the literature to test out the five key principles against what others have identified as important variables in empowerment. I will then discuss how these models, the three major categories and the five key principles I have identified in this study have influenced the development of a Model of Empowering Partnerships in Devolution.

7.5. Empowering Models

Empowerment was discussed in Chapter 2 of this thesis and the writers referred to there will be drawn on here to describe and discuss their models of empowerment.

7.5.1. Existing Models

Hornby (2000) developed a model for parental involvement which encompassed both parental contributions (information about their child; collaboration with service providers; resources – for example by fundraising and supporting other parents; policy through input into support and advocacy groups) and parental needs (communication regarding their child; liaison between service providers and parents; education - e.g. parent workshops; and support e.g. counselling, support groups). Hornby (2000, p. 27) suggested that this model could be used as a checklist to “ensure that procedures are in place to meet parents’ needs and to make sure that parents’ potential contributions are being fully utilized”. The checklist contains many of the elements which I identified as necessary in my study (e.g. information, collaboration, communication, liaison) however, while a checklist approach may be a useful tool for service providers to use, it still places the parent in a position where they are supporting the professionals rather than as a key player within an equal partnership (e.g. by the emphasis on fund raising, counselling and support groups).

Dunst, Trivette and Deal (1988) developed a set of guidelines for ‘enabling and empowering’ families. Enabling families occurred when opportunities were created for
family members to become “more competent, independent, and self-sustaining with respect to their abilities to mobilize their social networks to get needs met and attain desired goals” (Dunst et al., 1988, p. 94). Whereas, empowering families meant “carrying out interventions in a manner in which family members acquire a sense of control over their lives as a result of their efforts to meet their needs” (Dunst et al., 1988, p. 95). According to Dunst, Trivette and Deal (1988), the premise of the professional as the ‘expert’ as discussed in the medical model and the expert model (as described in Chapter 2 Literature) needed to shift in order to achieve enablement and empowerment of families. This model with its emphasis on enabling and empowering is moving closer to recognising parents as equal partners. However, the focus on interventions still places the power in the hands of professionals to offer enabling and empowering opportunities to family members.

Turnbull and Turnbull (2001), developed a sophisticated model of empowerment within a three-part framework consisting of 1) family resources including motivation and knowledge/skills; 2) professional resources including motivation and knowledge/skills; and 3) collaboration – bringing together the resources of parents and professionals. From this, Turnbull and Turnbull (2001) developed a Family Systems Framework which incorporated a range of inputs and outputs across a family life cycle which could result in the empowerment of families.
This model encompassed many of the factors discussed previously as influential in the way in which parents viewed their role and coped with having a child with a disability within their family. The model described a number of inputs or family characteristics, which would change across the family life cycle and were influenced by processes such as the extent of the families cohesion and adaptability (made up of factors such as the extent of the extended families involvement; the marital status of the parents; the input of siblings and the parental view of the child with a disability). The result is the outputs or how the family functions: the family’s economic situation, how the family spent its recreation time, the affection between family members and so on. The model described a complex set of variables that together influenced how a family operated. This model
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captures some of the complexity which I found in the relationship between significant others and supporting organisations in my study.

However, it is the work by Nolan, Grant & Keady (1996) which is closer to the findings of this study. In their work into how family care-givers coped with stress, they developed a model that conceptualised how individual beliefs impact on outcomes.

![Figure 3 Self Efficacy and Outcome Beliefs. (Nolan, Grant & Keady 1996 p. 67)](image)

In this model, the best outcome will be achieved when the person believes their action would work and believes that they could do whatever was required of them, the result was ‘assured action’ (upper left-hand quadrant). For example, in this study Bill, in the initial interview was confident that Bob would experience a good quality of life as long as Taradale was providing him with support. This model also introduced the concept of Self Efficacy as a continuum with ‘I can do it’ at one end and ‘I can’t do it’ at the other. According to Nolan et al.’s., (1996) model, the worst outcome would be achieved when a person believed their action would not work and that they could not do it resulting in ‘resignation/apathy’ (lower right-hand quadrant). For example, in this study, Bill, in the follow-up interview was feeling resigned because, due to his own ill-health, he was not able to ensure that Taradale provided adequate health care to Bob. In terms of the
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empowerment model, therefore, a family’s best hope of being enabled is when they both believed their actions would work and they were able to carry through these actions. Their model recognised the significant other/s as integral to the relationship between the person they cared for and the organisation/s which provided support.

Before describing the development of my model, I will summarise the key variables of the models of empowerment described in this thesis and how they relate to the five key principles which I have identified.

7.5.2. Key Variables of the Models

The literature identified a number of key variables as important in promoting family empowerment. The literature focussed on the interactions between families and professionals where the person with a disability is still living in the family home but using services provided by the professionals. While the situation of family members where their son or daughter is living in an out-of-home placement is somewhat different, the variables identified from the literature are relevant to this group as will be shown below.

1) The importance of *listening* to what families are saying while at the same time recognising that families are competent and capable (Dunst et al 1988; Gordon 1999; Hornby 2000; Turnbull & Turnbull 2001; Nolan et al., 2003). Listening is an important component in the communication process. Listening to what people are saying indicates respect for their viewpoint.

2) Recognising parents’ *needs* (Hornby 2000; Knox et al., 2000), respecting their *choices* (Gordon 1999; Knox et al., 2000) and harnessing their *resources* (Turnbull & Turnbull 2001). An individualised approach which recognises parents’ needs, respects their choices and harnesses their resources is essential in an empowered relationship.

3) Promoting in interactions with family members their *sense of control* over their own lives and the life of their son/daughter with a disability. This is
variously called sense of control (Dunst et al., 1988), self determination (Gordon 1999), and self efficacy (Nolan, et al., 1996). The idea of sense of control is integral to the empowering of significant others. Without this feeling of being in control, the relationship is based on an unequal footing with professionals holding the power.

4) *Collaboration* and *negotiation* between parents and professionals to ensure a *partnership* and the best possible outcomes for the person with a disability and their family (Dunst et al., 1988; Gordon, 1999; Knox et al., 2000; Nolan et al., 2003; Turnbull & Turnbull, 2001). Collaboration and negotiation are elements of communication which also incorporate respect between significant others and professionals.

**7.6. Development of a Model of Empowering Partnerships in Devolution**

**7.6.1. Five Principles of Empowering Partnerships**

A synthesis of the key features of the literature on family empowerment models and my own thematic analysis of the data in this study have led to identification of five principles of empowering relationships, which form the basis of the model of empowering partnerships to promote devolution as an *empowering process* for significant others:

1) Respect
2) Communication
3) Shared values
4) Common goals
5) Individualised approaches
**Respect** must exist between the organisation, the family and the person with a disability. Respect entails listening to the other person’s viewpoint and appreciating the right of the person to hold that viewpoint. Nolan et al., (2003) used the terms ‘confidence’ and ‘trust’ to describe key elements of the carer/professional relationship. I would argue that the term respect incorporates both confidence and trust. Nolan et al., (2003 p. 269) proposed the need to create ‘empathetic understanding’ between the person with a disability, their family and professionals so that each has some cognizance of and empathy for the pressures of their circumstances which may impact on the relationship. Respecting families as the ‘expert’ on their ‘child’ is essential. Even when a person has lived in an institution for a number of years, it is often the family which has kept track of treatments, medications, medical emergencies, likes and dislikes over time. Staff members come and go, records are of variable quality, but family members remember. It is equally important for family members to respect the training and experience of staff members who bring a broader view of what may be happening for their son or daughter.

**Communication** is vitally important in any relationship and involves dialogue and listening to each other’s viewpoint. Communication is not therefore just about providing people with verbal or written information. Developing relationships with significant others and with people with disabilities which facilitate good communication should be a priority for organisations. The importance of communication is clearly not a new concept but within this context it appears to be one worth re-stating. Nolan et al., (2003, p. 257) cite Zgola, (1999) “Optimal care depends on family and professional caregivers communicating well. If they are to communicate well they must operate with the same concepts and use a common vocabulary”. Nominating a central person within the organisation to act as the disseminator of information and take queries from parents can be a useful strategy. Likewise, convening regular meetings (both individual and group) enables family members to ask questions and share concerns before crises occur. The appointment of an independent family liaison worker/s is a useful strategy for providing family members with someone ‘outside the system’ with whom they can discuss concerns with.
Taradale did all of these things in the pre-devolution period however this study shows that maintenance of communication strategies and their adaptation to the new model of community based service delivery is important and perhaps more difficult to ensure. Nolan et al., (2003 p. 243) talked about good communication providing family members and professionals with opportunities, through discussion of each other’s experiences in providing care to the person with a disability, to learn more about the person and themselves.

When making plans concerning the lives of people with developmental disabilities, parties must have some shared values about what that life will be like. If the parties are viewing the life of the person from very different perspectives then they will work against each other rather than with each other. This may well have been one reason for the breakdown in communication between the significant others in this study and Taradale. It is vitally important in this process to ensure that the opinion of the person with a disability is ascertained as validly as possible. Family members and staff members, both of whom know the person well, are important in this process. The organisation needs to be open and upfront about its core values in providing a service to people with disability. Where these values change over time (such as in the case of moving from institutional to community based accommodation), the onus is on the organisation to inform and educate family members about the change and the likely impact on service delivery (Tabatabainia, 2003).

Common values, respect and communication between the parties are necessary conditions for the development of common goals. The disability sector has embraced ‘person-centred practices’ and the concept of individual planning for people with disabilities but many of the plans are of variable quality and occur on paper without being translated into practice. In proposing common goals as a principle of

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6 There is a very large literature in the disability field around individual or person centred planning. It is outside the scope of this thesis to consider this literature however reference is made to (Cummins, Baxter, Hudson, & Jauernig, 1996; Cummins, Jauernig, Baxter, & Hudson, 1994; Holburn & Vietze, 2000; Lyle

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empowering partnerships I am proposing a broader definition which should not focus solely on the person with a disability but should incorporate the family’s goals and the organisation’s goals. For example, if the family is planning a move interstate this will necessarily impact on the person with a disability and the organisation and if the organisation is changing the way it delivers services to clients this will necessarily impact on the person with a disability and their family. Nolan et al., (2003 p. 269) identified agreement over common goals of care as the determinants of a relationship between family members and professionals which is ‘integrated’ and ‘connected’.

**Individualised approaches** are crucial to the relationship. An organisation cannot take a ‘one size fits all’ approach to their relationship with families. This thesis has demonstrated the unique stresses and strains which are experienced within families across time. An organisation needs to be in touch and in tune with what is happening for families as factors such as divorce, ill-health and unemployment will impact on the dynamics of the family and their relationship to both their son/daughter and the organisation. While it is not the place of organisations to know the private business of families or to support them directly, if a sound relationship based on the principles of respect, communication, shared values and common goals has been established between the organisation and the family members, the organisation will be aware of stresses and strains in the family which may impact on their ability to cope with a major transition such as devolution. Nolan et al., (2003 p. 285) discussed the importance of what they called ‘synchronicity’ which they described as “the extent to which service systems work to the same ‘calendars’ as family carers and disabled people”.

Application of these five principles will promote an empowering partnership between the family, the person with a disability and the organisation. The form of the partnership will be different for each family. For some families it will include regular, hands-on engagement in their son or daughter’s life. For other families it may mean a more distant but sustainable relationship. Whatever it looks like, if it is developed

employing the five principles identified in this study, it will come closer to meeting
the needs of those involved in the relationship than was seen for the family members
interviewed for this study.

7.6.2. The Model

In developing this model I have brought together the key elements to emerge from this
study. Using a Symbolic Interactionist approach and a Grounded Theory method, this
study developed the core category of *devolution as a disempowering process*. There
were three major categories which led to the development of this core category: *getting
it right, parents forever* and *changing lives*. Having identified the core category I then
asked what would be required to ensure devolution is an empowering rather than
disempowering experience for significant others who are involved in it. The answers to
this question involved my consideration of the literature on empowering partnerships
and reflection on what the participants in this study told me was going wrong and what
was working. From this I developed the five principles of empowering partnerships:
*respect, communication, shared values, common goals* and *individualised approaches*.

In developing the Model of Empowering Partnerships in Devolution I have incorporated
the three major concepts and the five principles.

The model proposes that there are three central players in the lives of people with
developmental disabilities who are undergoing deinstitutionalisation: the person
themselves, their significant other/s, the supporting organisation/s which are providing
them with accommodation. These three central players form the triadic relationship as

The model describes the engagement of the three players through the application of the
five identified principles described previously of respect, communication, shared
values, common goals and individualised approaches to obtain an Empowering
Partnership which will work in the best interests of all three players. The principles
synthesize what participants told me was lacking in or was working in their relationship
with Taradale and were described in the three major categories: *getting it right, parents forever* and *changing lives*.

The model acknowledges that the partnerships will need to be flexible to accommodate changes over time: the temporal aspect of care giving as described by Nolan et al., (2003). Changes over time were one of the three major categories to emerge from the analysis of the data in this study represented in the theme *changing lives*.

The model also represents the external influences which will impact on the partnership such as society, community and government policy. The triadic relationship between the person with a disability, their significant other/s and the organisation/s which provides them with support must be viewed within this broader context and will be influenced by changes at this wider level.

In order to capture the relationships, I have drawn the three central players as overlapping circles. The major category *Getting it Right* is central to all three players and is drawn at the intersection of the three circles. The major category *Parents Forever* describes the relationship between the family member/s and the person with a disability and so is drawn where these two circles overlap. The major category *Changing Lives* is particularly relevant to the relationship between the supporting organisation and the family members as this relationship must be sufficiently flexible to accommodate these changes and so it has been drawn where these two circles overlap. As described previously, in order to ensure an empowering partnership, the five key principles are applied to this triadic relationship and so the wider circle contains these five principles. Outside of the model (represented with dotted lines) but impacting upon it is the wider context of the society and community in which people live and the more direct influence of the prevailing government policy. Across the bottom of the model is the dimension of time which includes, at the left hand side, the history of the person with a disability, their family members and the supporting organisation, through time to the future of all three.
Figure 4 – Model of Empowering Partnerships in Devolution

changes over time for triadic relationship and government policy, society and community
7.7. Summary

Through the application of the selective coding process of Grounded Theory, I identified the core category for the participants in this study of devolution as a disempowering process.

The implications of this core category on the three major categories of getting it right, parents forever and changing lives along with a review of the empowerment models in the literature, particularly the model by Nolan et al., (1996) and Nolan et al., (2003), led to the development of five principles of empowering partnerships.

The major categories and principles were represented in a Model of Empowering Partnerships in Devolution which is presented for application in future devolutions of people with severe multiple disabilities in order to ensure that devolution is an empowering rather than disempowering process for the person with a disability, their significant other/s and the organisation/s providing them with support.
Chapter 8.
Conclusions

Contents of Chapter 8:
  8.1. Overview of the study
  8.2. Limitations of the study
  8.3. Implications of the study
    8.3.1. Contribution to practice
    8.3.2. Contribution to policy
    8.3.3. Contribution to education
    8.3.4. Contribution to research
  8.4. Summary of findings

8.1. Overview of the study

This study is an original contribution to the understanding of how significant others of people with severe multiple disabilities experience deinstitutionalisation. The study identifies that significant others want to see that the organisation supporting their son/daughter is getting it right. They also want acknowledgement that they are the person’s significant other and the importance of this role as parents forever. Throughout their lives, changes will occur which impact on the level and type of involvement they can have in their son/daughter’s life and in the organisation supporting them. There needs to be an accommodation of their changing lives. Significant others seek a partnership between themselves, their son or daughter with a disability, and the supporting organisation. However, according to this study, they do not necessarily get it.

The major contribution of this study is an understanding that deinstitutionalisation will impact on significant others lives in different ways and indeed for some people it may be a disempowering process. The study identifies that involvement and engagement in
the process of devolution is necessary but not sufficient to ensure empowerment. In order to address this potential problem, this study has developed five key principles which inform a model of empowering partnerships in devolution.

This study also adds to the literature on families or significant others’ perspectives of deinstitutionalisation. Most studies of deinstitutionalisation which have spoken to family members have concentrated on their perceptions of the outcomes of devolution on their son/daughter with a disability (Cummins & Dunt, 1988; Cummins et al., 1990a; 1990b; Dunt & Cummins, 1990; Emerson & Hatton, 1996; Griffin & Dew, 2000; Kim et al., 2001; Mansell & Ericsson, 1996a; 1996b; Young et al., 1998; 2000). There have been only a few studies which have considered family members’ views of the impact of deinstitutionalisation on themselves (Booth, Simons & Booth, 1990; Funnell, 2002; Griffin & Dew, 2000; Johnson, 1998; Mirfin-Veitch et al., 1998; 2000; 2002; 2003; Tuvesson & Ericsson, 1996). These studies reported family members’ opposition to deinstitutionalisation prior to it occurring changed to support for community living post deinstitutionalisation. This study adds to this literature by highlighting the viewpoint of significant others who expressed a negative view of the experience post-devolution.

8.2. Limitations of the study

The study focussed on a small number of significant others of people supported by a non-government organisation on the outskirts of Sydney, NSW. While parallels may be drawn with the experiences of significant others of people with disabilities supported by other non-government and government services undergoing a similar process of devolution, the experiences, thoughts and feelings expressed by those interviewed are individual and therefore, unique. In order to consider how representative the views of the significant others who were interviewed are, it would be necessary to validate the model through interviews with significant others from other organisations undergoing devolution at the same time. It was however, outside of the scope of this study to do this and the choice of a symbolic interactionist methodology and grounded theory
method, did not require this. It would be useful to test the model of empowering partnerships in devolution developed in this thesis with other family members involved in deinstitutionalisation to see whether this model applies outside of this study.

Within the organisation, Taradale, only a small number of significant others consented to be interviewed. Therefore, the views expressed are those of people who self-selected to speak to me. While this meant that the views I heard may not have been representative of all viewpoints, it also meant that the people who spoke to me wanted to be interviewed and were generous with their time and input. The other work which I have conducted on deinstitutionalisation (Griffin & Dew 2000), and related international literature (Mirfin Veitch et al., 1998; 2000; 2002; Funnell, 2002; Tabatabainia, 2003) suggested that some of the issues raised by family members in the interviews I conducted have some concordance with the views expressed by other family members with a son or daughter with a disability undergoing deinstitutionalisation.

However, this study revealed a very different story to that described above of family members moving from opposition pre-deinstitutionalisation to support post-deinstitutionalisation. This differing view may have been due to the small number of people interviewed for this study which meant that their dissenting view was not aggregated out. Some variables which may have resulted in a different view to that usually seen in studies of deinstitutionalisation are:

- Self selection by participants to be part of the study;
- The severity of their son/daughter’s disability which meant they required high levels of personal care including health care;
- The sex of participants with, contrary to most similar studies, the majority of participants being fathers;
- The stress experienced by two of the three fathers due to their own or a close family member’s diagnosis of cancer;
- The dual roles which three of the initial five participants had of being both significant others and Board or staff members;
• Something particular about the history, geographic location or community which made up Taradale.

Whatever the reason, the analysis of their initial and follow-up interviews revealed that some of the participants moved from support pre-deinstitutionalisation to disgruntlement and outright opposition post-deinstitutionalisation.

Three of those interviewed were spoken to twice over an 18 month period and so the interviews represent a ‘snap shot’ of what was happening for these participants at each time. However, during the course of the interviews, participants were asked to reflect on previous time periods. Taking a retrospective approach is not unusual in studies of deinstitutionalisation. O’Brien et al., (2001) spoke to people with disabilities, their family members and staff nine years after deinstitutionalisation and asked them to reflect back on their experiences. They cautioned that there is a tendency for people to present past events in a more positive light than if they were asked at the time. However, given the 18 month period between interviews in this study, and that the interviews represented a ‘snap shot’ of what was happening in participants’ lives in relation to their sons/daughter with a disability at that time, recall was not an issue in this study.

It is also acknowledged that the focus of this study was on the significant others’ perceptions and while staff and a Board member were interviewed prior to the significant other interviews, the purpose of these interviews was to gain background information about the organisation and the process of the devolution. Staff and Board members have not been asked to comment on the content of the significant others interviews. Therefore, the perspective reported in this thesis is purposefully only that of the significant others who were interviewed.

Despite the limitations identified here, this study was successful in identifying the experiences of those significant others who were interviewed. The analysis of the data from their interviews revealed a different view of deinstitutionalisation than is usually
portrayed in the literature. This may be because the viewpoint represented in this study is a minority viewpoint or it may have been aggregated or averaged out in other studies or in their reporting. It is also noteworthy that, as mentioned in Chapter 1 (Introduction) there are only a small number of studies into deinstitutionalisation which focus on its effect from the viewpoint of family members.

This thesis has provided a voice to these significant others so that their viewpoint, which may not represent an ‘acceptable’ view within the current political and social climate of deinstitutionalisation and community living for people with disabilities, is heard.

8.3. Implications of the study

This study provides insights into the experience of some family members involved in the devolution of an institution for people with severe multiple disabilities. Until now it has been assumed that despite initial resistance to the idea of deinstitutionalisation, most family members are happy with the results post-devolution. This study suggests that this may not be the case for all family members. While government and organisations aim for family involvement in deinstitutionalisation, there is a gap between policy and practice when it comes to this involvement. As a result, some family members experience deinstitutionalisation as a disempowering experience. I propose that this is related to their initial out-of-home placement experiences and to changes which are occurring in their own lives at the same time as the devolution is occurring. Both these factors need to be set within the context of parents remaining parents forever.

8.3.1. Contribution to Practice

The results of this study present five principles of empowering partnerships in devolution and a model of how these are integral in the triadic relationship that exists between people with disabilities, their significant others and the organisation that
supports them. The study identifies that deinstitutionalisation may be a disempowering process for some people due to problems in getting it right, the lack of recognition of the ongoing role of parents in their sons/daughter’s lives; parents forever and the lack of recognition of the changes that occur within significant others’ lives which impact on their ability to engage in the deinstitutionalisation process: changing lives. This study shows that there is a need for organisations to build into the deinstitutionalisation process the empowering partnership principles of respect, communication, shared values, common goals and individualised approaches. These principles and the model which demonstrates their application within the triadic relationship will require organisations to reframe the way they see their relationship and obligation to people with a disability and their significant others so that these principles are the cornerstones of the process.

The principle of Normalisation, as described in Chapter 1, Introduction of this thesis has been widely adopted by policy makers and service providers in Western countries as underpinning service delivery to people with disabilities. While not underplaying the importance of respecting and integrating the rights and views of people with disabilities themselves in deinstitutionalisation and subsequent community living, it should not be forgotten that for a significant number of those still living in institutions, it is their significant others who will be required to make decisions on their behalf due to the severity of their cognitive disability. The knowledge, skills and empathy which significant others bring with them due to their life-long relationship with their son/daughter with a disability needs to be embraced for the value it adds all three players in deinstitutionalisation and subsequent community living. The development of an empowering partnerships model has implications for the ways in which organisations engage significant others in the process of devolution through their practices.

8.3.2. Contribution to Policy

The results of this study have policy implications for the way in which government departments’ monitor and implement family centred practices within organisations
undergoing deinstitutionalisation. It could be argued that policy makers pay lip service to the involvement of significant others in the process of deinstitutionalisation. Policy documents advocate the involvement of significant others, however how the implementation of this involvement is monitored is unclear. For example, in NSW this has included the appointment of Family Support Worker/s to liaise with organisations and significant others in deinstitutionalisation. However, this study shows that the appointment of such a person/s does not necessarily ensure that significant others will seek out and benefit from this help. Policy makers need to ensure that this contact and assistance is known about and accessed by significant others. Policy makers also need to ensure that organisations are supported to make the shift from an institutional based model of service delivery to a community based model. This study shows that this shift is not an easy one and requires considerable reorganisation of management structures and practices. Smaller, traditionally run organisations (such as Taradale) may not have the resources or skills necessary to do this. Thirdly, policy makers need to ensure that family empowerment principles inform their own contact (as well as the support organisations’ contact) with significant others.

8.3.3. Contribution to Education

This study has significance for support organisation management and direct care staff education in the area of deinstitutionalisation and community living. There is evidence within this study that management and direct care staff employed in organisations providing support to people with developmental disabilities have little understanding of how deinstitutionalisation affects significant others and how they can assist them through the process. Much of the training which is available to management and direct care staff employed in accommodation services centres around practical skills or issues such as manual handling; medication; first aid; behaviour support. These areas are, of course, very important for staff and this study highlights the importance to significant others of staff having appropriate skills in these areas. However, this study also points to the need for staff to understand the importance of family members in the lives of people with disabilities and in particular in the lives of people, like the people in this
Management and direct care staff need training in how to promote family members’ engagement and empowerment through their work practices. The participants in this study were particularly critical of middle and senior management of Taradale in this regard, post-devolution. The results of this study provides five principles and a model of empowering partnerships in devolution which could form the basis of training at both management and direct care staff levels.

8.3.4. Contribution to Research

The results of this study have generated several promising topics for future research to clarify and deepen the understanding of the engagement and empowerment of significant others in deinstitutionalisation. This study points to the need for further research with significant others to test how widespread the discovery of parents being disempowered by deinstitutionalisation is. There is a need for further research to determine whether feelings of disempowerment during deinstitutionalisation are peculiar to fathers or whether mothers also feel disempowered. There is also a need for further research to study what the impact of life events, such as the diagnosis of a life-threatening illness such as cancer, has on family members’ self efficacy, sense of control and resilience within the context of deinstitutionalisation.

8.3.5. Testing the model

According to Strauss and Corbin (1990, p. 23) in order to ensure that a theory or model is grounded, it must meet four central criteria: fit, understanding, generality, and control. Fit means that the theory or model encapsulates the “everyday reality” of the area studied and has been developed from data collected from participants. Understanding means that both participants and other practitioners/researchers in the area find the theory or model “comprehensible”. Generality implies that the theory or model will be applicable to other like contexts. Control implies that the theory or model should provide some future knowledge or action in relation to the phenomenon studied.
Future testing of the model developed in this thesis should apply these central criteria for qualitative research within Grounded Theory methodology. As this is outside the scope of this thesis, some suggestions are provided about how this may be done.

To test the fit and understanding of the model and its five underlying principles the model should be presented to the participants in this study. Participants could be asked for feedback either individually or as part of a focus group as to whether the model captures the essential elements of their experience of devolution and/or whether the five principles of empowering partnerships developed in the thesis: respect, communication, shared values, common goals and individualised approaches, would improve and enhance their experience of devolution.

This study included only a small sample of participants who were engaged in the devolution of an institution which had provided care and support to their severely disabled sons and daughters. The level of disability of their children, the particular history and service delivery model of the devolving organisation and the other life-changing events which were occurring concurrently in the participants’ lives were conditions which specifically applied to their situation and this study. However the model developed in this thesis is a combination of both the interpretation of the data using a Grounded Theory approach and a synthesis of the literature relating to families and empowerment. Therefore, a further test relates to the model’s transferability or generality (Bryman, 2001; Strauss & Corbin, 1990). In order to test transferability, generality and control, the model could be tested in two ways:

Firstly, a follow-up study could be conducted with the significant others involved with another organisation undergoing devolution. Purposeful sampling for the follow-up study may include participants who have different characteristics to the participants in this study. This may be in terms of the level of disability of their son/daughter; the nature of the organisation providing support; and their personal experiences. Participants could be interviewed in a similar way to that undertaken in this study with particular reference to the five principles of empowering partnerships developed in this
thesis. Participants could be asked to provide examples of how the five principles were or were not evident in their current experience of devolution. This will provide insights into whether the model is transferable across devolution experiences.

Secondly, retrospective interviews with significant others who have already been involved in a similar process of devolution could be conducted. They could be asked to reflect upon the application of the five principles and to discuss how important their application would be. How would applying these principles have made their experience of devolution different to what they had experienced? They could also be asked to identify other principles which they think important. As devolution or deinstitutionalisation of people with disabilities has been widespread throughout Australia, and the Western world, over the past 20-30 years, this would provide a more systematic and widespread theoretical sample with different conditions and variations which could then be built into the model hence enhancing its transferability (Strauss & Corbin, 1990).

Testing the model in these ways will address the issue of control (Strauss & Corbin, 1990) as the model may be more representative of others’ experiences. As noted previously, this thesis raises issues which have not been identified in research on deinstitutionalisation: that it maybe a disempowering experience for some family members. Testing the model with a broader sample means that the minority viewpoint will be explored. The model may also provide the impetus for organisations to change the way in which they interact with family members during the process of devolution and empower family members to seek the support they require during this process.

8.4. Summary of Findings

The aims of this research were to explore the extent to which significant others were involved and engaged in the process of deinstitutionalisation for their son/daughter with a disability and to determine whether involvement and engagement led to feelings of empowerment.
I interviewed two significant others once and three significant others twice over an eighteen month period in order to gain their views about what was happening for their sons/daughters as a result of deinstitutionalisation and to see what role they had to play in this process and its outcomes.

From the empirical data gathered, three major categories emerged representing the experiences of these significant others: *Getting it Right; Parents Forever; Changing Lives*. Examination of the relationships between these major categories resulted in the identification of the core category: devolution as a disempowering process.

I believe this study has made a valuable contribution to the study of deinstitutionalisation of people with developmental disabilities. It has highlighted the experience of significant others of people with severe multiple disabilities who are undergoing deinstitutionalisation. It has identified that for at least some significant others deinstitutionalisation is a disempowering process for a number of reasons.

The first of these reasons, which I have called *Getting it Right*, highlights the importance significant others place upon their relationship with the organisation providing support to their son/daughter. Significant others have entrusted the care and support of their child with a disability to the organisation however they still wish to remain the central figure in their child’s life and to be actively involved and consulted in any decisions affecting their child. Also included in *Getting it Right* is significant others’ concern about the household arrangements for their son/daughter. Moving out of an institutional setting is a major transition in the life of the person with a disability which is akin to them moving out of the parental home. Significant others want assurance that the new living environment will be better than the institution and will provide a pleasant, supportive environment to their son/daughter with adequate numbers and sufficiently trained staff to ensure their often complex care needs are being met.
The second reason why some significant others experience deinstitutionalisation as a disempowering process relates to what I have called *Parents Forever*. Significant others see themselves as providing life-long care to their son/daughter with a disability regardless of where they live. The placement of a child with a disability into out-of-home care is a very difficult decision for parents and the emotional feelings involved in this decision appear to resurface when deinstitutionalisation takes place. Significant others’ on-going role in the life of their son/daughter with a disability must be renegotiated with a change in living circumstance. This renegotiation occurs not just between the person with a disability and their significant other but also between the organisation providing support and the significant other. Significant others feel a particular responsibility to oversee the support provided to their son/daughter when they have complex care needs due to the severity of their disability, often associated with significant health problems. Significant others are also concerned about the emotional needs of their son/daughter moving into community accommodation: will they have friendly faces amongst their living companions? Will they be compatible? Will there be opportunities for families to be involved in their daily lives?

The third reason why some significant others experience deinstitutionalisation as a disempowering process is due to what I have called *Changing Lives*. Because deinstitutionalisation occurs over a number of years, events both positive and negative can impact on the lives of the significant others as well as their son/daughter with a disability. In this study two of the participants experienced negative live changes during the period of the deinstitutionalisation of their sons. One participant was diagnosed with cancer and the other participant’s mother, who became the primary caregiver for his son, was also diagnosed with cancer. This impacted by placing additional stress in the lives of these participants at what was an already stressful time and may have contributed to their negative attitudes towards the devolution. At a time when these significant others needed more reassurance and support from the organisation they reported the opposite: diminishing communication due to the decentralised management structure resulting from the devolution.
The identification of these three major categories and their implications in terms of the core category: devolution as a disempowering process, led me to identify a number of lessons to learned from the experiences of the participants in this study. I distilled from these lessons and other work on empowerment five principles: respect, communication, shared values, common goals and individualised approaches. The application of these principles may contribute to devolution being an empowering process. I developed a Model of Empowering Partnerships in Devolution which demonstrates the application of the five principles within the triadic relationship of person with a disability; significant other; supporting organisation. Underlying the development of this model is the assumption that people with complex needs should live in community rather than institutional settings. This model may be of use to others involved in the process of devolution.
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Appendices

The Appendices contain:

Appendix 1  University of Western Sydney Ethics Approval HE 2000/090
Appendix 2A  Participant Information Sheet
Appendix 2B  Participant Consent Form
Appendix 3  Initial Interview Participant Background Information Sheet
Appendix 4  Follow-up Interview Participant Background Information Sheet
Appendix 5  Initial Participant Interview Guide
Appendix 6  Follow-up Participant Interview Guide
Appendix 7  Summary of Key points of Initial Interviews
Appendix 8  Example of Interview Transcript

Note: these documents have been altered from the original used to remove the name of the organisation and replace it with the allocated pseudonym, Taradale. In the interview transcript, the participant’s name and that of his son have been replaced with their allocated pseudonyms.
Appendix 1: University of Western Sydney Ethics Approval HE 2000/090

Copy of the letter received from the University of Western Sydney Human Ethics Committee in response to the Ethics Application dated 9 August 2000.
UWS Nepean
PO Box 10, Kingswood NSW 2747 Australia

28 August 2000

Angela Dew
18 Catherine Crescent
Blaxland East NSW 2774

Dear Angela

Re: The re-engagement and empowerment of parents/families of children with severe development disabilities who are moving out of institutions and into community based settings. Registration HE 2000/090

The Committee has reviewed your ethics application for the above mentioned research project and has agreed to grant an ethics approval.

You are advised that the Committee should be notified of any further change/s to the research methodology should there be any in the future. You will be required to provide reports on the ethical aspects of your project upon request.

The Protocol No. HE 2000/090 should be quoted in all future correspondence about this project. Your approval will expire in September, 2003. Please contact the Research Ethics Co-ordinator, K Buckley on tel: 47 360 169 if you require any further information.

The Committee wishes you well with your project.

Yours sincerely

[Signature]

Professor Elizabeth Deane
Chairperson
UWS Nepean Human Ethics Review Committee
Appendix 2A: Participant Information Sheet

Study of Significant Others Involvement in the Relocation of ‘Taradale’ residents.

INFORMATION SHEET FOR SIGNIFICANT OTHERS

I am Angela Dew and I am a Master of Arts (Honours) student with the University of Western Sydney, Nepean – Social Community and Organisational Studies. The Ageing and Disability Department (ADD) is kindly assisting me to contact significant others (families/advocates) of residents living at Taradale by mailing out this information on my behalf.

I have 19 years experience working with people with disabilities and I am currently employed by the Centre for Developmental Disability Studies (CDDS) which is an independent academic unit affiliated with the University of Sydney. Over the past three years of working with CDDS, I have been involved in projects which have evaluated the deinstitutionalisation and transition into the community of children and adults with a developmental disability.

In recent years, government has stated that significant others of the residents of the institutions were to be encouraged to be more involved in the planning of the movement of their family member/friend from the institution. For my Masters research I am interested in following a group of significant others through this process as it unfolds to record and describe what it is like. I am hopeful that this will be of benefit not only to those significant others who participate but also to significant others who are involved in this process in the future.

I have agreed to provide ‘Taradale’ Board of Directors with regular feedback about issues relating to the process of the closure (presented without identifying participants). I have also agreed to provide ADD with a report at the end of my research with suggestions as to how significant others engagement may be improved for future devolutions.
The title of my thesis is the re-engagement and empowerment of significant others of children with severe developmental disabilities who are moving out of institutions into community-based settings.

In order to undertake this research, I need to talk to significant others and other stakeholders.

Should you be willing, you would be asked to participate in a series of in-depth interviews. I would like to speak to participants on several occasions during an 18 month period. The interviews would last for approximately one hour and would take place at a time and venue convenient to the participants. The interviews would be tape recorded so that I can be sure that I have the information ‘in the participant’s own words’ and for future analysis of the information.

Should you choose to participate in this research, you are assured that anything you tell me will remain confidential and your comments will be reported in a way that will preserve your anonymity. You may also withdraw from the research at any time. Any identifying information which is collected from you during the course of the research will be stored in a secure place and will be shredded once the research is complete.

Whether you participate throughout, withdraw at some point or decide not to participate at all in the research will have no consequence for the services delivered to your family member.

The research is independent of the process of the relocation of ‘Taradale’ and of ADD.

Should you choose to participate in the research, would you please complete the enclosed Consent Form and return this in the stamped self-addressed envelope.

Alternatively, you may ring me on (02) 8878 0513 (work) or (02) 4739 5904 (home). If I am not available when you ring, please leave a message and I will call you back as soon as possible.

I would welcome your call if you wish to find out more about the research.

Angela Dew

NOTE: This study has been approved by the University of Western Sydney Nepean Human Ethics Review Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research Ethics Co-ordinator (tel: 02 47360 169). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix 2B: Participant Consent Form

Study of
Significant Others in the Relocation of
‘Taradale’ Residents

SIGNIFICANT OTHER CONSENT

In signing and returning this form, I acknowledge that I have read and understood the accompanying Information Sheet and am giving my permission for Angela Dew to contact me for the purposes of research for her Master of Arts (Honours) thesis.

Resident’s Name:

Significant Other’s Name:

Relationship to the resident (eg mother, father, brother, sister, cousin, advocate, special friend):

Address:

Telephone number:

Best days/times to contact:

☐ Yes, I wish to participate in the research.

............................................(signature)..................................(date)

☐ I am unsure at this stage. Please call me so I can discuss this with you further.

Please return this form and the signed consent form (if consenting) to Angela Dew in the enclosed stamped self-addressed envelope. I will then contact you.

Thank you for your assistance.
Appendix 3: Initial Interview Participant Background Information Sheet

‘TARADALE’
MASTERS RESEARCH PROJECT
INITIAL SIGNIFICANT OTHER INTERVIEW

Date of Interview:

Background Information:

Name/s of significant other:

Address:

Telephone Number/s:

Best days/times to contact:

Relationship to person with a disability:

Are you the person/s primarily responsible for making decisions regarding your family member/friend with a disability?

What sorts of decisions have you been making for your family member/friend with a disability?

Name of person with a disability:

Age of person with a disability:

How long has the person with a disability lived at ‘Taradale’?
Where did the person with a disability live prior to living at ‘Taradale’?
Day placement of person with a disability:
1. School
2. Post School Options Programme at ‘Taradale’
3. PSOP elsewhere
4. No day placement
5. Other

Current Involvement with the person with a disability:
Are both parents of the person with a disability involved in the life of the person with a disability?

Do both parents work? (full time/part time)

Do you have other children? (please describe briefly your family situation):

How far away from ‘Taradale’ do you live? (distance and time)

How often do you see your son/daughter/friend with a disability?

Has the amount that you see them changed (increased or decreased) as a result of the devolution process?

Do you take your son/daughter/friend to your home for visits/overnight stays? (how often; duration)
Appendix 4: Follow-up Interview Participant Background Information Sheet

‘TARADALE’
MASTERS RESEARCH PROJECT
FOLLOW-UP SIGNIFICANT OTHER INTERVIEW

Date of interview:

Name of significant other:

Relationship to person with disability:

Name of person with disability:

Where they are now living: (not address just type of accommodation, number of others in house and suburb of house)

How long ago did they move?

One move or more?

Number of people living with them?

Number of staff supporting them?
Appendix 5: Initial Participant Interview Guide

Initial Interview regarding the devolution of ‘Taradale’

Taped Interview – open ended, these questions relate to issues which should be covered over the course of the interview.

1. Announcement of the devolution:

Describe for me what your feelings were when first become aware that ‘Taradale’ was to devolve?
Have your feelings about the devolution changed in the intervening period of time? In what way?

2. Involvement in the planning of the devolution

Tell me what involvement have you had in the planning of the devolution.
Do you feel that you have been involved enough?
How else could you have been involved?

3. Information about the devolution

Tell me who provides you with information about the devolution and does this information provide you with clear information about what is happening?
Are there other things that you want to know which are not contained in this information?

4. Contact and Support

Who do you contact if you are unclear about something or want further information?
Are people available to speak to you when you need to speak to them?
Have you had any contact with the Independent Family Liaison Worker (name person)?
(Can you describe the level and content of this contact?)
Who else/otherwise provides you with support?

5. Current involvement in the devolution

Is the level of involvement you are having in the devolution the level you would like to be having?
Is the involvement you are being asked to have now different to the involvement you have previously had in the life of your son/daughter with a disability? (If so, please describe how it is different)
6. Decision Making and Planning

Do you feel that you are more involved now in the decision making regarding your son/daughter’s life than you have been previously?
What consultation has occurred with you about possible alternatives for your family member when they leave ‘Taradale’? *(Can you describe the process which is occurring?)*
What is being planned for your son/daughter when they leave ‘Taradale’?

Either:

| If you are considering a ‘shared care’ arrangement or are bringing your child home permanently, how do you see this working? |
| Are you concerned about this arrangement? |
| What information have you been given about this type of arrangement? |

OR:

| If your son/daughter will be moving into a group home (or other supported accommodation) how do you think this will impact on your/your family’s life? |
| What information have you been given/do you know about this type of accommodation? |

What (if any) preparation is being done with your family member prior to a move taking place?

Outcomes

What are some of the positive things that have happened for your son/daughter since the announcement of the closure? What are some of the negatives?
Do you think that their planned accommodation option will be the best option for them?
What do you hope will happen for them in the future as a result of this move?
How do you think that the change in their accommodation will impact on you/the rest of your family’s lives?

Thank you

Mention possible re-interview after move.
Appendix 6: Follow-up Participant Interview Guide

Guide for Second Round Interviews

1. Tell me what this past two years has been like for you/your family?
   - Summarize and encapsulate the process. Focus on change, impact on siblings, parents and others. Relationship with ‘Taradale’.

2. What have been the ‘best’ things to come out of the devolution?
   - Focus on positives, achievements, growth, support, control, re-engagement, empowerment

3. What have been the ‘worst’ things to come out of it?
   - Focus on difficulties/problems, barriers to empowerment and coping strategies.

4. What/who has helped you get through this period?
   - Opportunity to reflect on people/processes which have assisted. This might be related to ‘Taradale’ or it might be family, support groups, church etc.

5. How has this experience been different for you than when you first placed ______________ in out of home care? What has made it better/worse this time?
   - Reflection on past experience of similar situation – transition point in person’s life. How does the family deal with these transitions?

6. What is ______________ ’s life like now?
   - Opportunity to tell what person’s life is like – benefits, problems etc. Cover issues such as standard of care, relationship with staff, compatibility, friendships, geographic location, choices, decision making.

7. What does the future hold for ______________ and you?
   - Opportunity to identify how they see life for son/daughter and themselves. Consideration of other transition points in person’s life. Issues such as resilience and adaptation to change. Empowerment.
Appendix 7: Summary of Key Points of Initial Interview

Devolution: How does it impact on significant others?

Angela Dew
MA (Hons) Student, University of Western Sydney
Summary of Initial Analysis for Significant Others Participants

Aims of the Research
- To identify the extent to which significant others have been involved in the planning and execution of the devolution;
- To comment on the possible re-engagement and empowerment of significant others throughout the devolution;
- To provide significant others involved in future devolutions with indicators of what they should be aware of throughout the process.

About the research
The research is being conducted for my thesis for a Master of Arts (Honours) from the University of Western Sydney. My decision to conduct research in this area has come about as a result of other work on deinstitutionalisation conducted by Tim Griffin and myself (including the evaluation of the closure of the Hall for Children) and studies in this area conducted by others e.g. Young, Ashman, Sigafoos, & Grevell, (2000) on the closure of the Challinor Centre.

Participants in the research
Eight consenting significant others (from the 38 residents then living at the institution managed by Taradale) responded to a mail out requesting participants and initial interviews were conducted with six people:

- Four (4) fathers and one guardian of four (4) male and one (1) female residents of Taradale ranging in ages from 5 yrs to late 20 years old;
- One (1) advocate of a female aged in her thirties.

The other two consenting people were not able to be interviewed due to their personal circumstances. A Board member and staff member were also interviewed.

The tape-recorded interviews were transcribed into Word documents and printed out. I then conducted analysis of the transcripts using a Grounded Theory approach. Five interviews were eventually used in the analysis as the advocate’s view lacked a personal knowledge of the person with a disability providing a more systemic advocacy view which has been incorporated into the background information provided by staff and the Board.
Preliminary Analysis

Five major themes have emerged from the analysis of the initial interviews conducted with five participants. Given the small number of participants included in the research, these themes cannot be said to be universal amongst the family members of people living at the institution managed by Taradale, however these themes emerged consistently amongst those interviewed and this lends some weight to the view that they may be representative of the views of some of the other significant others (who did not consent to participate in the research). The themes to emerge were:

1. **The positive relationship between parents/guardians and ‘Taradale’**

   “Devolution? You go hell, what are we going to do?”

   The majority of those interviewed spoke in glowing terms about Taradale. There was an evident sense of pride in the organization, trust and support for the organisation’s ongoing involvement with their son/daughter. Participants reported feeling more comfortable with the devolution because of the organisation’s continued involvement in providing a service to their son/daughter and they were keen to see the organization grow and prosper after the devolution so that this involvement would be assured. However, one person interviewed was dissatisfied with their interactions with the organization in relation to the future plans for their son/daughter. This parent saw Taradale and the Department of Ageing, Disability and Home Care (the NSW government department which is overseeing and funding the devolution of Taradale) as one in the same and reported his involvement with them as “a constant battle”.

2. **A lack of trust in government**

   “The money that’s being splashed around is not good…..when you think of some other families that are in such need”

   All of those interviewed expressed disillusionment and disappointment with the ‘bureaucracy’ of government which they believed gave mixed messages, played ‘games’ and historically had under-funded the organisation. Participants believe that they cannot influence what government will do, “I only wish there was something else we could do but we can’t so why fight it? Just go with the flow”, and expressed concerns about the high cost of the devolution, the waste of money by government and especially the long-term viability and sustainability of services to their son or daughter due to the propensity for government to “change its mind” and engage in “knee-jerk reactions” – this was seen to be contradictory and confusing behaviour on the part of government.

3. **The importance of quality of life, communication and continuity of care for their sons/daughters**

   Participants spoke about the poor physical health, frailty and high support needs with limited verbal skills of their sons/daughters, which necessitate special equipment and housing; medical interventions and increasing levels of care over time due to physical degeneration including the need for pain management and palliative care. “He/she has
osteoporosis so badly that he/she can have spontaneous fractures just from not being placed correctly (in wheelchair)”.

Issues related to the ageing of residents were also discussed by some participants with implications for the level and intensity of support able to be provided to their son/daughter as they got older. Participants did however see positives to community placement in terms of quality of life measures, they saw the separation of children from adults as very important for both age groups; they saw positives in residents having their own space and more individual time due to the smaller staff to resident ratios, and they hoped for greater social interactions and community access with more opportunities for choice making.

4. The impact of the devolution on the personal lives of the family

Participants discussed their lifelong involvement and commitment to their family member with a disability – a change in accommodation such as this devolution, removes some of the certainty regarding the person’s future and causes family members to become stressed about their and their family member’s long term prospects. Participants discussed competing issues such as distance and the constraints this placed on their ability to visit regularly and maintain a high level of input; poor health resulting in a need to “pull back” from more intensive involvement with both their ‘child’ and the organization; work pressures of running a business and other family members with siblings of the disabled person particularly mentioned by a few of the families.

5. Support for the current staff working at ‘Taradale’

All the participants believe that the current staff know the residents well, understand their needs, are able to communicate with them and in many cases have relationships with the residents built up over many years. This was seen to be a positive which may not be transported to the community settings. Participants were also concerned that the relative isolation of a group home in the community would result in isolation for both residents and staff and the lack of supervision and support for staff may result in lower quality care for residents. The institutional setting was seen to provide a measure of security against abuses to residents (there are always other people around to see what is happening). “It’s the security in knowing that you’ve got good staff and you’ve got enough there to see what is going on….I’ve seen it is some group homes…..the staff changed as often as you change your underwear”. Family members felt re-assured that current staff from Taradale would be employed in community settings.

The future

These five emerging themes and issues raised in an extensive review of the literature on families and empowerment have formed the basis for a second interview with some participants.
Appendix 8: Example of a Participant Interview Transcript

‘Taradale’
Significant Other Initial Interview
4/6/01
‘Bill’

Interviewer: Angela Dew
Interviewee: ‘Bill’

How long have you been on the Board?

About 11 years.

And were you there when the initial Transition Plan was put in place?

Yes.

How much involvement did you have in development of that plan?

Board don’t do that much in the way of leg work for it – you just look at the end result.

So you would have been involved in approving that plan?

Yes.

What were your feelings about that initial plan?

Make a home for the older children – it was one option. DADHC will not give this as an option. Said this is the way it will go – they talk about options but they are not giving options. Have to do it their way now. I’ve had a child in boarding school with 13 other kids in one room not even divided but here we are with children needing a lot of care and we can’t even care for them that way. I don’t mind the group home concept either, I think it is a really good deal and I think the kids will benefit from it but my greatest fear is who is going to pay for it? Over the last 12 years I’ve seen that many group homes start and fall into disrepair because of the funding. My biggest fear is, who pays for this? It is really a high cost option and I don’t know whether the government can sustain it.

So when did you first become aware that the government was to devolve Taradale rather than to expand on the site next door?

Taradale is going to expand anyway into group homes but still under the same umbrella. There will be more staff. It will be spread around the place. When did I become aware of it? I guess when we were told that Taradale would be the first cab off the rank.
As a Board Member would you have been aware of this before some of the other parents would have known about it?

Yes, but not that much before – would have only been a matter of days.

What were your feelings about that when you heard that? Do you remember? Were you pleased that that was going to happen or sorry that the other plan was not going to work?

We sort of expected that that was the way it was going to go. Shocked that it happened that quick but OK we’ll go down that path. But I still have reservations – it is a high cost scheme and there are more needy people who could do with those dollars. The dollars will only help a select few not the whole lot, the whole range. I suppose we are lucky that we have access to those dollars at the moment to set it up but that’s not the ongoing costs. There are plenty of dollars there to set it up, to get it off the ground which is good and it’s exciting – the Board’s having an exciting time but it still worries me looking 5 or 10 years down the track – it really concerns me because I don’t think the government – it is a political process – it comes back to who’s got the biggest voice whose got the most people? We are in the minority and will be soaking up huge amounts of money to keep these homes going.

So what do you see as the options with that?

OK well my idea on that is, I’ve been pushing more this way for a long time – is that we have to consider being self funded in the years to come and – going from a charity organisation with a focus on charity to being a business and changing the strategy of it as a business.

How would you do that? How would you raise money?

With Taradale and the services they currently provide, they are probably the leader in the field in NSW if not in Australia they have assets that they can sell, they have skills that they can sell. They have post school options program. You don’t run it as a charity anymore you start making it so that it is funding itself. They have also got the seating service that could make a return for Taradale. There are a lot of those areas that we have expertise in. We have palliative care. See it’s starting to turn the corner and we are starting to look at our business and that’s what we were doing when this thing bowled us over. We had set up a group to look at future directions and which way we were going to push this company. Oh yes, it’s very exciting and it has been put on the back burner but there’s a lot of work that has been done and lot of directions we are going to go in but it is slowly happening.

Do you feel that most of the Board thinks this is the right way to head?
Oh I think they all do – they can see. There are only a couple of parents left on the Board. Most of them are business people so they can see it they know the writing is on the wall and we will have to be self funding. So, yes, it’s getting there.

So, as you say, the Board is not involved in the day to day management of things.

Nor should they be.

What has been your involvement in the planning for the devolution? There are a number of committees set up I know, have you been active on these?

Devolution – you go hell, what are we going to do? We need properties, we need this, we need that so basically it is a big think tank and out of that comes what direction you are going to go it – buying a block of land, someone looking at plans, someone looking at houses. Most of that is S but she has support from P and some of the parents – some have been evaluating the houses um how are we going to run them? Looking at plans and procedures for how they will be run. How will we have communication between the houses? All those things start to drop out - what sort of design do we want in a house? I think I was involved in that I sat down and started putting ideas down so that people could throw darts at them – something to start from.

And was that through this committee process rather than at an actual Board meeting?

Future Direction Committee which has taken on this devolution process as well and there is not enough people to run both the devolution process and future directions. There is simply not enough people to go around. We recognised that we had to put one of them on the back burner which was future directions but we have still got to keep looking at that and that is something we do to make sure that we haven’t forgotten about it. If you go out and look at J’s blackboard sometime – just on future directions you can fill up a whole wall without even looking at devolution. There are still a lot of things still happening but they are not a priority. The priority is devolution. Mainly because of the timeframe. I don’t think we are going to get to the timeframe anyway but I don’t think anyone could simply because it is so long a process to find a house that is suitable and then modify it.

It’s better if you’ve got the time to take the time isn’t it?

It makes people want to get on and do it but when you sit down and analyse a time line properly you find that you can’t you just simply haven’t got the resources to do it in that time or you would be very lucky. You still have to run the business, you still have to run the home. You just can’t leave the home otherwise people would take a nose dive. Like things for um, OK we are going to have group homes – we are going to need more staff, what do the staff think? The feedback from the staff is that they are all edgy because they think they are going to lose their jobs but they can’t see so part of the process is feeding back information to the staff saying hey, you guys we need more staff and more qualified staff so they are starting TAFE courses.
So, do you feel that you have had enough involvement in the process?

Only because of where I sit on the Board. If I was a parent outside, I couldn’t answer that question. I have been involved in the process all the way.

I guess you have a different perspective because you wear both the hats?

And I do that because it is the only way that I can put something back in rather than taking all the time. It costs me absolutely nothing to have Bob up there since he turned 18 and even before then it was the only way that I could put anything back into the system to ensure that he was looked after.

Have you been on the Board a long time?

Ah 11 years and Bob has been up there 12 years.

You have certainly seen some changes?

I think there are only two of us left.

Again, this will be a bit different for you because of your position on the Board but who is providing you with information about devolution?

Newsletters. S.

So are you getting any information directly from DADHC or is it all coming through Taradale?

No, all through Taradale.

Do you think that is good? Does this make your identification with it stronger?

I don’t think DADHC has the skills to talk to families at this level. I think most people have confidence in S which is part of Taradale you know? It is more of a personal relationship that I think people build up with the person doing the job. I think that if DADHC came in you’ve got none of those personal relationships built up at all it’s a total stranger.

It’s a good point. So the information you have been getting is clear and has let you know what has been happening at each stage?

Yes.

Are there any things that you want to know about that you haven’t been told?
No. I see it all coming anyway or most of it.

So who do you contact if you need further information or you need to talk about it?

I’d go to S. No good ringing J because J would not have it down to that level of knowledge.

And you find that S is available whenever you want to speak to her?

Yes.

Have you had any contact at this stage with the Independent Family Liaison Worker, LX?

No. Why?

Has she phoned you?

No, what is she going to do for me? I think it gives the Department a nice, warm fuzzy feeling that they are doing something right in monitoring the process I suppose. As for the process of devolution happening, that’s being driven by Taradale and driven by the Board – which avenues they should go coupled with S and J’s experience and the contacts that they make in visiting other places that have started the process or have been through the process – trying to avoid the pit falls.

Do you think that is being fed back to other family members or are you hearing that because of your position on the Board?

That I really think it’s probably because I’m there and I don’t know whether other families would benefit from knowing any of that. I mean most of them are flat out with just day to day living and getting on with their lives let alone getting bogged down in that side of things and a lot of families go down that path, you leave your child up there, I was one that said I wanted to get involved but it’s very easy to ignore that side of it and just access the service because it’s a nice place for your child to live and it’s a lot of worries off your mind. If you have a child for awhile at home and then you don’t have that child there all of sudden you go how the hell did I cope full time and really you get on with your life and a lot of families don’t not care about their child but they find it very hard to go back. You go through cycles and you can’t judge anyone for what part of the cycle they are in but.

That’s very interesting for me from the point of view of this whole process then opens this up again because it makes you look then at what is going to happen.

Oh yea, yea you’re just getting things sorted out because you think that child, or whoever it is is going to be there for life and all of a sudden out comes the mat and you are into the unknown again.
So in terms of what is going to happen for Bob, a group home is being looked at for him?

Yes.

And is that one of the first houses?

*It will probably be September.*

And is that going to be a purpose built place?

No. *There is only going to be one of those at this stage. It’s too hard to find the land and reading the current newsletter it would appear now that people are now coming to the realisation that it is going to happen that they are getting a lot of requests to bring the children closer to their family home. That’s what I read in the newsletter. So, I would say that we will probably be looking at what we need to do to set that up. We’ve accepted that that is what is going to happen. We didn’t think that it would happen this quick. Just reading between the lines people going to want them off the mountains and closer to them and there a couple of options there. You have to look in the local area and see what is available see what services are there or do we set up our own service that is run through Taradale?*