MOVING OUT: THE IMPACT OF DEINSTITUTIONALISATION ON SALIENT AFFECTIVE VARIABLES, SOCIAL COMPETENCE AND SOCIAL SKILLS OF PEOPLE WITH MILD INTELLECTUAL DISABILITIES

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Dedicated to:

My parents

Brigadier Ronald Prussing

and

Brigadier Mrs (Emma) May Prussing

*For giving me a love of learning and encouraging me to accept the opportunities that they never had.*

and

Dr Robert John Dixon

*Beloved husband, best friend and partner in all aspects of my life, intellectual and spiritual mentor, lifelong inspiration*

And to my cherished sons

Jason Robert Richard Dixon

and

Justin John Ronald Dixon

*The brightest stars in the firmament of my life, bringers of great joy, whose bravery and strength gave me the inspiration to carry on, through the harshest times.*
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DECLARATION

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

..................................................

Roselyn May Dixon
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<th>Description</th>
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<tr>
<td>AAMR</td>
<td>American Association for Mental Retardation</td>
</tr>
<tr>
<td>AAMR-ABS</td>
<td>American Association for Mental Retardation-Adaptive Behavior Scale</td>
</tr>
<tr>
<td>ANS-IE</td>
<td>Adult Nowicki-Strickland Internal-External Scale</td>
</tr>
<tr>
<td>BFPLE</td>
<td>Big Fish Little Pond Effect</td>
</tr>
<tr>
<td>CNS-IE</td>
<td>Childrens Nowicki-Strickland Internal-External Scale</td>
</tr>
<tr>
<td>ComQol-I5</td>
<td>Comprehensive Quality of Life Scale-Intellectual 5</td>
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<td>SDQ III</td>
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ABSTRACT

Social competence and affective development (self-concept, self-esteem and locus of control) of people with intellectual disability has been valued as a desirable goal and is seen as the crucial variable in the attainment of full integration into the community. Although there is agreement that deinstitutionalisation has been beneficial for people with intellectual disabilities, it is recognised that social integration has not been achieved. As a consequence, many people lead lonely, isolated and socially restricted lives.

This thesis examined the social competency and affective functioning of people with mild intellectual disabilities through salient variables that impact on people with disabilities who have been deinstitutionalised. Its primary purpose was to extend the previous research on the impact of deinstitutionalisation by incorporating multi-dimensional self-concept, adaptive behaviour and quality of life, in combination with, self-esteem and locus of control, in a longitudinal/comparison design. It also aimed to examine the development of identity, self-esteem and social competencies from a qualitative perspective. Finally, it assessed the efficacy of an interpersonal cognitive problem-solving intervention which incorporated techniques for the development of maintenance and generalisation, and determined the impact of this intervention on real-life social behaviours.

The first study assessed the impact of deinstitutionalisation on multi-dimensional self-concept, self-esteem, locus of control, multi-dimensional quality of life and five factors of adaptive behaviour. Two groups of participants were the focus of this study. The first were people with intellectual disabilities who were moving into the community (Movers). The control participants were a second cohort who remained in another institution (Stayers). This study found that (a) for the multi-dimensional self-concept instrument (SDQ-III) there were significant changes in academic, physical appearance and emotion facets of multi-dimensional self-concept; (b) for quality of life as measured by the ComQol-I5 there were significant changes in the Objective Community and Objective Material and Subjective Material and Subjective Safety domains; and (c) there were also changes in adaptive behaviour as determined by the AAMD-ABS for three of the five factors. This first study
demonstrated a consistent pattern of results amongst the different constructs; there was no advantage gained by remaining in the institution and the advantages of deinstitutionalisation were exhibited in some facets of self-concept, some domains of quality of life and in major areas of adaptive behaviour.

The second study examined the development of social competency and self-esteem in five women with intellectual disabilities who were judged to be socially competent. It used a qualitative methodology to explore the development of the identity, socialisation and self-esteem of five women. The participants were a subset of the participants in Study 1. The results showed that a lack of socialisation experiences was the primary reason for the lack of social competencies and skills exhibited by the participants and that this lack of socialisation also had an impact on their self-esteem. The participants’ self-esteem had improved on moving to the community, lending support to Goffman’s theory of stigma rather than to social comparison theory in predicting the direction of the change. The women were using the same coping strategies they had used in the institution and these strategies seem to be utilised to protect self-esteem.

Finally, the third study reported on the design and implementation of an intervention to increase the social skills of people with intellectual disabilities, whose community placement was considered to be vulnerable because they exhibited challenging behaviours. It used a single subject multiple baseline methodology across pairs of subjects, to assess the impact of a social cognitive problem-solving technique on improving challenging social skills where the emphasis was on generalisation to the community and maintenance over time and generalisation to real-life social behaviours. Target behaviours chosen for intervention were idiosyncratic to each participant.

These findings have important implications for current theory of the self-concept for people with intellectual disabilities, the provision of programs and techniques to improve self-concept, and also for the provision of social skills programs to enhance the social competencies and hence, the social integration for people who have been deinstitutionalised.
CHAPTER 1

Introduction

Social competence and affective development (self-concept, self-esteem and locus of control) of people with intellectual disability have been widely valued as desirable goals and are frequently seen as crucial variables in the attainment of full integration into the community. However, although there is now wide recognition of the rights of people with intellectual disabilities to be fully integrated into the community, there have been few attempts to examine the impact of deinstitutionalisation on the affective development and social competence of people with mild intellectual disabilities. Although the consensus both here and overseas is that the physical placement of people with intellectual disabilities away from institutions and into the community has been largely beneficial, there is still an acknowledgement that social integration has not been achieved and that many people continue to lead lonely, isolated and socially restricted lives. Therefore, despite the acceptance for many years of the principles of normalisation, social role valorisation and deinstitutionalisation, there is some dissatisfaction with the outcomes, particularly in the area of social integration.

Historically, the principles of normalisation combined with the civil rights movement of the 1960s led to the deinstitutionalisation movement. One consequence of this movement has been to revolutionise service provision for people with intellectual disabilities. This has been reflected in the considerable effort in many Western countries to relocate persons with intellectual disabilities from large congregate institutions to smaller community-based facilities or into independent living environments. For example, in the U.S.A. over the past three decades, the significant reduction in the number of people with an intellectual disability living in large institutions has been associated with a corresponding growth in community-based living arrangements (Lakin, Braddock & Smith, 1994, 1995; Larson & Lakin, 1989). These trends have also been observed in the United Kingdom and many other European countries (Emerson & Hatton, 1996; Hatton, Emerson & Kiernan, 1995; Pedlar, 1990). In Australia, the deinstitutionalisation of people with intellectual disabilities and the development of community-based services began later than
elsewhere in the world and progressed more slowly than in either the UK or USA (Molony & Taplin, 1988; Young, Sigafoos, Suttie, Ashman & Grevell, 1998). In fact, the first integrative review for deinstitutionalisation using only Australian studies was published in 1998 (Young et al., 1998). However, most Australian states have now embraced the philosophies of normalisation, social role valorisation and deinstitutionalisation and are currently reviewing the provision of residential services for people with intellectual disabilities.

The integration of people with intellectual disabilities into the local community forms the essence of normalisation, “enabling people with disabilities to attain that which most non-disabled people expect as of right” (Brown & Smith, 1992, p.174). The provision of residential services in smaller community-based homes, which is the most common residential option under the new policies, is consistent with the principles of normalisation and social role valorisation. These two principles provide the underlying philosophical framework for the provision of many contemporary services in the field (Young et al., 1998) both in Australia and overseas. Smaller community-based services were implicitly mandated to provide the supports necessary to effect the integration of people with intellectual disability into the mainstream of society (Emerson & Hatton, 1996).

The process of supported physical and social integration in these smaller facilities was to provide the mechanism by which people with intellectual disabilities could experience the autonomy, choices, freedoms, dignity, respect and independence given to more valued members of the community. Integration has become almost synonymous with an increasingly independent lifestyle, based on the assumption that being placed physically in the community will automatically lead to being enabled to participate in community life (Carnaby, 1998). Therefore, the rationale for deinstitutionalisation was that it would lead to a substantial improvement in the quality of life experienced by people with intellectual disabilities. More specifically, it has been thought that there would be increases in adaptive behaviour and decreases in the likelihood of abuse and neglect (Blatt & Kaplan, 1966; Conway, Bergin & Thornton, 1996; Horner, 1980; Sobsey, 1994a; Thompson & Grabowski, 1972). It was also assumed that deinstitutionalisation would improve the social competence of people with intellectual disabilities and impact positively on related personal affective
One of the goals of deinstitutionalisation, that of physical placement in the community, has been achieved. However, although it is practice now to house people with intellectual disabilities within the community, the second goal of deinstitutionalisation, that of social integration, still needs to be accomplished. Szivos (1991a) emphasised that if we are to move away genuinely from the segregated institution model then we will have to focus on social integration and the formation of social networks and social relationships. Szivos (1991a) building on Festinger (1954) has used the nature of particular psychological processes to argue for a more critical approach to social integration of people with intellectual disabilities as a strategy. Difficulty with loneliness and low rates of social interaction have been identified as special problems among people with developmental disabilities. In fact, the lack of social interaction after the move to the community has been seen as a major source of dissatisfaction by these people (Jahoda, Cattermole & Markova, 1990). Results of several studies on their adjustment in the community setting suggest that personality and social behaviour are among the key variables that may affect successful adjustment.

The term social behaviour/social competence covers a number of variables such as personality characteristics, emotional stability, interpersonal behaviour and social skills (Gresham & Reschly, 1988). There is considerable evidence that poor social competence is an important variable, at least partially independent from IQ, that influences the behaviour of people with an intellectual disability (Wilson, Seaman & Nettelbeck, 1996). Poor social behaviour also has a major role in determining their quality of life (Greenspan, 1981). For Greenspan (1981) poor social competence is shown by a reduced ability to interpret behavioural cues, and the inaccurate attribution of motives and intentions of others. There can also be difficulties when evaluating alternate outcomes, and other empirical evidence suggests that people with intellectual disabilities have difficulty in generating alternative reactions when the specific situation has changed. Mathias (1990) has criticised Greenspan’s interpretation of social competence as too restrictive and suggested that this approach needs to be supplemented with other measures that relate to the practical-interpersonal competencies construct such as self-concept, self-esteem, locus of control and social
skills. Brown and Goldenberg (1993) called for the extension of evaluation in this field to incorporate the domain of psychological well-being.

Self-concept, self-esteem and locus of control have been considered to be important variables of psychological well-being. For people with mild intellectual disabilities, a strong relation exists between self-concept and acceptance of disability (Li & Moore, 1998) and low self-esteem is associated with impoverished social relationships. Self-identity, confidence and feelings of worth influence the way an individual interacts with the environment. Participating fully in society and being accepted by others requires a positive self-concept. Therefore, if people with disabilities are to achieve social integration it is imperative that there is a better understanding about the impact that deinstitutionalisation may have on their self concept, self-esteem and locus of control. Even though self-concept, self-esteem and locus of control are so crucial to the implementation of these policies, they have largely been ignored. Few studies, apart from the personal control paradigm emanating from Wehmeyer (1996) and his co-workers, go beyond the measures provided by the relevant subscales of the Adaptive Behaviour Scale (Mathias, 1990) or Quality of Life domains (Brown & Goldenberg, 1993).

People in all mild disability groups can exhibit deficient social skills and problem behaviours (Gresham & Macmillan, 1997). It is ironic that social competency deficits are used as one criterion in identifying people with mild intellectual disabilities. However, effective programs for teaching social skills have not yet been found. Socially related problem-solving ability is one of the components of social competency. A promising area of development is social-cognitive problem-solving interventions that have been implemented in vocational settings (Gow, Dixon, Balla, Dixon & Bader, 1994). As yet the application of such interventions in the community setting have not been developed and evaluated empirically.

More generally, research has found that when people with intellectual disabilities are moved from institutions into smaller community-based services, positive outcomes have been recorded (Emerson & Hatton, 1996; Larson & Lakin, 1989; Young et al., 1998). However, positive outcomes have not been always followed deinstitutionalisation. It is now being recognised that mere placement in the
community is not always sufficient (Jahoda et al., 1990). Individual characteristics of clients and the nature of the services received in the community may be very significant to maintaining normalisation and social role valorisation. One of the areas that has consistently been found to have an impact on community-based living is the social competencies and affective functioning of people with intellectual disability (Ralph & Usher, 1995). Given the recognised importance of social competencies and affective functioning, it is surprising that these have not been the focus of more research in either the Australian or overseas context. Although there is extensive recognition of the importance of assisting people with disabilities to develop and maintain satisfactory social lives, there is very little empirical evidence to guide families, service providers and researchers (Carnaby, 1998). This lack of authoritative feedback into policy making and implementation is problematic. Reviews of the few exemplary studies in this area of research have found consistent trends for a positive impact of deinstitutionalisation, particularly in the areas of adaptive behaviour and quality of life (Emerson & Hatton, 1996; Larson & Lakin, 1989). However, much of the research to date in these two areas has been seriously flawed. In the vast majority of studies investigators have failed to collect data in the prelocation environment, collected data at only one point in time or just after the move, or involved no comparison groups. These methodological flaws seriously impair the conclusions that can be drawn from these studies. The use of small sample sizes, unrepresentative samples and the collection of a restricted range of outcome data of unknown reliability and validity continue to plague this area of research (Emerson & Hatton, 1996). Few research studies have utilised either a longitudinal design or a comparison group and this limits the validity of the reported studies. Only a limited number of studies, and none in Australia, have utilised a range of instruments to evaluate a large number of psychometric and other variables. No study has used a multidimensional self-concept instrument with adults. This thesis addresses some of these deficits.

Social competence is a complex concept and applying this concept to the study of people with intellectual disabilities dictates that the research design must also be complex. This is because it is not always possible to apply the same principles of validity and reliability to this population as they may acquiesce, respond with response sets or not have the necessary linguistic abilities to interpret items beyond face value. This thesis examines the social competency and affective functioning of
people with mild intellectual disabilities through examining salient variables that impact on people with disabilities who are in transition, that is, older adults moving from institutionalised living to independent programming and community housing. Its first purpose is to extend the previous research by incorporating adaptive behaviour, quality of life, in combination with self-concept, self-esteem and locus of control. A second purpose is to examine, in depth, the development of social competency and the self in a small group of people with intellectual disabilities who are socially competent. The insights gained from these two aspects of the study are then used for the third purpose, that of designing an intervention to increase the social skills of people with intellectual disabilities. The research should provide information that will aid the transitional process by allowing service providers to aid social integration by developing programs that will enhance social competence. This thesis aims to address some of these issues by (a) critically evaluating the impact of moving into the community on the affective variables of adults with intellectual disability in comparison with a group who stayed in an institution; (b) identify the psychological and external factors that impact upon the perceived social competence of adults with intellectual disabilities who have recently moved to the community; and (c) elucidate which of two competing paradigms—stigma or social comparison theory—had greater saliency in relation to the impact of deinstitutionalisation upon the self-concepts and identity of adults with mild intellectual disabilities.

To address the aims of the investigation three complementary studies were devised with each of these interconnected studies using differing methodologies. The first (Study 1), has a longitudinal/comparison group design that examines the impact of deinstitutionalisation across the traditional areas of quality of life and adaptive behavior, and the more salient variables which have been shown to have an important impact on social competencies in the regular population (multidimensional self-concept, global self-esteem and locus of control). Study 2 uses a qualitative, ethnographic methodology to explore the development of social competencies and the self in a subset of participants engaged in Study 1. Study 3 employs a multiple-baseline methodology to assess the effectiveness of a cognitive social-skills intervention to improve the social skills of five participants in their living situation and the community.
The present investigation was designed to avoid some of the limitations of previous research by (a) capitalising on advances in self-concept theory, research and practice; (b) utilising multidimensional self-concept measurement instruments and a range of reliable instrumentation to evaluate a large number of psychological variables; (c) employing a longitudinal research design; and (d) utilising a synergistic multi-method research methodology employing both quantitative and qualitative methodology to fully investigate longitudinally the impact of deinstitutionalisation.

Although deinstitutionalisation is established and accepted, for many people with intellectual disabilities, physical integration has not been followed by their social integration. The research in this thesis may assist service providers to aid in the social integration of their clients by developing strategies to improve their social competence.
CHAPTER 2
Theoretical Perspectives:
An Overview of Deinstitutionalisation, Normalisation, Stigma Theory, Social Comparison Theory and Interpersonal Cognitive Problem-Solving Theory

Introduction

The final decades of the twentieth century have witnessed profound changes in how Western society views and cares for people with intellectual disabilities with a major change wrought by the deinstitutionalisation movement. This movement has encouraged a change in social policy that has resulted in many people with intellectual disabilities transitioning from an institution to a community-based setting. This chapter establishes the historical and philosophical basis of the deinstitutionalisation movement. First, the principles of normalisation and social role valorisation, guiding principles for the revolution in the provision of services for people with intellectual disabilities, are described in an historical context. Secondly, two opposing theoretical perspectives, stigma/labelling theory and social comparison theory, are described. These theories offer competing predictions in regard to the impact of deinstitutionalisation on the self-concepts of people with intellectual disabilities. Finally, the chapter concludes with a justification for the use of social cognitive problem-solving intervention as a powerful yet adaptive and simple technique for social skills interventions for people with mild intellectual disabilities who wish to live in the community.

Historical Overview

In the past, care of people with disabilities has been associated with paternalism, custodianism, punitive medical care, and discriminatory legislation often justified by the theory of Social Darwinism (Westbrook, Legge & Pennay, 1993). Consequently, it was widely assumed that people with intellectual disabilities had to be removed from the general population so that their genes would not be spread to the wider community. Dokecki, Anderson and Strain (1977) have also argued that the exclusion of people with disabilities resulted from the rise of capitalism with its emphasis upon individualism, achievement and independence (Westbrook et al.,
People with disabilities were not seen as contributing members to the new social order.

**Deinstitutionalisation Movement**

The civil rights movements of the 1960s, plus a valuing of the principles of normalisation (see later discussion), led to the current deinstitutionalisation movement (Emerson, 1985). Deinstitutionalisation has been characterised as an ideologically-committed social movement that is dedicated to the dignity of individuals and aims to improve the quality of life experiences of people with intellectual disabilities (Emerson, 1985). The essential goal of the deinstitutionalisation movement was the reversal of societal and personal devaluation experienced by people with intellectual disabilities as members of a devalued group (Wolfensberger, 2000). Before the principles of normalisation were developed and the policy of deinstitutionalisation was established, people with intellectual disabilities were stigmatised as deviant and devalued (Goffman, 1961). This characterisation was another justification for segregating people with intellectual disabilities and placing them in congregate care within institutions.

**Normalisation and Social Role Valorisation**

Normalisation is the provision of a lifestyle for people with an intellectual disability that is as close as possible to the cycle of life events that is appropriate for other people in that culture (Nirje, 1970). The principles of normalisation for people with mild intellectual disabilities first began with a seminal statement by Nirje (1970). Nirje’s statement inspired the normalisation formulation by Wolfensberger (1972). A more detailed exposition of this concept can be found in Wolfensberger and Glenn (1975). Although the normalisation formulation was the basis for service provision for people with intellectual impairment, its significance and validity has been extensively debated (Mittler & Sinason, 1996; Simpson, 1998). Social role valorisation has now overtaken the principle of normalisation in the field of intellectual impairment.

Social role valorisation is a “high-level and systematic schema based on social role theory” (Wolfensberger, 2000, p.105). It evolved from normalisation principles (Wolfensberger, 1983) but Wolfensberger (2000) claims that the concept has changed
so much that it should not be seen as a form of normalisation. Its key premise is that people’s welfare is dependent on the social roles they occupy. Traditionally, people with intellectual disabilities have been given roles of less value than others in society. People who fill roles that are positively valued in our society are given rewards, while those who are devalued may be badly treated. This implies that the life conditions for people with intellectual disabilities will not improve until the social roles they are seen to have can be upgraded. In discussing social role valorisation, Wolfensberger (1983) argued that a primary goal of human services should be the development of valued social roles.

The literature on normalisation and social role valorisation is vast and has been extensively reviewed by a number of authors including Flynn and Lemay (1999) and Wolfensberger (2000). Although there have been criticisms of the concept of normalisation and social role valorisation and the way these concepts have been operationalised (Simpson, 1998) there can be no doubt as to the important influence these concepts have on policy and service provision. These two principles provide the underlying philosophical framework for the provision of many services in the field of intellectual impairment (Young et al., 1998) both in Australia and overseas.

Normalisation has its theoretical roots in sociology; its most prominent theorist Wolfensberger has stated that it is in accord with Goffman’s (1961) attacks on institutions. In particular, the development of the interactionist deviancy and labelling theory provided a great deal of support for the deinstitutionalisation movement. Goffman’s (1961) seminal work, Asylums, had a major impact in providing a critique of institutions and the basis of the social model of deviant behaviour. As Wolfensberger noted, “in essence prevention and reversal of deviancy are what…normalisation is all about” (Wolfensberger, 1972, p.25).
Impact of Normalisation and Social Role Valorisation

One consequence of this movement has been to revolutionise service provision for people with intellectual disabilities. This has been reflected in the considerable effort in many Western countries to relocate persons with intellectual disabilities from large congregate institutions to smaller community-based facilities or into independent living environments. For example, in the US over the past three decades, the significant reduction in the number of people with an intellectual disability living in large institutions has been associated with a corresponding growth in community-based living arrangements (Lakin, Braddock & Smith, 1994, 1995; Larson & Lakin, 1989; Prouty & Lakin, 1996). These trends have also been observed in the United Kingdom and many other European countries (Emerson & Hatton, 1996; Hatton, Emerson & Kiernan, 1995; Pedlar, 1990).

In Australia, the deinstitutionalisation of people with intellectual disabilities and the development of community-based services began later than elsewhere in the world and progressed more slowly than in either the UK or US (Molony & Taplin, 1988; Young et al., 1998). In fact, the first integrative review for deinstitutionalisation using only Australian studies was published in 1998 (Young et al., 1998). However, most Australian states have now embraced the philosophies of normalisation, social role valorisation and deinstitutionalisation and are currently reviewing the provision of residential services for people with intellectual disabilities (Young et al., 1998).

The provision of residential services in smaller community-based homes which is the most common residential option under the new policies, is consistent with the principles of normalisation and social role valorisation. Smaller community-based services were implicitly mandated to provide the supports necessary to effect the integration of people with intellectual disability into the mainstream of society (Emerson, 1985). The process of supported physical and social integration in these smaller facilities was to provide the mechanism by which people with intellectual disabilities could experience the autonomy, choices, freedoms, dignity, respect and independence given to more valued members of the community. Integration has become almost synonymous with an increasingly independent life style, based on the assumption that being placed physically in the community will automatically lead to
being enabled to participate in community life (Carnaby, 1998). The rationale for deinstitutionalisation was, therefore, that it would lead to a substantial improvement in the quality of life experienced by people with intellectual disabilities. More specifically, it was thought that there would be increases in adaptive behaviour and decreases in the likelihood of abuse and neglect (Blatt & Kaplan, 1966; Conway, Bergin & Thornton, 1996; Horner, 1980; Sobsey, 1994a, b; Thompson & Grabowski, 1972). It was also assumed that deinstitutionalisation would improve the social competence of people with intellectual disabilities and impact positively on related personal affective characteristics such as self-concept and locus of control.

One of the goals of deinstitutionalisation, that of physical placement in the community, has been achieved. However, although it is practice now to house people with intellectual disabilities within the community, the second goal of deinstitutionalisation, that of social integration, still needs to be accomplished. Szivos (1991a) emphasised that if we are to genuinely move away from the segregated institution model then we will have to focus on social integration and the formation of social networks and social relationships. Effective social integration of people with an intellectual disability has been recognised as one of society’s greatest challenges.

Much debate has taken place in recent years over the continuing legacy of normalisation, its significance, validity, and its impact on services. However, although there is still a good deal of disagreement about the ethical and practical implications of some aspects of normalisation, there has been a general agreement about what normalisation is in theoretical terms: namely the sociologies of labelling and deviance combined with humanist philosophies and politics (Simpson, 1998).

**Summary**

Normalisation and social role valorisation principles have had a profound impact on the delivery of services to people with intellectual disability. Although, there is still debate about the implementation and impact on services of these policies, together with stigma theory they have provided a powerful philosophical justification for the deinstitutionalisation movement.
Theoretical Perspectives

Stigma Theory

Deviance theory arose out of the sociological study of crime (Lemert, 1972). This general theoretical approach has also been applied to people who are mentally ill and people with disabilities (Mercer, 1973). The key elements of deviance theory centre around the perceived violation of social norms and the taking on of a deviant social role. The study of this theory relates first to why society relates differently to this person and the second deals with the exploration of a new set of expectations and behaviours which are maintained once the individual has been defined as different.

Social deviance is the dominant paradigm through which sociologists have studied disability since the publication of Erving Goffman’s (1963) classic *Stigma: Notes on the Management of Spoiled Identity*. Goffman highlights the parallels between the social position of people with physical disabilities and that of other socially marginal groups. Susman (1994) defines social deviance as the perception of negative difference and stigma as evocation of adverse responses. Stigma refers to any persistent trait of an individual or group that evokes negative or punitive responses. Erving Goffman’s contribution was to combine these two concepts (stigma and deviance). He was also the first to study this combination in relation to people with disabilities. By joining the concept of stigma to that of deviance, Goffman (1963) made a significant contribution to the study of disability. He argued that stigma is best explained by reference to the notion of deviance, that is, deviation from prevalent or valued norms. Devalued groups are blamed for their flaws and viewed by society as culprits in their condition. Goffman’s theory is, in summary, that society’s adverse responses to people with disabilities, unfavourable images of them, and their own negative self-evaluations are explained by negative difference (Emerson, 1985). Importantly, Goffman sees that deviance is not an inherent property of the individual. A person is not deviant until they are perceived as different and this difference is given a negative connotation by society. It is not the functional limitations that constitute the greatest problems faced by people with disabilities but rather societal and social responses to it. Goffman (1963) contends that non-disabled people experience uncertainty and negative affect in the presence of the stigmatised (e.g.,
disabled) individuals and non-disabled people seek to avoid having stigma spread to them by avoiding close association with a person with a disability.

**Labelling Theory**

From a labelling theory perspective, a person is not intellectually impaired unless they have been labelled by themself or others. The label “mentally retarded” is a formidable stigma with deep historical roots in our community. The formal use of the term then justifies differential treatment. The label and the treatment occur because of the failing to meet certain competence standards expected of non-disabled members of society. Labelling and incompetence are seen as a result of society’s expectations or norms. Another society might not label the behaviour as deviant and thus the person would not be labelled as intellectually impaired. Once the person has been labelled, the person’s life becomes influenced by this label and they may never return to a normal existence. They must also behave in accord with their new social role. Thus they may demonstrate further deviant or incompetent behaviour (secondary deviance) that is a function of their label and differentiated treatment and expectations. This reinforces the label and removes the people further and further from normal social roles (Link, Cullen, Frank & Wozniak, 1987; Link, Streuning, Phelan & Nuttbrock, 1997; Camp, Finlay & Lyons, 2002).

Labelling theory seems to apply more to people in the mild intellectual impairment category. Many of these children are not identified until they reach school age when failure to learn leads them to be labelled as deviant. They may not be intellectually impaired in any other social context and would, for example, not be labelled in societies that do not have universal education.

Being labelled is hypothesised to have a profound effect on people’s identity. Goffman (1963, p.5) argues that people with demonstrable stigma are seen as “not quite human and reduced in our minds from a whole and unusual person to a tainted, discounted one”. In his study of stigma among people labelled “mentally retarded”, Edgerton (1993, p. 132), writes “the label of mental retardation not only serves as a humiliating, frustrating and discrediting stigma in the conduct of one’s life in the community, but it also serves to lower one’s self-esteem to such a nadir of
worthlessness that the life of the person is scarcely worth living”. Although this evaluation might be overly pessimistic, there is substantial evidence that after individuals are labelled there is a decrease in the expectations for behaviour and achievement and this leads to a self-fulfilling prophecy of lowered actual achievement and behavioural outcomes (Ashforth & Humphrey, 1997).

**Research Underpinned by Stigma and Labelling Theory**

Goffman’s contribution to theory has significantly influenced most subsequent social science research in the area. Under this theoretical perspective, any disability can carry with it a stigma. A stigma is not merely a difference but a characteristic that deeply discredits a person’s moral character (Bogdan & Taylor, 1982; Goffman, 1963; Levine and Langness, 1985; Link et al., 1997). Numerous studies have demonstrated how people with disabilities are stigmatised and rejected by society (Bogdan & Taylor, 1982; Edgerton, 1993; Goffman, 1963). Szivos-Bach (1993) states that for people with intellectual disability, their poor sense of self arises from the knowledge that they are part of a stigmatised group.

Using Goffman’s analysis as a starting point, Wang (1992) feels the social production of stigma creates a second affliction in addition to the original condition. Murphy (1987) has found that the four most far-reaching changes in the consciousness of the disabled as a result of the stigma of deviance are: “lowered self-esteem; the invasion and occupation of thoughts by physical deficits; a strong undercurrent of anger; and the acquisition of a new, total and undesirable identity” (p.108).

The classic work of Edgerton (1967) employed participant observation for studying the lives of people with an intellectual disability who had moved out of an institution into the community. The main concern was to identify reactions to stigma based on the concepts of Goffman (1963). In his study Edgerton argued that people with an intellectual disability “denied” their disability and tried to pass for “normal”. Edgerton (1993) also noted that institutionalisation in itself is stigmatising and it was a fact that most of the residents in his study were very ashamed of being institutionalised. For example, in Taylor’s (2000) study, one of his informants referred
to his institution as a criminal institution rather than a facility for people with intellectual disability. Edgerton’s participants who had been institutionalised used any other reason such as epilepsy or learning disabilities to describe themselves and never admitted to being intellectually impaired. Similarly, Zetlin and Turner (1984) indicated that their participants were aware and frightened of being stigmatised. More recently, Abraham, Gregory, Wolf and Pemberton (2002), explored the relations between self-esteem, community participation, age, stigma and social support for adults with intellectual disabilities living in the community. They also, found that self-esteem had a negative association with the experience of stigma.

The relation between stigma and self-esteem is, therefore, reasonably well established. However, little empirical research has actually shown how the social stigma associated with having an intellectual impairment affects the self-concept of the person. Research seems to take stigma, as an active factor, for granted and then studies how people manage it, rather than how it impacts on self-concept.

Some studies have examined the way in which people with disabilities react to the stigma associated with their conditions. Although the stigma paradigm has been influential, other research indicates that stigmatisation is not inevitable. Even if people with intellectual disabilities are aware of their membership of a stigmatised group, they may be able to use strategies that will help them maintain their identity, independent of the stigma, and aid in the development of a positive self (Zetlin & Turner, 1984). For example, Edgerton (1993) reported that people with disabilities engage in coping strategies including deviance disavowal and denial of disability, and tried to pass for non-disabled to cope with their stigma. In addition, Susman’s (1994) research found that people with disabilities use denial and concealment and other techniques to manage socially. Similarly, Becker (1981) felt that coping strategies to deal with stigma develop as part of a normalisation process and that this can be seen as a positive trait even though it leads to the internalisation of a socially devalued identity.

Other strategies to cope with stigma have also been described in the literature. Heyman, Swain, Gillman, Handyside and Newman (1997), using a grounded theory approach, studied six adults with intellectual disabilities who were unable to find
fulfilling social roles. These adults adopted one of two coping strategies in the face of rejection and stigma: fatalism (which they likened to external locus of control) or non-confirmed identities (e.g. fantasising—a role such as adventurer, hero, or lover, which is not reinforced or recognised by significant others). They found that neither of these coping strategies supported self-worth. Another study (Jahoda, Markova & Cattermole, 1988) explored acceptance and noted how some people were able to accept their intellectual impairment, but at the same time rejected the view that this made them less worthy people.

**Zetlin and Turner’s Typology**

Zetlin and Turner’s (1985) widely cited work has also shown that people with intellectual disabilities are very aware of stigma. Zetlin and Turner (1984) produced an extensive typology of how the participants coped with stigma and related the “type” of response to the features of participants’ background and circumstances (see Table 2.1). The extended typology of coping strategies that they developed is currently still being used for analysis of qualitative research with people with intellectual disabilities (Angrosino 1997). In their typology, people with disabilities cope socially by using strategies that they then use to define their self-image. They suggest that there are four possible responses:

1. *Acceptors*—they accepted their disabilities and took all of the blame onto themselves. (Acceptance in Zetlin and Turner’s typology)
2. *Tactical dependents*—these sought out and perhaps even manipulated benefactors who compensated for what they could not do. (Qualification in Zetlin and Turner’s typology)
3. *Blame Attribution*—they acknowledge their disability but blame significant others for their failures. (Vacillation in Zetlin and Turner’s typology)
4. *Deniers*—this group refused to accept their handicap and went to great lengths to prove their competence. (Denial in Zetlin and Turner’s typology)
Criticisms of Goffman’s Theory

The Goffman analysis has been criticised and these criticisms centre on the notion that the theory perpetuates the passivity and victimisation of people with disabilities. Even Goffman claims that the meaning of disability is a social, therefore, a changeable construction. Goffman does, however, hold that people can be active creators in the reality in which they live (Susman, 1994). People with disabilities may have the ability to reject society’s impression that they are negatively different. Mest (1988) reports that his participants were aware of their stigma but only internalised some of it. Edgerton (1967) has shown that people with intellectual disabilities can manage stigma and yet maintain self-esteem through the use of coping strategies such as denial and passing, that is, denying that one has a disability or passing as a normal person. Marcel Calvez (1993, personal communication) feels that “Stigmatisation itself is not inevitable. The imputation of handicap is not an inescapable response of the members of the community to the interaction”. In relation to labelling theory, Edgerton (1993) describes labelling as a continuing interaction between the labeller, labelled and many other significant persons. He concludes that, “This interaction is akin to negotiation and thus while the label has great potential for destructive self-fulfilment, this fulfilment is not inevitable” (p.231).

Another criticism that sociologists have raised is that the theory does not deal with actual deviant behaviour. The final criticism is that it does not deal with the possibility that successful social control mechanisms, such as successful interventions and changes in social awareness that can be engineered through changes in social policy.
### Table 2.1
Zetlin and Turner’s (1984) Typology—Summary of Descriptive Characteristics for Each Attitude Group

<table>
<thead>
<tr>
<th>Attitude Towards Handicap [sic]</th>
<th>Acceptance</th>
<th>Qualification</th>
<th>Vacillation</th>
<th>Denial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Willingness to discuss handicap Parental attitude towards handicap</td>
<td>Open/casual Acceptance</td>
<td>Casual/guarded Acceptance/qualification</td>
<td>Reluctant Ambivalence/avoidance</td>
<td>Very reluctant / avoid topic Ambivalence/avoidance</td>
</tr>
<tr>
<td>Parental practices</td>
<td>Promotion of self-sufficiency</td>
<td>Promotion of self-sufficiency</td>
<td>Overprotection</td>
<td>Overprotection/overregulation</td>
</tr>
<tr>
<td>Sample members’ focal concerns/strategic goals</td>
<td>Normative/accomplishment</td>
<td>Progress/growth</td>
<td>Deviance disavowal</td>
<td>Routinisation</td>
</tr>
<tr>
<td>Current attitude toward parental and agency dependence</td>
<td>Positive</td>
<td>Positive</td>
<td>Negative</td>
<td>Negative</td>
</tr>
<tr>
<td>Past use of services</td>
<td>Low use</td>
<td>High use</td>
<td>High use</td>
<td>Low use</td>
</tr>
<tr>
<td>Affiliative relationships</td>
<td>Prefer nonhandicapped/nurturant or authoritative toward handicapped peers</td>
<td>Prefer mildly handicapped/warm relationships; reject severely handicapped</td>
<td>Prefer mildly handicapped or non-handicapped; shallow, unstable relationships, reject severely handicapped</td>
<td>Few or no peers; prefer family relationships</td>
</tr>
<tr>
<td>Well-being quality of life (self-report)</td>
<td>Content</td>
<td>Content</td>
<td>Miserable</td>
<td>Content</td>
</tr>
<tr>
<td>Reference group (Social comparison group)</td>
<td>Positive reference group-non-disabled Upward comparison on goals and attainments not related to intellectual disability</td>
<td>Negative reference group-severely handicapped Downward comparison</td>
<td>Negative reference group-severely handicapped Downward comparison</td>
<td>Positive reference group-non-disableds Deny disability-try to pass as non-disableds</td>
</tr>
</tbody>
</table>

N.B. Acceptors=Acceptance; Qualifiers=Tactical Dependents; Vacillators=Blame Attributors; Denial=Deniers
**Summary**

To conclude, the stigma paradigm and its special application, labelling theory, has been the most influential in the field of the development of social competencies and related affective variables for people with intellectual disabilities. Philosophically and historically it is closely aligned with the principles of normalisation and the policies of deinstitutionalisation that have been so influential in transforming the provision of services for people with intellectual disabilities. Research to date confirms that people with intellectual disabilities are aware of their membership of a stigmatised group, but suggests that they use coping strategies to handle stigma. Edgerton (1973) described the concepts of denial and passing. Zetlin and Turner’s (1984) work expanded the description of coping strategies and links coping strategies to the development of consistent self-images by which the person with disabilities manages a stigmatised identity. Hence, there is an acknowledgement by the theorists that poor self-images may not be inevitable and that people with intellectual disabilities could use strategies to counter the negative impact of stigma.

**Social Comparison Theory**

Social comparison theory is a competing theoretical orientation that is now considered to have influence in the field of intellectual disabilities (Dagnan & Sandhu, 1999). According to this theory, one’s self-concept is largely determined by the ways in which one is treated by significant others. The relation between the self and the perception of others is the basis of social comparison theory. Also, a boost to self-concept is associated with a positive affect and a threat to self-esteem is associated with negative affect. Chronic levels of low self-esteem tend to be related to affective states such as depression and anxiety (Beach & Tesser, 2000).

Festinger (1954) in his seminal work on social comparison suggested that when individuals are uncertain about their opinion or abilities, they will compare themselves with others to evaluate their own situation. In his original formulation (1954), Festinger suggested that people have choice in whom they compare themselves with and will prefer to compare themselves to those who are similar on the
dimension in question. Social comparison research emphasises the flexibility that people have in deciding on a relevant context in which to represent themselves.

Since the original theory, researchers have stressed that other motives apart from self-evaluation are involved in social comparison. Previous research has identified at least three motives for social comparison: self-evaluation, self-improvement and self-enhancement. Self-evaluation is believed to occur in low-stress situations that emphasise rational evaluation of one’s ability. Under these conditions individuals compare themselves with similar or slightly better off others to acquire the most meaningful and useful information (Festinger, 1954; Wills, 1981). Self-improvement also leads to comparisons with others who are similar or better off (Wood, 1989). In situations where the self-esteem is threatened, there are three possibilities: people may minimise comparisons (Brickman & Bulman, 1977), avoid upward comparisons (Steil & Hay 1997) or try to self-enhance by making downward comparisons (Crocker, Thompson, McGraw & Ingerman, 1987; Wills, 1981; Wood, Taylor & Lichtman, 1985). In the face of a threat to self-esteem, people may prefer to compare themselves with others they perceive as “worse off” than themselves. This can result in an increase in subjective well-being because downward comparisons appear to boost self-esteem and reduce anxiety (Gibbons, 1986).

Many of the studies in the 1980s and 1990s were inspired by downward comparison theory (Wills, 1981), which held that individuals under threat, such as people with intellectual disabilities who have been institutionalised, will improve their subjective well-being by comparing themselves with someone less fortunate. Empirical studies have validated this claim, using different definitions of threat including negative feedback, (Gibbons & McCoy, 1991), low self-esteem (Smith & Insko, 1987), depression (Pelham, 1991) and illness (Buunk, Collins, Taylor, Van Yperen & Dakof, 1990).

Researchers postulate that self-esteem tends to be correlated with social comparison choices: individuals with high self-esteem tend to make upward comparison choices, whereas low self-esteem individuals tend to make upward comparisons only when there is no threat to their self-esteem (Wood, 1989). However, Gibbons and McCoy (1991) found that only people with low self-esteem
showed a positive affective response after using downward comparison. Wills (1981) suggested that downward comparison was achieved when the person actively derogated another person of lower status. Wills contended that when people face threats to their self-esteem, those with low self-esteem are most likely to use downward comparison. However, Crocker et al. (1987) suggested that members of a low-esteem group actually derogated others less than members of a high-esteem group.

Other research has shown that for enhancement purposes, compared with people with low self-esteem, people with high self-esteem were better at making either upward or downward comparisons (Buunk et al., 1990). Buunk et al. concluded that the affective consequences of a comparison are not intrinsic to its direction (p.1239). Research has also shown that downward comparisons can also result in negative feelings if such a comparison results in assimilating oneself to a group one does not want to be associated with (Wood et al., 1985; Tesser, 1986) and upward comparison can also result in positive feelings whereby such comparisons result in reflected glory if you can assimilate with the group (Tesser, 1986; Marsh & Craven, 2002). Hence social comparison theory has been useful in predicting the nature of social comparison processes.

**Contrast and Assimilation Effects and Big Fish Little Pond Effect (BFLPE)**

In educational settings, Marsh and Parker (1984) proposed a frame of reference model called the big fish little pond effect (BFLPE), which is well documented in the academic self-concept literature (Marsh & Craven, 2002). This theory postulates that it is better, for self-concept, to be a big fish in a little pond, than a little fish in a big pond. In this formulation, academic self-concept is influenced by the other students in the immediate context, in addition to one’s own ability and academic accomplishments. The BFLPE is essentially an external frame of reference effect. Marsh and Craven (2002) have defined the terms contrast and assimilation. Contrast means when the judgement of a target stimulus shifts away from the context and assimilation means when the judgement shifts towards the context. Marsh and Craven have defined these terms as purely descriptive and suggest the use of more meaningful terms for assimilation are reflected glory and identification and for
contrast, negative social comparison or negative BFLPE. BFLPE and social comparison result in either contrast (negative social comparison) effects or assimilation (positive social comparison, reflected glory) effects (see Figure 2.1).

**Research Examining Assimilation and Contrast Effects and the BFLPE**

Assimilation and contrast effects have been studied using Marsh and Parker’s (1984) BFLPE. A large study to evaluate the predictions of social comparison theory was undertaken around the time of reunification of the East and West German school systems after the fall of the Berlin Wall. Prior to the reunification, there were important cultural differences in the two systems East German schools had only experienced mixed-ability classes, whereas West German classes had been taught in ability-segregated classes for the previous two years. In the reunification, the ability-segregated model from West Germany was adopted across Germany. Consistent with a priori predictions, the research provided strong support for the social comparison processes posited to underlie the BFLPE in that after two years the negative contrast effects of being placed in academically streamed classes were just as evident in East German schools, as they had been in West German schools. In another landmark study in Hong Kong, Marsh, Kong, and Hau (2000) evaluated the generalisability of the BFLPE to different school settings. This study examined the juxtaposition between assimilation (reflected glory) effects and contrast (negative social comparison, BFLPE) effects in a school setting. This research had critical theoretical and substantive implications. The research demonstrated that in educational settings, negative contrast effects are stronger than assimilation effects. The assumed benefits associated with special settings for gifted students and with mainstreaming academically disadvantaged students were based in part on assimilation effects predicted by labelling theory/stigma theory. Although these two effects work in opposite directions, they are not mutually exclusive (Marsh & Craven, 2002). The BFLPE is the net effect of counterbalancing assimilation and contrast effects.

The confusion in the research about upward and downward comparisons is better explained by acknowledging that upward and downward comparisons can be both beneficial and detrimental to self-esteem. If the aim is to enhance the self-esteem after some threat, which could be envisaged as the life experience of people with
disabilities, then upward comparison could have both negative and positive dimensions. Upward comparisons that are positive could be conceptualised as assimilation and be labelled as reflected glory (Marsh & Craven, 2002). They lead to the affective emotions of admiration and inspiration. However, when people make upward comparisons but cannot identify with the comparison group, they will not assimilate, hence will not benefit from reflected glory. They will have to contrast and this can lead to the negative affective emotions of envy and resentment.

Conversely, if people make downward comparisons to enhance their self-esteem, there may be a positive outcome if they can contrast themselves with the comparison group which leads to the affective emotions of pride and perhaps schadenfreude (malicious enjoyment of another’s misfortunes). Whereas, if a person makes a downward comparison, but cannot contrast themselves with the comparison group, then this is a negative comparison and could be seen as negative assimilation. This state is associated with the negative emotion of worry, that one might become like this.

It could be thought that people with high self-esteem use upward and downward comparisons to enhance their self-esteem, but are they being selective? Are they assimilating after using upward comparisons or are they identifying upwards and making lateral comparisons, a strategy that allows them to feel like one of the group, therefore, able to benefit from reflected glory, and when they make downward comparisons, are they benefiting from positive contrast effects? People with low self-esteem may be using the same process but in reverse. They may not be able to assimilate after using upward comparisons and therefore, they have to contrast and feel envy or resentment. Alternatively, they may use downward comparison but not be able to benefit from the contrast effect (as suggested by Gibbons, 1985) because they are too close to the comparison group. They, therefore, assimilate and then suffer the negative emotion of worry.
Leary, Tambor, Terdal and Downs (1995) found that rejected participants, such as people with disabilities who have been institutionalised, showed greater negative feelings than a comparison group drawn from the non-disabled population. Another study also showed that behaviours or situations associated with exclusion are also linked with decrements in self-esteem (Suls & Wheeler, 2000). In a study that examined the relation between social comparison, self-esteem and depression for people with intellectual disability, Dagnan and Sandhu (1999) found that positive correlation occurred between self-esteem and social comparison on the achievement dimension. Depression was significantly related negatively to social comparison on the social attractiveness and group belonging dimensions, and with positive self-esteem. It can be concluded from the results of this study that social comparison, and self-esteem and depression are interacting in the same way as they do for people without an intellectual disability.

**Downward comparison.** Downward comparisons have been demonstrated in people with intellectual disabilities. Gibbons (1985) showed that people with intellectual disabilities engaged in derogation or downward comparison of other stigmatised group members. Zetlin and Turner (1984) confirmed this pattern. Gibbons (1985) determined that people who were living in an institution rated themselves as smarter and more attractive than did those who were living in group homes. In other words, people whose major reference group was now the non-disabled population in the community were not able to use downward comparison as easily as those in institutions. Gibbons (1986) also found that there was a group-concept problem in that the participants rated other people with disabilities less favourably than themselves. He considered that this was evidence for a downward comparison process. Edgerton and Sabagh (1962) thought that people who lived in institutions may be able to “self-aggrandise”, in other words, enhance their self-esteem by using downward comparisons by comparing themselves to other people who have a greater degree of intellectual impairment than themselves. Gibbons argued that this process was reflected in his results and that people in the community were more realistic in their self-evaluations because they were including nondisabled people in their reference and social comparison groups.
Gibbons found that although there is some evidence of downward comparison, there was little evidence of the benefits that might be associated with this process for people who do not have disabilities. His participants did not rate themselves highly on the dimensions to which they unfavourably compared other people with disabilities, these dimensions being marriage partner and dating partner. However, he might have had different results if he had evaluated other dimensions. Szivos-Bach (1993) asked people with an intellectual disability to complete a researcher-developed self-esteem scale for themselves, for three “comparison others” and for their “ideal self”. The comparison others were the participant’s best friend with an intellectual disability that they were attending a TAFE course with, their favourite sibling, and a person who did not have an intellectual disability. The highest self-esteem scores were given to the ideal self followed by the person who did not have a disability, the person’s rating of themselves, and their favourite sibling and, lastly, the friend with an intellectual disability. These results indicate a tendency to make downward comparisons to others with an intellectual disability. Szivos (1990) found no relation between these choices and whether the students attended an integrated or segregated setting. Those in the integrated setting looked on themselves less favourably as well.

**Upward comparison.** Tracey (2002) found that children with mild intellectual disabilities, who were integrated into regular classes, had a lower self-concept than a comparison group of children who were placed in a special class. This finding could indicate that the children integrated into regular classes were making negative upward comparisons (contrast) and were no longer able to make the self-enhancing downward comparisons with other students who were academically poorer than they were. This frame of reference effect is the BFLPE. This downward comparison positive effect (contrast) can be balanced by a reflected glory or upward comparison positive (assimilation) effect. However, assimilation depends on the affinity or identification a person can make towards the comparison group. If the differences between the person and the comparison group are too great, then reflected glory might not have an impact. This may be the case for people with intellectual disabilities, particularly those who have been excluded from the regular community by institutionalisation or whose self-esteem is constantly under threat, such as children with mild disabilities who are constantly exposed to academically more capable peers. This negative
upward effect (contrast) may have a greater impact on self-concept if it cannot be balanced by self-enhancing downward comparisons with other people with intellectual disabilities because the individual has been moved from the segregated environment (e.g., institution or the special class).

In fact, Tracey’s (2002) research suggests that the move to community living may have deleterious effects on the self-esteem of people with intellectual disability. The closer they come to living in the community, the more likely they will experience feelings of negative difference. The current process of social integration in the community would inevitably lead people with intellectual disabilities to make comparisons with non-disabled others. Given that non-disabled people have not suffered the experience of exclusion, have had different life experiences and occupy a more privileged place in society, people with intellectual disabilities are at risk of feeling, at best, uncomfortable as a result of making such comparisons.

The above research leads to an interesting anomaly in the predictions that could be made by these two competing theories about the effect of community placement on the self-esteem of people with intellectual disabilities. From stigma theory, integrated placement, such as community living, competitive employment and integration into regular classrooms at school might raise self-esteem as the individuals receive positive appraisals about their “normality”. Conversely, social comparison theory would predict that self-esteem might decrease because of unfavourable upward comparisons (contrast) with non-disabled reference groups and the inability to make downward comparison with comparison groups of other people with intellectual disabilities. However, there are interesting reconceptualisations of this problem that indicate that these anomalous predictions may be overly simplistic. Upward comparison by people with disabilities can produce negative effects because they realise that others are more able than they are.

In the academic setting this comparison process is the BFLPE (Marsh & Craven, 2002). However, this is conceptualised as the counter-balancing influences of a larger (negative) contrast effect associated with upward comparison and a smaller (positive) assimilation effect associated with reflected glory and identification with the more able group. Social comparison theory (Gibbons, 1986; Szivos-Bach, 1993),
the competing paradigm, would predict that people with intellectual disabilities living in the community will make comparisons with non-disabled groups and as such their self-concept will decrease because of negative frame of reference effects. Again, there are indications that this hypothesis is too simplistic and does not take into account newer developments in social comparison theory or research (Wills, 1981; Tesser, 1986; Buunk et al., 1990). Participants may view context in different ways (Haslam & Turner, 1997) and display “selective industry of the mind” (James, 1890). For example, people may choose to make either upward or downward comparisons and be quite selective as to which groups they use for comparison. Also the benefits they gain to their self-esteem may relate to counterbalancing assimilation and contrast effects (see discussion above).

One important example of recent research is Finlay and Lyons’ (2000) study which used social comparison theory to show that people with disabilities use strategies to present themselves in positive ways. These include emphasising similarities between themselves and those without intellectual disabilities, avoiding upward social comparisons relevant to intellectual disabilities (intra-subject comparison or discounting), and by making downward comparisons with those who are less able or have less acceptable moral behaviour. These findings correspond to Crocker and Major’s (1989) view that belonging to a stigmatised group may facilitate in-group comparison and attribution of unwanted feedback to the group perception rather than to the self.

In a recent ethnographic study of a large family that included many individuals who had been diagnosed with intellectual disabilities, Taylor (2000) suggested that most research in this field assumed that people with disabilities would automatically be experiencing the negative impact of stigma and therefore research was designed around this assumption. In his longitudinal study over a period of 10 years, he found that, in contrast to the prediction that would be made by stigma theory, the family had constructed a world in which disability was not stigmatising or problematic to their identities. The family defined themselves in terms of their family relationships and the skills that each one of them brought to maintaining the family economically and emotionally. This led Taylor to argue that the negative impact of stigma is not inevitable. He acknowledged that disability is problematic for identity, but that there
are ways of constructing social realities that act as a buffer to protect the self-concept from the stigma imposed by society. This family was able to achieve this buffer after a long period of residing in the community and achieving normalised roles such as “parent, grandparent, sister, brother, wife, husband, home-maker, and economic provider” (p. 84).

**Social Comparison and Zetlin and Turner’s Typology**

The most comprehensive description of responses to being labelled and the impact on the self-esteem was presented by Zetlin and Turner’s (1984) research. Using ethnography, they studied a large number \(N = 48\) of participants with intellectual disabilities who had never been institutionalised and were living in the community. They developed an extensive typology (see Table 2.1) based on their findings of the modal attitudes each participant had towards their disability. The typology was based on four distinct attitudes of participants based on their willingness/reluctance to discuss their disability, the anxiety related to the acknowledgement of having problems, the importance they gave to their disability in day to day living and the strategies they used to cope with their disability. The results led to the development of the four difference types of people who differed in their self-perceptions and the strategies they used to cope with their social reality. The other major finding of their study was the paramount influence that parental attitudes and expectations had had on the development of the participants’ attitudes towards themselves (p.115).

In another ethnographic study Angrosino (1992) utilised Zetlin and Turner’s typology to examine the “capacity of self-conceptualisation and the articulation of self-hood” (p.173) of participants who had been admitted to a structured residential program because of court orders or behavioural difficulties when in the community. The findings supported the application of the typology to the participants, and made suggestions about the relationships between coping strategies and self-images.

Zetlin and Turner’s typology has not been applied to long-term institutionalised people with intellectual disabilities who are assessed as socially competent. This typology has potential because it presents a model for the social
comparison strategies such as upward/downward comparison and the reference
groups that they are using to make these comparisons. The typology is the only
conceptualisation that has synthesised the two theoretical paradigms that predominate
in the deinstitutionalisation literature. It may offer insights into the way people with
disabilities respond to stigma and labelling and into the coping strategies they use to
protect their self-esteem. Therefore it seems particularly appropriate for the
participants in this investigation.

Summary

Social comparison theory, the competing paradigm to stigma theory, offers an
understanding of the effect of deinstitutionalisation on the development of the self for
people with intellectual disabilities. When self-esteem is threatened as a result of a
stigmatised identity, people can engage in a range of downward and upward
comparisons that are then combined with contrast and assimilation effects. The
BFLPE is one conceptualisation that has bearing on this problem. Zetlin and Turner’s
typology has been shown to be salient for the description of the development of
identity and self-conceptualisations in people with intellectual disability. It also
provides a mechanism by which the two competing theories can be critically
examined.

Social Comparison and Stigma Theory Reconsidered

Wills’ (1981) conceptualisation of downward comparison to enhance a
vulnerable self-concept could be perceived as a coping mechanism when the self is
under threat (Gibbons & Gerrard, 1991). However, the impact of such comparisons
upon self-concept may also be temporary (Gibbons & Gerrard, 1991). Tesser (Beach
& Tesser, 2000) has proposed a self-evaluation maintenance model underpinned by
the notion that people have a basic motivation to maintain or enhance self-evaluation,
and to maintain a positive view of the self. Under the model, people may engage in
self-evaluation, which can be negative, but if they engage in reflection they could
bask in the reflected glory of people who are achieving. As such the dual processes of
contrast as proposed by Marsh and Craven (2002) may be operating whereby both
upward and downward comparisons can both have a positive and a negative impact.
Whether assimilation or contrast occurs depends in part on the expected affinity of an individual with perceived superior or inferior others. If the person uses upward comparison but cannot identify with the comparison individual or group then the contrast effect has a negative impact on their self-esteem. Conversely, if the person used downward comparisons to enhance their self-esteem they need to be able to contrast themselves from the group, who they perceive as worse off. If they cannot contrast themselves, then they will identify with the worse-off group and the impact upon their self-esteem will be negative (see Figure 2.1).

Some writers have combined these two theoretical orientations and view stigma as an external societal process, and social comparison as the individual’s response to a stigmatised identity (Dagnan & Sandhu, 1999). The sequence by which stigma and social comparison combine follows the pattern described by Mead (1934): social label, awareness of societal reaction, performance of social label, revision of self-label, and performance of role implied by social label. As the result of some crisis, a person is labelled as deviant and in the past was excluded from participating in conventional groups and using ordinary means to carry out the routines of everyday life. Mead hypothesised that this exclusion caused a drastic and often irreversible change in public identity that is eventually assumed as a low self-image. The deviant’s behaviour then becomes congruent with the others’ definition of the deviant (e.g., people in institutions develop institutionalised behaviours such as over-dependency, passivity, wariness of new experiences and people) and results in depressed self-concept.

These assumptions paint an overly gloomy outcome for the impact of deinstitutionalisation upon the self-concept of people with intellectual disabilities. Recent conceptualisations of social comparison processes emphasise the active nature of social comparisons (i.e., people have a choice in whom they compare themselves with and on what dimensions). This is in contrast to BFLPE in educational settings where the context (the classroom setting) and salient dimension (academic achievement) are imposed on the person. The presence of “normal” others in the social environment does not mean that people with intellectual disabilities will use them for comparison processes. The implication of this more dynamic conceptulisation of social comparison processes suggests that it is crucial to examine
the social comparisons people with intellectual disabilities make in order to assess the extent to which a stigmatised or negative social identity is presented. For people who were conceptualising themselves as having a negative social identity, it would be necessary to ascertain whether people with intellectual impairments were using upward comparisons and using dimensions that were of relevance to the category, such as skills, intelligence, employment, and socially valued goals. The research to date has shown that upward comparisons were rarely made by people with intellectual disabilities (Festinger’s theory predicts few upward comparison being made by low social value groups) and downward comparisons were made mostly with other people with intellectual disabilities (Gibbons, 1985, Szivos, 1990).

**Summary**

In conclusion, the competing hypotheses of stigma theory and social comparison theory may be too simplistic a dichotomy to address the formation of the self for people with intellectual disabilities who have been deinstitutionalised. They will be aware of their membership of a devalued group as all of them have suffered the rejection of society and have been placed in congregate care. However, there are ways that people who are members of stigmatised groups can construe themselves positively. They may choose groups and dimensions with which to make comparisons that demonstrate “selective industry of the mind” (James, 1890). They may use small numbers of comparisons and they may use intra-subject comparison or “discount” the importance of certain attributes where they will be judged as inferior.
Figure 2.1. Proposed Conceptual Framework for Relation Between Social Comparison Theory, Stigma Theory and “Big-Fish-Little-Pond” Effect.
Implications of the Theoretical Bases for the Present Investigation

People with intellectual disabilities are members of a stigmatised category (Edgerton, 1993). For a variety of reasons they are less likely to achieve socially-valued goals such as being employed, having children, living independently or living with partners. Evidence for negative evaluations by society is numerous (Finlay & Lyons, 2000). Social identity theory and research on stigma suggest that membership of a devalued social category can have negative implications for self-esteem and people might engage in coping strategies to restore or maintain their self-esteem. This is reflected in people with intellectual disabilities (Edgerton, 1993; Jahoda, et al., 1988). However, whilst some researchers stress the salience of this aspect of identity and the consequent implications for self-esteem (Stokes, 1992; Szivos & Griffiths, 1990; Szivos-Bach, 1993), social comparison theorists point out that that the salience of particular social identities may vary. In order to be able to state that people with intellectual disabilities experience a negative social identity, it is important to show that this identity is salient. Self-categorisation may not necessarily follow from being designated as a member of that group. The implication is that membership of a stigmatised group may not have the type of implications for the self-esteem and for behaviour that would be suggested for such a negatively-valued social group. Newer conceptualisations in social comparison theory suggest that people with intellectual disabilities may use selective processes in relation to groups and dimensions that may bolster their self-esteem.

In his original formulation Festinger (1954), proposed that comparisons would be characterised by a unidirectional drive upward, whereby people would seek comparison with slightly superior others in order to gain information on how to improve. Earlier research has provided support for the unidirectional drive upward in non-threatening circumstances (Wood, 1989). Other studies have shown that social comparison can serve this function even when groups are under threat. For example, Buunk et al. (1990) found that cancer patients were able to benefit from both upward and downward comparisons. Downward comparisons are not the only way to deal with threat. Upward comparison strategies may also serve as effective coping strategies. Gibbons (1994) has found that people who are under constant threat may
use differing strategies to downward comparison. They may use downward shift, discounting intrapersonal comparisons and decrease the number of social comparisons that they make.

Given the evidence for maintenance of the self, it is not surprising that little change has been found for the self-concept of people with disabilities whose circumstances are altered. How one feels about oneself at a particular time is strongly influenced by the immediate social context, changes in context can produce changes in self-concept (Turner, Oakes, Haslam, & McGarty, 1994). Substantial and enduring changes in self-concept have been demonstrated during times of life transition (Deutsch, Fleming, Brooks-Gun, & Stangor, 1988; Zirkel & Cantor, 1990), such as moving from an institution to the community. These findings are not contradictory as the “self is consistent in its motives and conservative in its strategies” (Zirkel & Cantor, 1990, p. 220), yet can be responsive to environmental changes.

As yet there is very little definitive research resolving the competing predictions of stigma and social comparison theoretical perspectives. It is imperative then that people with intellectual disabilities understandings of stigma and social comparison processes be assessed to discover whether one paradigm or the other has greater explanatory power. These understandings may help service providers to develop programs and interventions that will be able to enhance the self-esteem of people with intellectual disabilities. In order to address some of the issues described above, the present investigation was designed to test the competing predictions of stigma and social comparison to elucidate the impact of deinstitutionalisation on the self-concepts of people with intellectual disabilities and to ascertain the nature of comparisons made by such deinstitutionalised adults.
Social Competence

The Importance of Social Competence for People with Intellectual Disabilities

Whilst stigma theory combined with social comparison may explain the internalisation of a lower social status by the persons themselves, these theories do not explain the lack of social competencies that prevent people with intellectual disabilities from interacting with others, except those social competencies linked to self-esteem. As such the problem of social competencies remains central to the development of the self-esteem of people with intellectual disabilities who have been institutionalised. People with intellectual disabilities lack social competencies; they do not have the resources to interact with others according to the expectations of an ordinary context such as living in the community. There can be various reasons for this lack that are expressions of a self-fulfilling prophecy whereby people with “handicaps”, act according to their label and therefore become “handicapped”. It is obvious that a person who has spent most of their life in a closed institution will develop institutionalised competencies that are not relevant out of this context. These could be thought of as conforming, passive and dependent behaviours. A person who has been allocated a minor status will be faced with pressures to develop competencies relevant to this status (e.g., the competencies to act according to the cultural definitions of a “handicapped” person).

The acquisition of social competencies is the ability to make sense of one’s environment and to elaborate the social meanings of one’s acts. It involves more than learning the norms of behaviour. It is the acquisition of principles that allow the person to interpret his or her world and to interact with others in social contexts. Acquisition of social competencies cannot just be conceived in terms of primary socialisation (the learning of codes and rules of a context), but in terms of secondary socialisation (the construction of the self). It could be argued that the person with disabilities has had a primary socialisation that has not been followed by a secondary socialisation. Furthermore, it could be asked if this primary socialisation provides the person with the basic resources to be able to facilitate a secondary socialisation and the acquisition of social competencies.
Few people would question the importance of social competence in the overall
development and adjustment of all people. The ability to interact with peers and
significant adults is one of the most important elements of development. Social
competence, defined as the ability to establish and maintain interpersonal
relationships also predicts long-term psychological and social adjustment (Gresham,
Sugai & Horner, 2001). Social competence is particularly important for people with
disabilities (Gresham & MacMillan, 1997). Historically, social competence has been
used as a criterion for disabilities such as intellectual impairment (Gresham,
MacMillan & Siperstein, 1995). In addition, the social skills of people with
intellectual disabilities have an important bearing on their social integration (Huang &
Cuvo, 1997). The normalisation philosophy implies that social integration is best
practice. If social integration is accepted as best practise then it is imperative to know
how integration can be enhanced. There are three logical pathways for achieving an
enhanced level of social integration. These are changing contextual variables,
changing the behaviour of people with intellectual disabilities and changing the
behaviours of other people such as neighbours in the community. Thus, it appears
reasonable to infer that if people with intellectual impairment are taught valid social
skills and the environmental conditions are supportive, then social integration should
improve. Also, it is important to note that social skills have long been considered a
salient predictor of quality of adult life (Gumpel, Tappe & Araki, 2000).

There is some evidence that the social interactions of people with intellectual
disabilities are different from the non-disabled population (Ralph & Usher, 1995).
Although the results of the research are not entirely consistent, in general the research
has found that people with intellectual disabilities have more interactions with
professionals employed to assist them in various ways. As such they interact with
fewer people throughout the week and they have fewer interactions overall.

Several studies have examined community adjustment of people with
intellectual disability and have shown that these people become increasingly socially
isolated over time and tend to engage in activities in their own homes (Thurlow,
Bruininks & Lange, 1989). Leisure pursuits typically include sedentary activities,
such as watching television, or activities, such as bowling, arts and craftwork
(Schleien, & Ray, 1997). These people are lacking the social and physical skills to
engage in more socially inclusive activities (Schleien & Ray, 1997). However, most of these studies have concentrated on people with moderate to severe disabilities. Therefore, there is still a need to involve people with intellectual disabilities in social skills training, so that these discrepancies can be overcome and social integration for people with intellectual disabilities in the community can be more successful.

To redress the lack of social integration that can take place on deinstitutionalisation of people with intellectual disabilities, it is important for practitioners to develop structures and programs that provide opportunities for the development of social skills. Without these programs people with intellectual disabilities may continue to be excluded from many social contexts.

**Conceptualisation of Social Competence**

There are many definitions of social competence. To date, researchers have not reached a consensus on a general definition of social skills. McFall (1982) proposed a definition that combined the social skills component with the social competence component. Chadsey-Rusch (1992) defined social skills as goal-oriented, rule-governed, and learned behaviours that are situation specific and vary according to social context: they involve both observable and non-observable cognitive and affective elements that assist in evoking positive or neutral responses and avoiding negative responses from others. The social validity definition of Gresham (Gresham & Reschley, 1986) defines social skills as “socially significant behaviours exhibited in specific situations that predict important social outcomes” (Gresham, et al., 2001, p. 332) for the individual concerned. An important distinction in this definition is between social skills and social competence. In Gresham’s view (Gresham et al., 2001) social skills are the specific behaviours that an individual uses to perform competently on specific social tasks. Social competence is an evaluative term based on judgements that a person has performed competently on social tasks (McFall, 1982). These judgements may be based on the opinions of significant others, comparisons to explicit pre-established criteria, comparisons to normative samples or observed outcomes of social performances. In summary, social skills are behaviours that have to be taught, learnt and performed; by comparison, social competence is evaluation of these behaviours within and across situations (Gresham et al., 2001).
Interpersonal Cognitive Problem-Solving Social Skills Interventions

A number of social skills interventions have been described in the literature. The majority of these have focussed on teaching employment-related social skills (for a review see Huang & Cuvo, 1997). Recently there has been a move to teach leisure skills (O’Reilly, Lancioni, & Kierans, 2000a`). One of the most widely recognised obstacles to the normalisation of people with intellectual disabilities is their excessive dependence upon external agents for learning and maintenance of behaviour. Successful adaptation to normalised settings, a primary goal of the socialisation process implicit in the concept of normalisation, is that people with intellectual disability will become less dependent on highly structured learning programs, and become increasingly self-regulating (Feretti, Cavalier, Murphy & Murphy, 1993).

Self-management techniques are a potentially important set of strategies that can be used to enhance appropriate skills for people with disabilities (Koegel, Harrower & Koegel, 1999). Four strategies have been recorded in the literature, including self-monitoring or self-recording, self-assessment or self-evaluation, self-instruction and self-reinforcement (Agran, Salzberg & Stowitschek, 1987). Social problem-solving skills have long been recognised as an important technique for social skills interventions (Elias & Tobias, 1996) and typically involve a set of skills such as problem identification, solution generation, and solution choice. Research and training has focussed primarily on the early work of Meichenbaum and Goodman (1971).

Several researchers have advocated using a cognitive-process problem solving approach to teach social skills because it may promote generalisation (McFall, 1982; Chadsey-Rusch, 1986; Hollin & Trower, 1988; Park & Gaylord-Ross, 1989). In two studies, Park and Gaylord-Ross (1989) demonstrated that the cognitive process approach leads to generalisation of social behaviours across settings in young people with intellectual disabilities. With a cognitive-process approach, individuals are taught a generative process rather than specific component behaviours (Hollin & Trower, 1988). There have been few applications of its use because it relies on receptive and expressive skills and may be thought of as inappropriate for individuals with intellectual impairment. However, Collet-Klingenberg and Chadsey-Rusch
(1991) also demonstrated that two of three participants with moderate “mental retardation” [sic] could learn this approach. Because appropriate social skills are crucial to the success of people who wish to live in the community (Chadsey-Rusch, 1986; Greenspan & Shoultz, 1981; Salzberg, McConaghy, Lignauris-Kraft, Agran, & Stowitschek, 1987), there is a need for training approaches that are effective, convenient to use, and teach the complexities of social interactions. The strength of this approach is that it teaches a strategy that could be generic to all social situations, promoting generalisation as has been found by previous research demonstrating the transference of social skills acquired to other settings (Park & Gaylord-Ross, 1989; O’Reilly & Chadsey-Rusch, 1992; O’Reilly & Glynn, 1995; Rosenthal-Malek & Yoshida, 1994).

However, the efficacy of training remains unclear (Gumpel et al., 2000). The research has focussed mainly on intervention-oriented studies that have used behavioural observation or performance skills to evaluate their impact (e.g., Park & Gaylord-Ross 1989). King, Lancaster, Wynne, Nettleton and Davis (1999) evaluated the efficacy of cognitive therapy for anger management with 11 adults with mild intellectual disabilities in a group therapy format, which led to improvements in self-report measures of self-esteem. Caregiver reports indicated improvements in emotional and behavioural adjustment. However, absence of a control condition seriously compromised this research. Nevertheless, the problem-solving approach seems to be an effective strategy for promoting social skills for people with mild and moderate levels of intellectual disability (O’Reilly & Glynn, 1995; O’Reilly, Lancioni & Kierans, 2000a; O’Reilly, Lancione & O’Kane, 2000b). With this approach, the person is taught a process which includes discriminating a problem (decoding), identifying alternative responses, selecting the most appropriate response for the situation, performing the behaviour and evaluating the effectiveness of the social behaviour.

**Implications for the Present Investigation**

The importance of social competence for people who wish to be deinstitutionalised cannot be overstated. It is important for service providers to develop appropriate programs that can address the social competence and social skills...
deficits of many people with intellectual disabilities. A number of social skill interventions have been described in the literature. However, it is vital for people who wish to reside in the community to be self-regulating and not have to rely on paid carers. One technique which shows promise is the interpersonal cognitive problem-solving approach because it has the potential to promote generalisation and maintenance. These features will be essential elements for any effective intervention for people who wish to live in the community. They will no longer be able to rely on the daily presence of staff to implement and reinforce the appropriate behavioural responses for the development of social skills. Without social skills programs people with intellectual disabilities may continue to be excluded from many social contexts.

Summary

This chapter has described the theoretical bases of this thesis. First, the concepts of normalisation and deinstitutionalisation were defined. The links of these principles to Goffman’s Stigma Theory and its special application labelling theory were outlined. Secondly, the competing theory of Social Comparison was outlined. The application of downward and upward comparisons and their relevance to the enhancement of the self for people with intellectual disabilities were emphasised. A new conceptualisation of assimilation and contrast was offered that might shed light on the diverse research results. Thirdly, the implications of these theories for people with intellectual disabilities were stated and the concern was raised that more research is needed to tease out the relative importance of these competing paradigms. Zetlin and Turner’s typology was suggested as a useful way of integrating the two theoretical formulations. Finally, it was proposed that because social integration is still a major issue, it is necessary to implement social skills training programs that can enhance people’s social integration Interpersonal cognitive problem-solving skills programs were shown to be of potential value because of their emphasis on an overall strategy that can be generalised across different contexts.
CHAPTER 3

Conceptual and Measurement Issues:
Affective Variables, Social Competence and Social Skills

Introduction

Deinstitutionalisation has expanded with little empirical support since the 1980s in Australia. There is a need to examine the process closely. This examination is essential to effect a better transition for people with intellectual disabilities and enduring positive outcomes. Four variables, self-concept/self-esteem, locus of control, quality of life, and adaptive behaviour are important constructs themselves, as well as constructs of considerable potential significance for people with intellectual disabilities. These variables are likely to be especially important for people with intellectual disabilities who will experience or have experienced deinstitutionalisation. This chapter presents a rationale for the significance of each of these constructs as it pertains to people with mild intellectual disability who have been, or will be deinstitutionalised. The conceptual and measurement basis for each of the affective variables will also be examined. Importantly, the implications of the conceptual and measurement issues in relation to these constructs for the present investigation will be presented. Hence this chapter will identify how the present investigation will capitalise on, and extend, recent advances in theory, measurement and research design for these four affective variables as they relate to people with intellectual disabilities. Finally, the conceptual and measurement issues relating to social competence are also discussed.

The Significance of Self-Concept as an Important Outcome and Mediating Variable

The enhancement of self-concept is seen as a desirable outcome for many reasons. Nathaniel Branden (1994), an eminent philosopher and psychologist, attested to the pervasive significance of this construct by stating:
I cannot think of a single psychological problem—from anxiety to depression, to underachievement at school or at work, to fear of intimacy, happiness or success, to alcohol or drug abuse, to spouse battering or child molestation, to co-dependency and sexual disorders, to passivity and chronic aimlessness, to suicide and crimes of violence—that is not traceable, at least in part, to the problem of deficient self-esteem.

A positive self-concept has been associated with positive psychological health, achievement and positive relationships (p. xv).

High self-esteem/self-concept implies feelings of control, self-determination and autonomy. Those with low self-concept often lack self-respect and feel they are unworthy, insignificant, and inadequate (Tam, 1998). As such, a positive self-concept is widely regarded as a desirable goal throughout life (Hattie, 1992). According to Coopersmith (1967), people with a positive self-esteem are more likely to lead active lives and to have a sense of determination; they are better able to tolerate internal and external stress; they tend to have better physical health, enjoy better relationships, value independence and anticipate more success. In fact, a positive self-concept has not only been thought of as a valued state of itself, but positive self-concept is also considered to impact on other desirable psychological outcomes (Madonna & Philpot, 1996; Chapman, 1988). There is a large literature relating to the impact of academic self-concept as a mediating variable for many desirable educational outcomes. These include academic behaviours such as task persistence, subject selection and educational aspirations (Craven, Marsh & Burnett, 2003; Marsh, 1990; Marsh & Yeung, 1997, 1998; Marsh, Hau & Kong, 2002). Other research has defined self-concept as pivotal to success for adults in work, relationships and quality of life (Crowder & Michael, 1989; Brown & Goldenberg, 1993; Reiter & Bendor, 1996; Craven et al., 2003). A high self-concept has also been shown to be negatively related to other psychological states such as depression (Madonna & Philpot, 1996). A high self-concept is obviously a much sought after goal in educational and vocational settings for its possible positive effects on improving motivation, achievement and personal fulfilment across the lifespan (Petrovski & Gleeson, 1997).
Historical Overview of Self-Concept Research

Self-concept theory was first formulated by James in 1890. At that time, James theorised that there was a hierarchical order to the self (Bracken, 1996). Although the specific structure of the self, outlined by James, has not been borne out in current research (Shavelson, Hubner & Stanton, 1976), James’ proposition that self-concept is multidimensional has been validated. During the behaviourist era of the 1950s to the 1970s, James’ original formulation of multidimensionality was ignored and self-concept was conceptualised as a global construct (Coopersmith, 1967). Research studies utilising the unidimensional model of self-concept have historically predominated in the field of intellectual disability as well. However, over the past two decades a substantial amount of research by Marsh and his colleagues (see Marsh & Hattie, 1996) has demonstrated that self-concept is a multidimensional construct (Marsh, 1989a). These researchers have theorised that a general global self-concept score masks important distinctions that individuals make in their self-concept relating to different domains in their lives. Also, they have argued that the dubious use of global self-concept has led to the contradictory findings which are prevalent in general population self-concept research, as well as self-concept research for people with intellectual disabilities. The acceptance of the theoretical multidimensionality of self-concept also has implications for its measurement in that the instrumentation utilised needs to be capable of measuring multiple domains of self-concept.

Distinctions have also been made between self-concept and self-esteem. Coopersmith (1967) has defined self-esteem as follows:

By self-esteem we refer to the evaluation which the individual makes and customarily maintains with regard to himself: it expresses an attitude of approval or disapproval and indicates the extent to which the individual believes himself to be capable, significant, successful and worthy. In short, self-esteem is a personal judgement of worthiness that is expressed in the attitudes the individual hold towards himself (pp. 4-5).
Self-concept has been defined as:

…a person’s perceptions of self formed through experience with one’s environment, influenced by interactions with significant others, and attributions of one’s own behaviour (Shavelson et al., 1976).

However, much of the research in the area of intellectual disability fails to discriminate between these two constructs. In fact, historically many writers have used the terms self-esteem, self-worth and self-concept as though they are all interchangeable and this is also reflected in the literature for people with intellectual disabilities. This has often resulted in research that has focussed on a unidimensional model of self-concept whereby general self-esteem has been the sole focus of research rather than capitalising on more recent theoretical conceptualisations of self-concept as a multidimensional construct, which is discussed in the following section.

**The Multidimensional Model of Self-Concept**

There are a number of models that have conceptualised a multidimensional self-concept (for a review see Marsh & Hattie, 1996). However, the model that has received the most empirical support is that of Shavelson et al. (1976) who attempted to remedy the significant problems in self-concept research by proposing a multifaceted hierarchical model of self-concept. They suggested that self-concept is a multidimensional structure containing multiple dimensions or facets; the multiple dimensions become more context specific lower down the structure; the context specific facets become increasingly stable with age; and that facets contain both the elements of evaluation (affective) and description (cognitive; adapted from Shavelson et al., 1976).

In this model a general self-concept factor is at the pinnacle or apex and the next level down is represented by higher order factors such as academic and non-academic self-concept. As the hierarchical model unfolds, each higher order factor becomes differentiated into more specific lower order factors (Marsh, 1990). For example, the higher order factor of social self-concept is further divided into peer self-concept and significant others’ self-concept. The subdivisions of each factor are
measured by specific indicators or items that aim to capture the various aspects of the self. Although this model has been very influential in subsequent self-concept research with the general population, it has never been used to examine the self-concept of adults with intellectual disabilities.

**The Measurement of Self-Concept**

At the time Shavelson et al. developed this model, none of the unidimensional instruments available were appropriate measures for this new conceptualisation of the self. To address this need, Marsh developed the Self-Description Questionnaire (SDQ) instruments to measure the different areas of self-concept that were derived largely from the Shavelson et al. model (Marsh, 1988, 1989b). Extensive theoretical and empirical research (reviewed by Byrne, 1996) has provided strong tests of the Shavelson et al. (1976) model (Marsh & Craven, 1997). The extensive work of Marsh, using the SDQ instruments, has supported the multidimensionality of self-concept and the domains proposed by the Shavelson et al. model. It has also led to an important revision of the theoretical model for academic self-concept which incorporates frame of reference effects, which has become known as the Marsh/Shavelson model (Marsh & Shavelson, 1985). The use of the SDQ instruments has also extended theoretical conceptualisations about the structure of self-concept and its relation to other constructs. The SDQ instruments are considered to be the strongest self-concept measures available internationally (Hattie, 1992; Marsh & Craven, 1997). The instruments have been evaluated to have excellent construct validity and psychometric properties (Byrne, 1996; Hattie, 1992). In addition they have recently been employed in research with children with disabilities (Johnston, 2001; Tracey, 2002) and hence have the potential to be useful in research with adults with intellectual disabilities which is the focus of the current investigation.

**The Significance of Self-Concept and Self-Esteem Constructs for People with Intellectual Disability**

Enhancing self-esteem/self-concept is widely regarded as a desirable goal for the general population (see discussion above), but it is of particular importance for people who have a higher incidence of failure and lack of control of their lives and who may be perceived as vulnerable, such as those with intellectual disability (Zetlin
Few researchers have focused on the personality characteristics of people with intellectual disability (Zigler & Balla, 1982); most researchers have traditionally focused on cognitive aspects of the disorder and ignored social and personality factors. However, Zigler and Burack (1989) proposed that the same factors that impact on the personality of the regular population, impact on people with intellectual disabilities. There are some studies that have demonstrated that people with disabilities are subject to the same psychological processes as typically developing peers. For example, for people with intellectual disabilities, depression has been associated with low self-concept; this construct and other psychological constructs have been shown to operate in the same way as in the regular population (Benson & Ivins, 1992; Petrovski & Gleeson, 1997; Dagnan & Sandhu, 1999).

A consistent theme in the personal and social psychology literature is that people with mild intellectual disabilities display lower self-concept and exhibit more problem behaviours. However, Zigler and colleagues theorise that the life experiences, particularly the social deprivation of institutionalisation, has led to the development of these personality characteristics in people with intellectual disabilities and particularly emphasised the development of dependency on others that is exhibited by many people with intellectual disabilities. Zigler and Burack (1989) also suggested that institutionalisation results in low aspiration levels, outer-directed problem-solving styles and low self-concepts.

Zigler’s contentions relate to the social constructionist theories of Mead (1934). Mead (1934) suggested that social experience plays a large part in the development of the self-concept. In other words, the personal histories of people play an important role in their perceptions of themselves and others in interpersonal situations. There are a number of common experiences that might damage the self-concepts of people with intellectual disabilities: they may have a history of failure (Zigler & Burack, 1989) or social isolation, social deprivation and stigma (Jahoda et al., 1988, 1990). Jahoda, Pert, Squire and Trower (1998) support the notion that a vulnerable sense of self may lead to an increased likelihood of inappropriate behaviour and aggression in interpersonal situations. Jahoda et al.’s research built on the findings of cognitive behavioural theorists and found that perceptions of
interpersonal interactions were filtered through the self-concept, that is, people with intellectual disabilities will respond to social situations differently from non-disabled people, dependent on their level of self-concept, and not necessarily because of intellectual inadequacy.

Although a high self-concept is, in itself, considered a significant outcome for people with intellectual disability, it could also be highly valued as an important mediating factor in the successful deinstitutionalisation of adults with mild intellectual disabilities. If perceptions of interpersonal interactions are filtered through the self-concept, then self-concept will have an impact in the area of social integration, the area of greatest need for people with mild intellectual disabilities who are being deinstitutionalised (Jahoda et al., 1990). Szivos (1990) has also found that high self-esteem was needed for successful integration into community settings.

Research has not, however, consistently found that individuals with learning, physical and sensory disabilities have lower levels of self-esteem and self-concept than their typically developing peers (Chapman, 1988; King, Shultz, Steel, Gilpin & Cathers, 1993; Llewellyn & Chung 1997; Silverman & Zigmond, 1983). A more consistent pattern has been that people with these disabilities score lower on the domains of self directly related to their disability (Chapman, 1988; Cooley & Ayres, 1988; Grolnick & Ryan, 1990; King et al., 1993). For example, Grolnick and Ryan (1990) found that students with learning disabilities scored lower on measures of cognitive competence and academic self-regulation relative to the non-disabled control groups, but they did not differ on general self-perceptions. King et al. (1993) found that adolescents with physical disabilities differed on some subscales related to physical competence, but their overall self did not differ from the normative sample. The multidimensional self-concepts of people with physical disabilities in Hong Kong were only lower on the subscales that related to physical self-concept and material self-concept (Tam, 1998). Martinez and Sewell (1996), using the Tennessee Self-Concept Scale, found no differences between a matched sample of students with visual impairment in a mainstreamed college environment and their sighted peers. In addition, an Israeli study found there were no differences between the self-concept of adults with learning disabilities and “non-handicapped adults” (Reiter & Bendov, 1996). Given that none of these studies specifically examined people with mild
intellectual disabilities, such people particularly those who have been institutionalised, may be seen as more vulnerable to developing a negative self-concept because of differing life experiences (Zigler & Burack, 1989). Hence, recent research suggests that self-concept is a significant variable for consideration in examining the impact of deinstitutionalisation. If these people have low self-concepts, it could mitigate against them being able to socially integrate into the community. However, as yet the research literature is inconclusive about the impact of deinstitutionalisation on the self-concept of people with mild intellectual disabilities.

Limitations of Previous Self-Concept Research on People with Intellectual Disabilities

The use of the unidimensional model of the self may help explain some of the numerous anomalies that have occurred from the attempts to measure the self-concept of people with intellectual disabilities. As with the general field of self-concept research, research with people with intellectual disabilities has had the same problems as has self-concept research more generally (i.e., the lack of theoretical bases, lack of theoretical research designs, poorly designed instruments and reliance on unidimensional instruments which still persists in this research area). These problems have resulted in conflicting patterns of results. Other problems specific to research with people with intellectual disabilities include small sample sizes due to the nature of the population that do not permit psychometric evaluation of measurement tools or sophisticated statistical analysis. The use of small sample sizes also results in more difficulty in achieving statistical significance so there is a tendency to over-interpret chance results.

To overcome small sample sizes, some studies include students with a range of disabilities. However, Johnston (2001) has found that different disability groups of children score quite differently on multidimensional measures of self-concept and recommends that it is unwise to group people with differing disabilities together when assessing multidimensional self-concepts. Therefore, the results of studies combining participants with different presenting disabilities could be confounded. Some of these anomalies, along with the difficulties in testing people with intellectual disabilities, actually led to the call for the abandonment of using standardised measures of global
self-concept for adults with intellectual disabilities (Zetlin & Turner, 1988). Zetlin and Turner and others advocated the use of qualitative interviews to examine the self-concept of people with intellectual disabilities.

**Current Self-Concept Instrumentation for People with Mild Intellectual Disabilities**

Over the past 20 years there have been many efforts to assess the self-concepts of persons with intellectual disabilities. In general as discussed above, researchers have used unidimensional self-report scales and have obtained conflicting results. Explanations of these conflicting results have included mention of more general problems with the measurement of self-concept itself. Such criticisms have been directed at the vague and incomplete state of self-concept theory, over reliance on conventional assumptions about personal attributes and roles, inappropriate item selection for the target group, and reliance on self-report measures. Therefore, the conceptual and methodological issues in relation to self-concept research that have been identified with the general population are further compounded in the assessment of self-concepts in people with intellectual disabilities (Zetlin & Turner, 1988; Zetlin, Heriot & Turner, 1985). As a consequence, serious doubts must be raised about the results obtained from unidimensional instruments that are based on outdated theory.

Many of the studies that have used measurement questionnaires to report on self-esteem must be questioned as to their theoretical and psychometric appropriateness (e.g., Szivos, 1990 Szivos-Bach, 1993; Barlow & Kirby, 1991) because researchers have not demonstrated the reliability of instrumentation for people with mild intellectual disability. Szivos (1990) and Szivos-Bach (1993), in two widely cited studies, used 24 items selected from different self-esteem questionnaires (the original sources of these items were not mentioned) to cover the key dimensions considered by Coopersmith (1967) as important to self-esteem (power/significance, virtue and values, and competence). Szivos then used this measure to assess self-esteem in the 1990 study and self-esteem and social comparisons in the 1993 study. The other criterion for inclusion of items on Szivos’ scale was that the items not be too confusing for people with intellectual disabilities. Participants \((N = 50)\) were individually administered the instrument and were asked to place a counter representing themselves on a picture of a ladder. The ladder had five rungs; each rung
was then translated into a Likert scale from 1 to 5. The author also factor analysed the self-esteem scores and found five factors that were called positive self, social competence, being different, anxiety, and work competence. However, no scores were reported for the subscale scores. This was a very small sample on which to base tests of validity for 24 items. The author did not recognise self-concept was a multidimensional construct and therefore only used global self-esteem scores in the subsequent studies using this scale (Szivos-Bach, 1993). In this later study, using data from the same 50 participants as the 1990 study, Szivos-Bach (1993) assessed the validity of her self-esteem measure by correlating it with a stigma scale that contained researcher-devised items and items utilised in previous research, for example, from Kuh (1985) and Piers-Harris (1964). The correlation of the self-esteem items with the stigma items was 0.54 and the self-esteem alpha for this questionnaire was 0.90. The author claims these results indicated acceptable scale homogeneity. No other statistics relating to scale characteristics were reported. In the preceding study in 1990 (Study 2 in the same paper), Szivos administered the Piers-Harris Self-Esteem Questionnaire (1964) to seven people engaged in an intervention program. The instrument was modified to remove all references to school because the participants were attending a vocational college, but the actual changes are not described. Szivos did at least present the items of the modified self-esteem scale utilised; other researchers have not felt compelled to even document the self-esteem instrument utilised. For example, Barlow and Kirby (1991) did not specify the scale utilised at all, and just noted that there were 14 questions which assessed self-esteem and also did not present the psychometric properties of the instrumentation utilised. In addition when attempts have been made to validate instrumentation difficulties have been encountered. For example, Dagnan and Sandhu (1999), using a shortened (six items) version of the Rosenberg Self-esteem Scale, conducted a principal components factor analysis followed by a varimax rotation that accounted for 58% of the total variance. The scale had a mean item correlation of 0.34 and an alpha value of 0.62. These authors tried to validate their scale, but exploratory factor analysis statistical techniques are rarely applied to such a small sample size ($N = 47$) and the stronger test of confirmatory factor analysis was not used.
Given multiple researcher-devised scales have been utilised, research with people with intellectual disabilities has not been characterised by the use of standardised instruments with demonstrated psychometric properties. Only one study that the author knows of (Reiter & Bendov, 1996) reported the subscales of the *Tennessee Self-Concept Scale* (Fitts, 1964) for 30 people with learning disabilities. Many investigators have adapted the administration, wording and response formats for existing scales without assessing the impact these changes had on the reliability and validty of these measures (e.g., Dagnan & Sandhu, 1999, Jiranek & Kirby, 1990, Griffin, Rosenberg, Cheyney & Greenberg, 1996). For example, Jiranek and Kirby (1990) and Dagnan and Sandhu (1999) did not pilot instrumentation modifications or demonstrate the psychometric properties of the instrumentation employed with their participants with mild intellectual disability.

At present, most studies (see chapter 4) conducted have relied on unidimensional instruments such as the *Rosenberg Self-esteem Scale* (Rosenberg, 1965) or the *Coopersmith Self-Esteem Inventory* (1981) because they are short, easy to administer and have simple response formats. However, modifications of the Rosenberg scale were frequently used to make the scale easier for adults with intellectual disability. Jiranek and Kirby used the 10-item version the *Rosenberg Self-Esteem Scale* with the response format modified from a four-point scale to a “Yes/No” format. No attempt was made to pilot this modification or assess the impact on the results. Dagnan and Sandhu (1999) used a six-item version of the original scale (Rosenberg, 1965) to assess self-esteem of their 47 participants: the language of all items was simplified and a pictorial representation and blocks were used to help participants respond to the five different categories. Griffin et al. (1996) assessed the self-esteem of their large group of participants (*N* = 200) with the *Coopersmith Self-esteem Inventory-Adult Form* (Coopersmith, 1981). The responses allowed for each item to be changed from “like me” and “unlike me” to “yes” and “no” to enhance comprehension of the items for the participants. This adaptation was pilot tested, but unlike most research with adults with intellectual disabilities, the test was then group administered unless the participants could not read the items. Group administration has not been considered to be appropriate for people with mild intellectual disability since Zetlin et al. (1985) and Zetlin and Turner (1988) raised concerns about the
standardised testing of self-concept of people with intellectual disabilities, emphasising the lack of validity of responses under group testing conditions.

Hence, research examining the self-concept of people with mild intellectual disability has suffered from flaws similar to those in self-concept research in other areas. These include tests that have been researcher constructed with undemonstrated psychometric properties, unpiloted changes to test items, differing administration regimes and scoring formats. Adherences to the unidimensional model of self-concept and methodological problems have plagued this area of research. This has resulted in questioning the validity of such research results with adults with intellectual disabilities.

**Summary of Self-Concept**

To summarise, self-concept is an important mediating and outcome variable both in the general population and for people with mild intellectual disability. Over the past 20 years there have been theoretical and measurement advances in self-concept in the general population (Craven et al., 2003; Marsh, Craven & Debus, 1998). The most significant finding is that self-concept is a multidimensional construct (Marsh, 1990). These major developments have not been reflected in the study of self-concept of people with intellectual disabilities, where the outdated unidimensional model and its associated measures still dominate research.

**Implications for the Present Investigation**

Therefore, self-concept research with adults with mild intellectual disabilities seems to be characterised by the methodological weaknesses that have predominated in earlier self-concept research in the general population. As such, the structure of the self-concept of adults with mild intellectual disability has yet to be determined. Furthermore, self-concept measurement instruments that account for a multidimensional theory of self-concept and with demonstrated reliability and validity are yet to be identified for, or utilised with, this population. The present investigation attempts to address some of these issues. First, research on people with intellectual disabilities should also reflect the advances in self-concept theory in the general
population. The research design of the present investigation was underpinned by a multidimensional theory of self-concept. The SDQIII (Marsh, 1989b, see chapter 6) was selected as the strongest available measurement instrument with demonstrated psychometric properties for the general population. A larger-sample size of adults with intellectual disabilities than usually reported was also utilised in the present investigation to facilitate the application of advanced statistical tests to test the psychometric properties of the instrumentation employed. In addition, given previous research (Szivos, 1990; Szivos-Bach, 1993; Griffin et al. 1996) has used the Coopersmith Inventory to assess self-esteem, this instrument was utilised as a basis for comparing and contrasting the results from the present investigation with results in the previous literature. However, self-concept researchers have advocated that future research needs to include both multidimensional measures of self-concept and unidimensional measures of self-esteem (Marsh & Craven, in press; Marsh, Craven & Martin, in press) in order to capitalise upon a construct validity approach to the study of intervention effects (Craven, Marsh & Burnett, 2003). The inclusion of this instrument also enabled comparison with the SDQIII to test whether multidimensional instrumentation has potentially stronger explanatory power than global self-esteem measures alone in relation to adults with mild intellectual disability.

**Locus of Control**

*Significance of the Locus of Control Construct*

The locus of control construct has assumed considerable importance in educational/motivational research. Recent reviews cite many studies on the implications of the concept for cognitive, motivational and personal-social performance (Lefcourt, 1991). People who have greater control in their life are likely to have a higher quality of life, and this is true for the general population as well for people with intellectual disabilities (Wehmeyer & Schwartz, 1998). Significant relations between locus of control and desirable educational outcomes (e.g., self-concept, academic achievement) have been found in many studies. Since its conceptualisation, the locus of control construct has been applied to a wide variety of disciplines and populations to explain individual and group variability in motivation, personality and learning. Characteristically, external locus of control has been
associated with progressively more maladaptive outcomes, whilst an internal locus of control is associated with adaptive ones (Fournier & Jeanrie, 1999). The predictive power of this variable is further strengthened by the evidence that internal orientation is systematically related to behaviours that lead to more successful adult outcomes (Wehmeyer, 1994a).

**Theoretical Background**

In 1966, Rotter described the concept of “(internal or external) reinforcement control”, also called locus of control in these terms:

> When a reinforcement is perceived by the subject as following some action of his own but not being entirely contingent upon his action, then, in our culture, it is typically perceived as the result of luck, chance, fate as under the control of powerful others or as unpredictable because of the great complexity of the forces surrounding him. When the event is interpreted in this way by the individual we have labelled this as a belief in external control. If the person perceives the event is contingent upon his own behaviour or his own relatively permanent characteristics, we have termed this a belief in internal control (p.1).

Therefore, locus of control refers to an individual’s perception of the degree of control that they have over what happens to them and over what constitutes their sources of reinforcement. The locus of control construct, as defined by Rotter (1966), is a generalised expectancy for internal or external control of reinforcements. Internal control refers to the individual’s belief that outcomes depend on one’s own behaviour. External control is the belief that outcomes depend upon factors beyond the individual’s control (Stipek & Weisz, 1981).

Other authors who have explored this concept have expanded and applied it in different contexts. Burns (1984) suggested that the locus of control is associated with the general attitude that one has towards oneself, one’s own behaviour and one’s capacity to influence events. He added that individuals with an external locus of control feel that not only do they lack control over what happens to them, but also
they actively look for external control in their environment precisely because of their feelings of incompetence. Strickland (1989) defined the “internal-external” beliefs of a person as expressing his/her perception of the degree of dependence or independence between one’s action and behaviour and the events that occur in one’s life. In his model, Parkes (1989) defined an internal person as seeing himself/herself as the deciding element in what happens to him/her and as feeling that he/she has the power to change or influence the course of events. The external person sees external forces as determining the unfolding of his/her life and grants himself little power to change or influence the course of events. Finally, Lefcourt (1991) considered that locus of control permits a better understanding of why certain people react actively and with determination when faced with difficulties, whereas others feel powerless when faced with the same difficulties. Moreover, it has been suggested that differences in locus of control may explain why people differ in the way they respond to successful or unsuccessful experiences. The locus of control construct has also been incorporated into self-attribution and self-efficacy theory and research (Bandura, 1997) and other psychological research. For example, Kalechstein and Nowicki (1997), in a meta-analysis, found that academic achievement motivation was negatively related to externality. In addition, Greve, Anderson and Krampen (2000) found that high self-efficacy was negatively related to externality.

Overall, the locus of control construct has proven itself to be highly useful in distinguishing the active and passive attitudes of individuals in relation to their environment. In spite of the importance that the locus of control construct has assumed, major theoretical and methodological criticisms have been raised in relation to research examining this construct. Dubois (1987) and Rotter (1990) have affirmed that locus of control has been studied independently of a theoretical context. Although the social learning theory and locus of control research of Rotter (1966) have influenced all subsequent work in the area of self-attributions, the single dimension of internality/externality has been seen as inadequate to explain the self-attribution process. Weiner (1974) and other attribution theorists have argued that at least a further two dimensions are necessary: stability (stable-unstable) and controllability. Phares (1976) pointed out that locus of control seems to have been incorrectly thought of as a stable personality trait, a dichotomous variable opposing external or internal individuals like two distinct populations. Finch, Shanahan, Mortimer and Ryu (1991)
discussed several studies which suggest that the orientation of control does not constitute a set personality trait but rather an individual response to successes and failures in life. Lefcourt (1991) considered that locus of control is not a characteristic to be found in individuals but rather as a response to situations that individuals find themselves in. Lefcourt (1991) and Rotter (1975) have also raised the possibility of breaking down locus of control into more specific subconcepts, and Levenson (1974) has also proposed a multidimensional representation of the locus of control.

Locus of control is an important construct, where internal locus of control has been associated with positive outcomes. There are still conceptual and methodological inconsistencies, mostly related to whether locus of control is a unitary or a multidimensional construct.

**Methodological Issues**

Apart from the theoretical issues that have arisen in regard to the concept of locus of control, there are important methodological issues that have characterised this area of research. Rotter (1966) originally postulated that whilst locus of control may not vary over given different situations, the construct should generalise across situations for each individual. However, there is increasing evidence that locus of control does not operate uniformly across different situations, but is multifaceted, much in the same way as self-concept. Secondly, Joe (1971) concluded his extensive review of the literature by recommending the use of specific rather than generalised measures. In other words, there has been a call for measures that do not just measure the dichotomous internal or external locus of control, but may offer a multidimensional view of locus of control. Also, there has been a move away from generalised scales to scales that are situation specific such as vocational/career scales (Fournier & Jeanrie, 1999). Thirdly, there has been increasing recognition that self-attributions do not generalise over success and failure outcomes (Marsh & Richards, 1986), as there is evidence to suggest that people may have an internal locus of control for success outcomes, but externalise failure outcomes, thus creating a self-serving bias (Dixon, 1985).
Significance of the Locus of Control Construct for People with Mild Intellectual Disabilities

Apart from the work of Wehmeyer and his colleagues, locus of control research has rarely been applied to people with intellectual disability. A major reason for this is that the measurement of locus of control, like self-concept, relies on self-report measures. Some researchers and practitioners have tended to view self-report information from this population as unreliable. However, a change from the deficit model of disability to the rights model of disability has led to changes in attitude and methods of research (Antaki & Rapley, 1996). Although self-reporting methods are now seen as important for this population, there are still questions about the reliability and validity of the measures used to test such perceptions for adults with intellectual disabilities.

In the research that has been conducted with adults with intellectual disabilities, the limited results have been consistent, that is, people with intellectual disabilities have highly external control orientations whereby they ascribe control over what happens in their lives to luck, chance or the influence of powerful others rather than to their own actions and choices. Therefore, people with intellectual disabilities score in a more external direction on locus of control scales than people without disabilities (Wehmeyer, 1993a, 1994a; Wehmeyer, Kelchner & Richards, 1996). This occurs even when inflation of scores for acquiescence has been taken into account (Wehmeyer, 1994a). Hence, results of locus of control research for people with mild intellectual disability are unlike those reported in the self-esteem/self-concept literature where there seems to be little consistency. While there is a typical developmental trend for people in the general population to become increasingly internal with age, this trend does not occur for children and youth with intellectual disability (Wehmeyer, 1994c). Wehmeyer suggests that the perceptions of adolescents and adults with intellectual disabilities remain external across the life span.

There are several reasons put forward as to why people with intellectual disabilities hold perceptions of external control. First, the environments in which they are educated, work and live are segregated and interactions with nondisabled people have often been shown to have created dependency. Research has shown that
individuals with intellectual disabilities have had limited opportunities to make choices which affect their quality of life (Stancliffe & Wehmeyer, 1995), experience limited autonomy (Wehmeyer & Kelchner, 1994) and become over-reliant on nondisabled adults to initiate and engage in activities (Zigler & Burack, 1989). Secondly, individuals with intellectual disabilities also experience considerable failure in their lives that may contribute to external perceptions of control. Thirdly, they tend to be causal “unrealists” (Wehmeyer, 1994b) whereby they do not seem to understand the contributions of effort and ability to positive outcomes and believe more in the influence of unstable external forces (e.g., luck, chance or the influence of powerful others).

It is not known whether external control perceptions may change when adults with intellectual disabilities are deinstitutionalised. Some studies suggest that internal locus of control scores are increased on deinstitutionalisation (Tossebro, 1995; Wehmeyer et al., 1996). Importantly, studies of adults living in more normalised settings have concluded that internal locus of control orientations have been associated with better outcomes including: increased autonomy and independence (Wehmeyer et al., 1996), more positive employment outcomes (Wehmeyer, 1994b) and a better quality of life including greater opportunities to make choices in their lives (Wehmeyer & Schwartz, 1998). The scores are still largely external in comparison to the general population, but they have moved in a more internal direction. Individuals with intellectual disabilities who have more internal locus of control compared to other people with intellectual disabilities also have a higher quality of life.

There has been increasing recognition that self-attributions do not generalise over success and failure perceptions of control (Marsh & Richards, 1986). In fact, in other populations there has been the recognition that these attributions may be asymmetrical and self-serving (i.e., internal for success and external for failure). In relation to adults with intellectual disabilities, there seems to have been little recognition of this development. Wehmeyer and his co-workers report global locus of control scores in all of their studies with adults. This probably reflects the instrumentation that is usually used for adults (either the Rotter or Nowicki-Strickland...
Scales) that do not separate success and failure outcomes, and do not balance causal attributions for internality and externality.

Given the limitations of the instrumentation commonly used, it cannot be determined if adults with intellectual disabilities use the self-serving bias that is prevalent in the nondisabled population whereby successes are attributed to internal causes and failures to external causes in order to enhance self-esteem. However, previous research (Marsh & Richards, 1986) would also predict that as people with intellectual disabilities have such a long history of failure, they may be less able to capitalise upon self-serving biases and are, therefore, less able to enhance their self-esteem in this way.

Locus of Control Instrumentation for People with Mild Intellectual Disabilities

Despite the rapid advances and large amount of research being conducted in this area, instrumentation is, as yet, relatively undeveloped. The instruments vary greatly in content and form and the results of empirical studies of a general measure of locus of control have been inconsistent up until now. This has led researchers to recommend the development of more domain specific scales (Lefcourt, 1991).

The only measure that has been consistently utilised for adults with intellectual disabilities is the Adult version of the Nowicki-Strickland Internal-External Scale (ANS-IE; Nowicki & Duke, 1974; Nowicki, 1981; Wehmeyer, 1993a, 1993b). Locus of control as measured by the ANS-IE is generally agreed to be multidimensional (Wehmeyer, 1994a). Although the factor structure of the ANS-IE has been examined for adolescents and adults without disabilities, there have been few studies demonstrating the psychometric properties of this instrument when used with adults with intellectual disabilities, although available research suggests that the locus of control construct is multidimensional for adults with mild intellectual disability. For example, Finch, Kendall, Spirito and Mikulka (1981) examined the factor structure of the ANS-IE and found a four-factor structure representing three general themes of helplessness, superstition and futility. These authors concluded that the ANS-IE factor structure compares favourably with the children’s version of the Nowicki-Strickland (CNS-IE) indicating both developmental consistency and
construct validity. Wehmeyer (1993a) examined the factor structure for people with intellectual disabilities using a principal components factor analysis with varimax rotation. Criterion for item inclusion was a factor loading of at least .30. A minimum of three items was required to establish a coherent theme for a factor. Construct validity was assessed by examining relations using the Pearson-product moment correlation co-efficient between the ANS-IE and the selected sub-scale scores from the Self-Description Questionnaire-II (SDQ-II) (Marsh, 1990). It was hypothesised that scores for the Parent, Same and Opposite Sex, General, School, Physical Appearance, and Ability subdomains would be conceptually related to locus of control. The factor analysis suggested that the ANS-IE had adequate structural validity and factors were consistent in these with those identified by other researchers. The construct showed adequate construct validity when compared with the conceptually related SDQ-II. ANS-IE scores were significantly correlated with total SDQ scores ($r = -.18, p = .01$). ANS-IE scores attained low correlations with subscale scores from the Parent Subscale ($r = .23, p = .002$) and the Physical Ability Subscale ($r = -.17, p = .01$).

In a further study designed to examine the reliability of the ANS-IE, Wehmeyer (1994a) reported qualified support for the use of the instrument for people with intellectual disabilities. The Cronbach alpha was 0.77, comparable to findings from other studies examining internal stability of the instrument (0.74 to 0.86). The test-retest reliability for people with intellectual disability on the ANS-IE was 0.53, which is lower than that reported in the norms (0.83) by Nowicki and Duke (1974). However, a major finding was that acquiescence was not a significant problem on this measure (Wehmeyer, 1994a).

In conclusion, Wehmeyer, (1994a) has found that the ANS-IE was a useful tool for people with intellectual disabilities, particularly those in the mild range of disability. He also considered that the test had adequate validity and acceptable reliability. Wehmeyer thought that acquiescence might account for one-point differences, but that this did not invalidate the use of the scale. Wehmeyer’s research has shown that people with intellectual disabilities are competent to provide valid self-reports of control. Acquiescence, which has been a major issue in this field, seems to have much less effect than has been commonly feared (Wehmeyer, 1994a).
Factor analyses of scores from locus of control scales from people with intellectual disabilities show that the factor structure is similar to people without intellectual disabilities. Therefore, although there might be better ways of measuring this construct (i.e. use of an instrument that can distinguish between internal and external attributions and a more situation specific scale or multi-dimensional scale), this measure that was designed for the regular population seems to hold validity for people with intellectual disability as well.

Wehmeyer and his co-workers have highlighted some of the characteristics of locus of control in people with intellectual disabilities. However, although Wehmeyer (1993a) described the locus of control construct as multidimensional, his subsequent research reports only total scores. The limited research to date has found that adults with intellectual disabilities have a high external orientation in perceptions of locus of control. The research does not allow predictions to be made separating success and failure outcomes. In overseas research, people’s perception of locus of control seems to have responded to changes in environment and placement, particularly where people are given more autonomy and choice.

**Summary of Locus of Control**

Locus of control is an important construct in the psychological literature, with internal orientations of control being associated with psychological health and better outcomes. Previously the concept was thought to be a stable trait that generalised across situations. However, current theory implies that the construct goes beyond the dichotomous internal/external orientation to multidimensionality, and that it would be more appropriate to measure the construct with situation specific scales such as vocational or family scales. For people with mild intellectual disability, only one scale has been used, the ANS-IE (Nowicki & Duke, 1974). Even though the construct has been recognised as multidimensional by the major researcher in this field (Wehmeyer), he has always used this unidimensional scale, which also does not allow for the separation of internal and external attributions for success and failure outcomes. In spite of these inadequacies, Wehmeyer and his co-workers have developed a body of research that does characterise the locus of control construct for people with intellectual disabilities whereby people with intellectual disabilities have
been found to be highly external compared to the general population and to not follow the normal developmental pattern of increasing internality across the lifespan, but remain external into adulthood. However, for those people with intellectual disabilities who are more internal compared to others within this group, the relations to other related variables, such as quality of life, seems to be in the predicted directions.

**Implications for the Present Investigation**

The ANS-IE (Nowicki and Duke, 1974) was chosen for the present investigation to assess locus of control because despite its recognised shortcomings, it is the only scale that has been used with people with intellectual disabilities.

**Quality of Life**

The quality of life (QOL) construct had its beginnings in the deinstitutionalisation movement of the 1970s and the related concept of normalisation. Quality of life is now extremely important in the field of intellectual disability. Schalock (1996a) feels that this construct has the potential to replace normalisation as the guiding principle for service delivery. Much research has described the concept over the past 15 years. Previous research based on the quality of life construct was characterised by a plethora of definitions, models and ways of measuring quality of life. Although there are still many areas of controversy in the area (Hatton, 1998; Taylor, 1994, Schalock, 2000), over the past five years there has been a developing consensus of the definition and measurement of this construct (Schalock, 1996a; Felce & Perry, 1995; Hatton, 1998; Cummins, 2000; Schalock, 2000).

When quality of life first attracted attention in the field of intellectual disabilities, Landesman (1986) challenged professionals to determine what was meant by the term *quality of life*, to develop ways of evaluating and measuring the construct and to identify variables in environments that were associated with a better quality of life. Since Landesman’s (1986) article and the work of Schalock (1990) and others, it has been suggested that quality of life is the foremost issue and guiding principle in
the design, delivery and evaluation of services for people with intellectual disabilities and their families (Goode, 1989; Schalock, 1990). Felce and Perry (1995) have emphasised that quality of life is being increasingly viewed as the ultimate criterion for the assessment of service delivery to people with intellectual disabilities.

Previously, there was a plethora of definitions and measuring techniques for assessing QOL. However, researchers (e.g., Schalock, 1996a; Felce & Perry, 1995; Hatton, 1998) in the 1990s have developed a broad consensus, concerning the nature of the quality of life construct, its measurement, and the purpose of measuring quality of life in services for people with intellectual disabilities (Borthwick-Duffy, 1990; Brown, 1993; Goode, 1994; Schalock, 1990, 1996a, 1996b).

The burgeoning consensus in this area in relation to the nature and measurement of quality of life has been seen by some researchers (Schalock, 1996b; Felce & Perry, 1995) as an exciting development; whilst others view these developments with alarm and caution against adopting the concept as a key outcome measure for assessing services (Wolfensberger, 1994; Edgerton, 1990, 1996; Taylor, 1994). Some commentators doubt the usefulness of the concept. Wolfensberger (1994) warned that the use of the term was so charged that rational debate had become inhibited and that the notions of quality of life and value of life were becoming so fused that they were being used to justify withdrawal of effort and resources, and even life itself. Wolfensberger also drew attention to the origins of the concept as a focus of the well-being of populations not individuals. He alerted workers to the problem of imposing a definition of quality of life that does not take into account individual difference.

**Theoretical Background**

Currently there are over a 100 definitions and models of quality of life (Cummins, 1997b). Before 1974 there were only four articles between 1968 and 1970 dealing with quality of life that related to people with intellectual disability. Hughes, Hwang, Kim, Eisenman and Killian (1995) reported 87 studies between 1972 to 1993 that met their research criteria. This rapid increase reflects the interest and importance
of the concept but also the lack of consensus which existed up until 1995 regarding its meaning. Definitions have ranged from the very inclusive such as the following:

Quality of life has been defined as a concept that reflects a person’s desired conditions of living related to home and community living, employment and health functioning. As such quality of life is a subjective phenomena based on a person’s perception of various aspects of life experiences, including personal characteristics, objective life conditions, and the perceptions of significant others (Schalock, 1990, p.141).

To the more controversial, deriving from a sociological paradigm:

Quality of life is a matter of subjective experience. That is to say the concept has no meaning apart from what a person feels and experiences. As a corollary to the first proposition, people may experience the same circumstances differently. What enhances one person’s quality of life may detract from another’s (Taylor & Bogdan, 1990, pp.34-35).

Quality of life has also been viewed as the discrepancy between a person’s achieved and their unmet needs and desires (Brown, Bayer & Brown, 1988; Parmenter, 1988; Goode, 1990).

Despite numerous attempts to define the construct of quality of life, its definition is still seen by some to be imprecise. In the preceding definitions, a central theme is the discrepancy between subjective and objective criteria for defining quality of life. The term subjective refers to the individual’s point of view and the term objective refers to the societal point of view. Some authors (Edgerton, 1990; Taylor & Bogdan, 1990) argue that only the subjective domains are relevant. However, many writers caution against assuming that one can define a decent or reasonable quality of life just from subjective domains (Edgerton, 1990) because individuals differ in what they consider important. Hatton (1998) has since argued that the assessment of subjective factors should be abandoned because of the difficulties of measuring such factors. However, Felce and Perry (1995) warn against the adoption of only objective measures as it could lead to the imposition of professional definitions of quality of
life. In fact, in the past few years, the emphasis has swung back onto subjective assessment as being more important. In response to the objective versus subjective debate, Schalock (2000) has counselled that there is a need to move beyond this distinction to a multidimensional conceptualisation of quality of life where the emphasis is on multiple assessments of the core dimensions. Notwithstanding these alternative views, there is broad agreement among writers who favour the concept that quality of life is multi-dimensional and that it includes objective and subjective domains. It is also hypothesised to include a third dimension of personal satisfaction (Felce & Perry, 1995; Cummins, 1997c) even though the latter construct has been difficult to operationalise and adequately measure for people with intellectual disabilities.

In the mid 1980s, the concept of quality of life began appearing in the developmental disabilities literature. Initially, quality of life was referenced to the population at large and thus objective normative comparison to the general population was considered to be appropriate. Alternatively, Flanagan (1982) suggested that quality of life should be evaluated within the context of people with intellectual disabilities (i.e., differently from the general population). Other authors have also questioned whether or not quality of life should be considered the same for all persons within a given language/cultural grouping (e.g., Cummins, 2000). However, it is now thought (Goode, 1990, 1994) that quality of life should be conceptualised similarly for persons with or without disabilities. Cummins (1997b) states that it is imperative that all definitions and models of quality of life be referenced to the general population, both in their conception and operational measures.

Conceptualisation of what is a quality of life for people with disabilities has been clarified since the 1980s (Cummins, 1998) and techniques for direct client interviews have been developed (Heal & Seligman, 1990). Although authors have developed different models, there is now considerable overlap between domains in the models that suggest critical factors that influence a person’s perceived quality of life. Models in the past have stressed process (Goode, 1990), community adjustment (Halpern, Nave, Close & Nelson, 1986), programmatic intervention (Brown et al., 1988), person-environmental interactions (Parmenter, 1988, 1992) and program improvement/outcome evaluation (Schalock & Keith, 1993; Schalock, Keith,
Hoffman & Karan, 1989). Schalock (1996a) sees the consensus in relation to these models as characterised by social indicators, psychological indicators and goodness of fit/social policy perspectives. Social indicators generally refer to external environmentally-based conditions such as health, social welfare, friendships, standard of living, education, public safety, housing neighbourhood and leisure. These indicators may be defined as a direct normative statistic. The goodness of fit/social policy perspective proposes that quality of life is related to a match between a person’s wants of needs and their fulfilment. Schalock et al. (1989) have demonstrated a positive relation between measures of quality of life and the goodness of fit between a person and his/her living and employment environments.

**Models of Quality of Life**

Although the specifics of models have differed, there is now a broad agreement about what constitutes quality of life in services for people with intellectual disabilities (e.g., Brown, 1997; Cummins, McCabe, Romeo, Reid & Waters, 1997; Felce & Perry, 1995; Goode, 1994; Schalock, 1990, 1996a, 1996b, 1996c; see Table 3.1). General quality of life models as well as models for people with intellectual disabilities emphasise the multidimensional nature of quality of life (for reviews see Felce & Perry, 1995; Hughes et al., 1995). Although researchers have proposed slightly different dimensions, the developing consensus highlights eight core quality of life dimensions: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights (Schalock, 1996b; see Table 3.1). Together these dimensions provide coverage of key aspects of life. However, they are conceptualised as being separate, if not independent, of each other. Consequently, it is important to measure separately multiple domains to gain a comprehensive picture of a person’s quality of life. Also it has been found that objective and subjective measure of life quality are poorly related to one another (Cummins, 1997a). Each of these dimensions has several components. Current models do not specify how related or independent these components of the dimensions are, but there is a general assumption that as many components as possible should be considered to provide quality of life assessment.
Schalock (1996b) has summarised (Table 3.1) the eight core quality of life dimensions and associated indicators based on the work of a number of authors (Borthwick-Duffy, 1995; Cummins, 1997a; Hughes, et al., 1995). Cummins (1997b) and Felce and Perry (1995) have described a model that mirrors the developing consensus in the field. This model conceptualises quality of life as having three major components: first, the circumstances of each individual’s life; secondly, what the individual values from a subjective point of view; and, thirdly, the satisfaction of the individual in light of their own individual system.

### Table 3.1

<table>
<thead>
<tr>
<th>Schalock</th>
<th>Felce</th>
<th>Cummins</th>
<th>Hughes and Hwang</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional well-being</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td>X (Social)</td>
<td>X (Intimacy)</td>
<td>X</td>
</tr>
<tr>
<td>Material well-being</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Personal development</td>
<td>X (Productive)</td>
<td>X (Productivity)</td>
<td>X</td>
</tr>
<tr>
<td>Physical well-being</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

**Core Quality of Life Dimensions (from Schalock, 1996b)**

- Self determination | X (Productive) | X (Productive) | X |
- Social inclusion | X (Social) | X | X |
- Rights | X (Civic) | X (Safety) | X (Civic responsibility) |

In summary, quality of life has become an important construct in the field of intellectual disability that has effected program development and service delivery for people with intellectual disability. In the 1980s, the concept was ill-defined and there were major conceptual and measurement issues. These included the following questions: What were the indicators? Is quality of life a unitary or multi-dimensional trait? and Should quality of life be the same for all individuals in a social group? These conceptual questions have largely been answered and there is broad agreement as to the indicators. Quality of life is similar for all people and is not defined...
differently for people with an intellectual disability, and quality of life is multidimensional (Schalock, 2000). The measurement issues have been harder to answer, including the validity of the continued use of total scores, whether objective or subjective factors are more important, the relation between objective and subjective scales, how to measure subjective indicators for people with intellectual disabilities, how to deal with problems such as acquiescence, and how to measure personal satisfaction.

The Measurement of Quality of Life

Unitary vs. multidimensional. A basic point made repeatedly in the literature is that quality of life is a multidimensional construct. Therefore, it follows that comprehensive quality of life assessment must include objective and subjective components. However, over the past decade proponents of quality of life models that relate to people with intellectual disabilities have increasingly emphasised the importance of subjective indicators (e.g., Brown, 1997a; Cummins et al., 1997; Felce & Perry, 1995; Goode, 1994; Schalock, 1990, 1996a, 1996b, 1996c). Subjective assessments of quality of life, whether in terms of subjective well-being or satisfaction with various aspects of life, are emphasised as being central to an authentic model of quality of life that respects the aspirations of the individual. For example, Schalock (1996c) advocates that quality of life is best understood from the perspective of the individual. This recent focus on subjective assessments of quality of life adds complexities to the previously mentioned models as within each dimension (each with its own components) both objective and subjective indicators are now assessed (see Table 3.2).

Total scores. As mentioned previously, summing and subjective assessments of a number of quality of life dimensions is a process fraught with difficulty. Investigators have recently attempted to address this problem by assessing the individual’s values (e.g., Cummins et al., 1997; Felce & Perry, 1995). These ratings are then used to weight scores on particular quality of life dimensions. Thus, if an individual rates material well-being as extremely important, then this dimension will weigh more heavily on that person’s total score. This way of summing dimensions respects the values of different individuals, yet still allows total quality of life scores
to be produced. It, however, still contains the assumption that quality of life is a unitary construct that is a product of life circumstances and the perceived importance of various life circumstances for the individual, as the models do emphasise the individual’s experience. However, most systems for assessment also provide methods for summarising and standardising the experience of individuals to produce quality of life scores that can then be compared (e.g., Cummins et al., 1997; Felce & Perry, 1995; Keith & Schalock, 1994). How the different dimensions and components within those dimensions are summed is a major problem (Felce & Perry, 1995) because any method for producing a single quality of life statement contains implicit assumptions about the relative importance of different dimensions of quality of life. In recent models used with people who have intellectual disabilities, authors have recommended turning to the subjective judgments of people with intellectual disability to weight the overall importance of particular domains (Cummins et al., 1997; Felce & Perry, 1995). This procedure helps resolve the problem of producing summary quality of life “scores” from the complexity of multidimensional quality of life assessments. In fact, Schalock (2000) no longer advocates use of total scores for quality of life comparisons; he recommends that there should be a change in research designs so that they no longer concentrate on between-groups or between-conditions design. He advocates a multivariate within approach where there is an emphasis more on the relations between predictor variables and quality of life (Dixon, Marsh & Craven, 2003). Another reason for the abandonment of total quality of life scales is that objective and subjective quality of life are very poorly correlated (Cummins, 2000).
<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>EXEMPLARY INDICATORS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional well-being</td>
<td>Safety, Spirituality, Happiness</td>
</tr>
<tr>
<td></td>
<td>Freedom from stress, Self-concept,</td>
</tr>
<tr>
<td></td>
<td>Contentment</td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td>Intimacy, Affection, Family</td>
</tr>
<tr>
<td></td>
<td>Interactions, Friendships, Supports</td>
</tr>
<tr>
<td>Material well-being</td>
<td>Ownership, Financial, Security, Food</td>
</tr>
<tr>
<td></td>
<td>Employment, Possessions, Socio-economic status, Shelter</td>
</tr>
<tr>
<td>Personal development</td>
<td>Education, Skills, Fulfilment</td>
</tr>
<tr>
<td></td>
<td>Personal competence, Purposeful activity, Advancement</td>
</tr>
<tr>
<td>Physical well-being</td>
<td>Health, Nutrition, Recreation, Mobility</td>
</tr>
<tr>
<td></td>
<td>Health care, Health insurance, Leisure, Activities of daily living</td>
</tr>
<tr>
<td>Self-determination</td>
<td>Autonomy, Choices, Decisions</td>
</tr>
<tr>
<td></td>
<td>Personal control, Self-direction, Personal goals/values</td>
</tr>
<tr>
<td>Social inclusion</td>
<td>Acceptance, Status, Supports, Work environment</td>
</tr>
<tr>
<td></td>
<td>Community activities, Roles, Volunteer activities, Residential environment</td>
</tr>
<tr>
<td>Rights</td>
<td>Privacy, Voting, Access</td>
</tr>
<tr>
<td></td>
<td>Due process, Ownership, Civic responsibilities</td>
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</tbody>
</table>
Difficulties Measuring Quality of Life of People with Intellectual Disabilities

Most measures of quality of life rely on interviewing either individuals or their proxies. There are a number of methodological concerns about measuring the quality of life of people with intellectual disability. Chief among these are acquiescence, the use of proxies, the tendency towards socially desirable responses and the lack of effective communication systems (Goode, 1990; Heal & Seligman, 1990; Parmenter, 1992).

Acquiescence. Acquiescence has long been recognised as a major source of response inconsistency when interviewing people with intellectual disabilities (Heal & Seligman, 1996). Heal, Novak and Chadsey-Rusch (1985) suggest overcoming this by interviewing individuals using types of questions that seem natural and then statistically correcting for response bias. Antaki and Rapley (1996) present interesting, yet contradictory findings, that acquiescence has been over-rated. Matikka (1996) found that acquiescence for her participants with intellectual disability was markedly lower than the results obtained by Heal and Seligman.

Proxies. The use of proxies is often necessary to assess an individual’s quality of life (McVilly, Burton-Smith & Davidson, 2000). There have been varying findings in the research literature about the congruence between self-reported ratings of quality of life and those made by proxies. Overall research findings to date indicate a need for caution when interpreting proxy-based data. Correlations are generally low, or there may be a discrepant picture of agreement (Rapley, Ridgway & Beyer, 1998; Stancliffe, 1999, 2000).

Problems with subjective well-being in quality of life assessment. Borthwick-Duffy (1990) has suggested that quality of life is a subjective construct that resists numerical scoring. An alternate view, presented by Hatton (1998), has highlighted the conceptual and methodological problems that occur if only subjective quality of life was relied on. These include the disenfranchisement of people with severe intellectual disability, the meanings that different participants bring to quality of life assessments, and the use of subjective well-being as an indicator of quality of life. The problems with interviewing people with intellectual disability are well documented (Heal &
Seligman, 1990), although they may have been over-stated particularly for people with mild intellectual disabilities. However, there is an extra complication that occurs with quality of life interviews of people with intellectual disabilities. This concerns the meanings that people with intellectual disability bring to the quality of life interview. Recent evidence suggests that people with intellectual disabilities view quality of life interviews as tests of their fitness to remain or move to the community rather than as research that will have no potentially negative consequences (Antaki & Rapley, 1996). Antaki & Rapley have also found that interviewers have expectations of people with intellectual disabilities that lead them to downgrade answers that do not fit with these expectations (Antaki & Rapley, 1996).

Hatton (1998) suggests that subjective indicators should be excluded but Felce and Perry (1996a) point out cogent reasons why subjective indicators are needed to safeguard people with intellectual disabilities. To assess the impact of moving by only objective criteria could lead to a professional-driven model that is largely irrelevant to the aspirations and values of people with intellectual disability. Judging the quality of life of people with intellectual disabilities could lead to “the tyranny of the typical” (Hatton, 1998, p.108) where all people with intellectual disabilities have to conform to a lifestyle decreed by middle-class professionals to be typical or desirable (Edgerton, 1990, 1996; Taylor, 1994; Wolfensberger, 1994).

Another problem relates to general psychological research concerning subjective well-being over the lifespan. Intuitively, it would be thought that people would be happier if they enjoy a better standard of living, better health, more friends, and so forth. However, Edgerton (1990, 1996) has suggested that subjective well-being is influenced by personality and disposition rather than objective life circumstances, and life circumstances remain stable over the life span. These findings have profound implications for this area. If quality of life is dependent on personality, then long-term improvements cannot be expected beyond short-term euphoria. There is mixed evidence for this from the deinstitutionalisation literature (Hatton 1998; Emerson, 1999). Typically there were short-term improvements after moving from an institution but little long-term change. This contrasts with the findings of Schalock (1996a) who found that quality of life improved after 10 years of placement in the community. The contrasting evidence could also be explained by the possibility that
the placement in the community did little to change real circumstances of people with disabilities except for their immediate physical surroundings. Schalock (1996a) found that significant program, philosophy, and service changes were needed to bring about the change.

**Difficulties in measuring personal satisfaction.** The assessment of the third variable in the quality of life model is not unproblematic. First, people generally report high levels of satisfaction particularly as their expectation of services are so low (for reviews see Emerson and Hatton, 1994, 1996). Also, as discussed above, personal satisfaction may reflect more internal temperament than external conditions. Thirdly, little relation has been found between objective and subjective reports. Edgerton (1990) and others have cited research where significant changes in life conditions may only induce temporary changes in quality of life reports. Satisfaction may not be a subtle indicator. It may be an unresponsive indicator, sensitive only to gross and immediate changes. Satisfaction is a measure of comparison; it is impossible to divorce it from context and frame of reference effects. The ability to change life conditions to achieve optimal subjective quality of life cannot be assumed. Most people with disabilities lack independence, real life experience and real adult autonomy. They are “often forced to inhabit worlds of other people’s construction” (Felce & Perry, 1995, p. 66). Certainly it cannot be assumed that life style reflects individual choice. Socially devalued people may be particularly prone to having low expectations and report satisfaction rather than dissatisfaction even under adverse life conditions.

Research has supported the prediction that people with intellectual disability will remain philosophical about their present living situation and optimistic about the future in spite of adverse conditions such as poverty, poor housing, threats to health and safety, victimisation, social isolation, personal loss, and failure to gain and maintain employment (Close & Halpern, 1988; Edgerton, Bollinger & Herr, 1984). Felce and Perry (1995) found that even though residents were housed in very different physical environments, from impoverished hospital wards to high quality community housing, there was no differentiation between satisfaction with their circumstances. There is a large volume of research that reports the independence of objective and subjective life quality (Cummins, 2000). The reason that has been postulated is that
people adjust to their objective living conditions and reach homeostasis and that unless they are subject to frequent cold, hunger or concerns for their safety, most people have a strong tendency to report that they are approximately 75% satisfied with their life (for a review see Cummins, 1998).

**Measures of Quality of Life**

Many scales for measuring quality of life have been developed over the last two decades and are reviewed in Cummins (1996). He concludes that two scales that show promise are the *Quality of Life Questionnaire* (Schalock & Keith, 1993) and the *Com-Qol* (Cummins, 1997). These two scales are the ones most commonly recommended for use as they are the most extensively, psychometrically validated quality of life measures (Rapley, Ridgway & Beyer, 1998). The *Quality of Life Questionnaire* has four sections (Schalock & Keith, 1993), three of which concentrate on objective data and a fourth that addresses satisfaction. However, how to combine the objective and subjective appraisal is not specified. In addition, this scale is designed to give equal weighting to every aspect and ignores the fact that individuals may weight different aspects as more important to them than others. Alternatively, researcher assumptions about the relative importance may be used to generate a weighting structure.

Cummins has developed parallel forms of the Fourth Edition of the *Com-Qol* either for people with intellectual disability (Com-Qol-15, Cummins, 1997a) or for the general population (ComQol-A, Cummins 1997a). The *ComQol* assesses objective and subjective quality of life within seven life domains (see Table 3.2 and Figure 3.1). Subjective quality of life is derived by separately measuring the importance and satisfaction of each domain. These scores are then combined as the product of satisfaction and importance to yield a weighted measure of subjective quality of life (Cummins, 1997c). This differential weighting approach is consistent with the concept that well-being stems from the fit between the individuals’ perceptions of their objective situations and their needs, aspirations and values (Felce & Perry, 1995). In both cases (the Cummins and the Schalock and Keith models) the method of combining items for assessment can be seen as quite arbitrary. Other potential limitations are response validity and relevance of the data to population norms. To
address response validity, Cummins has designed a pretest protocol that allows for differences in competence to be assessed and provides slightly different response formats. Research has indicated that people with mild to upper moderate levels of intellectual disability can reliably respond to the scale without the need to use proxies (Cummins et al., 1997). The issue of data referability of population norms is addressed through using the parallel forms of the scale (Verri, Cummins, Petito, Vallero, Monteath, Gerosa & Nappi, 1999). Cummins et al. (1997) have confirmed that the scales yield the same gold standard satisfaction data (i.e., people with mild intellectual disabilities reported the same subjective means as people without disabilities). This finding has also been supported by cross-cultural research using the ComQol measures (Verri et al., 1999). Therefore, the Cummins instrument can be seen as an excellent attempt to solve the conceptualisation and measurement issues of the 1980s and 1990s in quality of life research.

**Summary of Quality of Life**

Based on the models outlined above, a number of quality of life instruments were developed and there is now considerable consensus about the way that quality of life is measured. Current thinking is that these core dimensions can be measured using a multi-methodological perspective (Schalock 2000). After 1995, a consensus developed for the definition, model and measurement of the construct. There are still problems with measurement that relate to the objective and subjective nature of the concept and more generally to the difficulty of any measurement with people with intellectual disability. There is some suggestion that quality of life may not respond to changes in a service delivery if it is more reflective of an internal personality disposition and that people with intellectual disability exhibit homeostasis similar to the general population.
Numerous quality of life surveys have been produced in the last twenty years. Efforts to measure quality of life have not received as much attention in the literature as the conceptualisation of the construct (Schalock, 2000). Generally researchers have focussed on either objective or subjective indicators. The objective indicators may give some indication of community or collective life. Subjective factors focus on the person’s evaluations of psychological well-being or personal satisfaction. The previously mentioned difficulties in defining quality of life in terms of objective or subjective conditions has led researchers to try to combine both, along with some measure of personal satisfaction. This model was selected as the best available model for purposes of the present investigation.

**Implications for Present Investigation**

The present investigation tries to address some of the problems with conceptualisation and measurement of quality of life in the following ways. First, it uses a multi-dimensional measure of quality of life that assesses both objective and subjective indicators over a range of agreed-upon domains. It also includes a measure of personal satisfaction. At the inception of this research, the Cummins model and the associated instrument ComQol-I5 (Cummins, 1997a) was considered to be the
Adaptive Behaviour

Importance of the Construct

Because of problems with the identification of IQ (Jenkison, 1996), the concept of adaptive behaviour was added to the definition of intellectual disability (Grossman, 1983). In the early 1960s, the American Association for Mental Retardation (AAMR) formally included adaptive behaviour in its definition of intellectual impairment. Consequently, adaptive behaviour became a required construct in the diagnosis. Adaptive behaviour may or may not have been included in assessments prior to that time. In the following years, the AAMR published the AAMD Adaptive Behaviour Scale (AAMD-ABS, Nihira, Foster, Shellhaas, & Leland, 1974), which has become one of the most widely used instruments for assessment and programming for people with intellectual disabilities (Stinnett, Fuqua, & Coombs, 1999). Today, adaptive behaviour is routinely considered by psychologists, in conjunction with general intellectual functioning and other relevant factors, when a diagnosis of intellectual impairment is made.

Theoretical Background

There is still professional disagreement regarding what specifically constitutes adaptive behaviour, although the construct of adaptive behaviour has become the focus of increased attention in the fields of psychology and special education. There is no single definition of adaptive behaviour that is universally agreed upon in the professional community, but in the past decade or two, there appears to be at least an increasing level of agreement regarding some of the important aspects. Until very recently, the most widely used explanation of adaptive behaviour was that provided by the AAMR. The AAMR Manual on Terminology and Classification (Grossman, 1983) includes adaptive behaviour as an essential component in the diagnosis of intellectual impairment. Adaptive behaviour was defined as significant limitations in
an individual’s effectiveness in meeting the standards of maturation, learning, personal independence, and/or social responsibility that are expected for his or her age level and cultural group (Grossman, 1983, p.11).

The 1992 AAMR definition of intellectual impairment is a departure from earlier conceptualisations (e.g., Heber, 1961; Grossman, 1983) in that it is more specific regarding adaptive behaviour. Intellectual impairment is currently defined by the AAMR as follows:

Mental retardation [sic] refers to substantial limitations in present functioning. It is characterised by significantly subaverage intellectual functioning existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation [sic] manifests before 18 (p.5).

In contrast to earlier definitions, there are now 10 individual adaptive behaviour areas that can be considered when making a diagnosis of intellectual disability. An individual must show limitations in at least two of these. This new definition has resulted in renewed interest in determining the dimensional structure of adaptive behaviour.

Although the term adaptive behaviour implies the attainment of those skills necessary for adaptation and the reduction or absence or problem behaviours, the more conceptually and research-oriented literature typically distinguishes between these two components (Bruininks, Thurlow, & Gilman, 1987). In 1992, the American Association on Mental Retardation stipulated that a positive diagnosis of intellectual disability can only be made in the presence of both deficient adaptive behaviour and below-average measured intelligence resulted partly from the fact that most studies reported low correlations between IQ and adaptive behaviour (e.g., Huberty, 1986). Adaptive behaviour is defined by measures of what a person can do. Unlike IQ, it is normally regarded as a minimum criterion for performance.

Theoretical Issues
There is still no sound theoretical base for the concept of adaptive behaviour, and hence a lack of construct validity for measures of adaptive behaviour. The concept can be criticised on at least three grounds. First, there is a lack of clear guidelines, standards or suggested procedures for assessing adaptive behaviour, although there are now psychometrically, norm-based instruments such as the AAMR-Adaptive Behaviour Scale (AAMR-ABS). A major problem is deciding what constitutes a deficit, impairment or limitation. Adaptive behaviour is defined by measures of what a person can actually do. As a result, most people in the non-disabled population would score full marks for most tests of adaptive functioning. It is only when people have an intellectual disability that one would expect a significant spread of scores. For people with mild or borderline intellectual disability, it is probable that adaptive scores may show a ceiling effect. In addition, the psychometric definition of adaptive behaviour is inconsistent with the needs-model of disability as this definition relies on a concept of a deficit rather than the concept of ability and rights.

Secondly, the concept of adaptive behaviour itself is vague and ill-defined. A perusal of adaptive behaviour scales will demonstrate a lack of agreement, not only on the number of factors or dimensions that make up adaptive behaviour, but also on the number and identity of specific skills involved in successful adaptation. Bruininks et al. (1987) examined studies of adaptive behaviour and identified 10 skill clusters as important for community adjustment. The emphasis on each of these clusters varied from study to study. The factors mentioned were social-emotional development, self-help, consumer, domestic, cognitive, community orientation, vocational, motor and communication. The AAMR-ABS (Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, Spitalnick & Stark, 1992) lists 10 adaptive skills areas in which limitations may occur. These overlap with those of Bruininks et al.(1987), but are by no means identical.

There are disputes as to whether adaptive behaviour is unidimensional or multidimensional in structure. Using a multi-trait, multi-method technique, Widaman, Stacy and Borthwick-Duffy (1993) obtained support for a four-factor model of adaptive behaviour, incorporating cognitive competence, social competence, social
maladaptation and personal maladaptation. In comparison the AAMR-ABS test developers (Nihira, 1969a, 1969b, 1976) obtained three factors for Part A which they described as personal self-sufficiency, community self-sufficiency, and personal-social responsibility, and two factors for Part B which they described as social maladaption and personal maladaption. These findings have had substantial influence on subsequent thinking about adaptive behaviour, but ensuing research (Meyers, Nihira & Zetlin, 1979; Huberty, 1986) has shown that the factors vary in their relative importance across age-groups and levels of disability. Moss and Hogg’s (1997) factor analysis corresponded closely to Nihira’s own factor analysis of the ABS (Nihira, 1976), however, Moss and Hogg found only two factors in Part A instead of three.

Thirdly, the distinction between intelligence and adaptive behaviour is obscure. Perhaps adaptive behaviour can be considered as the application of intelligence in practical everyday life. Some studies report correlations between the two in the moderate range (Huberty, 1986; Jenkinson, 1996).

As opposed to quality of life where conceptualisation has dominated, much of the research on adaptive behaviour has been concerned with its measurement rather than theoretical aspects (Harrison, 1987). It is difficult to separate the concept from the content of the available adaptive behaviour scales (Luckasson et al., 1992).

**Measurement Issues**

**The dimensionality of adaptive behaviour.** Determining the structure of adaptive behaviour is a difficult and unresolved problem. The literature is equivocal, but two contrasting positions can be identified. Adaptive behaviour can be conceptualised as a single-factor or multi-factor construct (Widaman, Borthwick-Duffy & Little, 1991). There has been support for a single, broad personal independence factor across a number of independent studies (Bruininks, McGrew & Maruyama, 1988; Hug, Barclay, Collins & Lamp, 1978; McGrew & Bruininks, 1989; Millsap, Thackery & Cook, 1987; Nihira, 1969a, 1969b). McGrew and Bruininks
(1989) summarised the factor analytic research published since 1965 that examined the adaptive behaviour construct. They cite evidence of a large general factor that can be interpreted as personal independence, and weaker evidence for as many as five other adaptive behaviour dimensions. However, limitations with the single-factor studies have been noted. Methodological and scale variables have influenced the number of derived factors reported across studies (e.g., sample demographics, variables analysed, analytic methods selected and results obtained). Some contend there is only weak, qualified support for the single-factor model (Widaman et al., 1991).

Empirical research has provided stronger evidence for the multi-factor conceptualisation of adaptive behaviour (e.g., Guarnaccia, 1976; Lambert & Nicoll, 1976; Nihira, 1976; Silverman, Silverman, Lubin, & Sersen, 1983). These studies differ widely in terms of the method of analysis used, the level of analysis (item parcels, individual items, or subscale), scale representation of adaptive behaviour domains, sample demographics, and variables analysed. The results support the multidimensionality of adaptive behaviour, but there is disagreement as to the number and description of the factors.

In a review of factor analytic studies, McGrew and Bruininks (1989) have suggested that adaptive behaviour is a multidimensional structure. McGrew and Bruininks (1989) sought to determine whether the structure of adaptive behaviour varied as a function of research methods; adaptive behaviour scale differences; sample characteristics such as age, placement and living experiences; “handicapped” status or degree of intellectual disability. They examined 16 studies and found, as noted previously, consistently the presence of one to three factors (McGrew & Bruininks, 1989). However, McGrew and Bruininks found that none of the single factor studies used the AAMD-ABS. They found that personal independence or independent functioning is the most widely accepted dimension of adaptive functioning and is the first factor that emerges in factor analytic studies (Guarnaccia, 1976; Nihira, 1969a, 1969b). The next factor to emerge is that of motivation and autonomy to manage one’s own affairs as well as those of others. An alternative explanation of this factor is as the social responsibility factor described by Guarnaccia (1976) and Lambert and Nicolls (1976). This factor relates to social interpersonal
factors and reflects those behaviours important for getting along with others (Reschly, 1987). The social responsibility factor is consistent with the research that investigated the relation between adaptive behaviour and social skills (Gresham & Elliott, 1987). In fact, Gresham and Elliott’s (1987) analysis of the AAMD-ABS was that a substantial portion of it concerns social behaviour.

The analysis of the maladaptive behaviour domain was less complex, with one exception, all samples produced two-factor solutions (Nihira, 1969b). Meyers, Nihira and Zetlin (1979) described the first factor as a personal adaptation factor that typically describes behaviour directed inwards in an autistic-like, self-abusive or stereotypic manner, while social adaptation includes aggressive, destructive behaviour, directed outwards towards other people.

**Summary of Adaptive Behaviour**

In spite of its importance in the field of intellectual disability, there has been much more emphasis given to the measurement of adaptive behaviour than to its conceptualisation. Much debate has centred around whether it is a unidimensional or multidimensional construct. McGrew and Bruininks (1989) found that the majority of factor analytic studies had determined that adaptive behaviour was multidimensional, particularly if the AAMD-ABS was used. Although there is some debate about the number of factors, there is support for the five-factor model of the AAMD-ABS as presented by its authors. The most consistent finding was the presence of a personal independence factor with the second most common being a social-responsibility factor. Analysis of the maladaptive behaviour domain was less complex because all samples, with one exception, produced the two-factor solution.

**Implications for the Present Investigation**

The *AAMD-Adaptive Behavior Scale* (AAMD-ABS) (Nihira et al., 1974) is one of the most widely used measures of adaptive and maladaptive functioning of people with intellectual disabilities. The AAMD-ABS taps the largest number of dimensions and has the greatest representation of the social interpersonal aspects of adaptive behaviour (McGrew & Bruininks, 1989), which is the focus of
deinstitutionalisation and of this research study. For this reason it was chosen to measure this construct. In the standardisation of the scale, five independent factors were identified: personal self-sufficiency, community self-sufficiency, and personal-social responsibility, which constitute Part 1 of the scale, and social adjustment and personal adjustment which are behavioural measures and constitute Part 2 (Nihira et al., 1974). The authors contend that for research purposes the factor scores should be the unit of comparison, so that was the chosen comparison for this research study.

**Social Competence**

*Significance of Social Competence*

Social competence is particularly important for those with developmental delay or mild intellectual disability (Gresham & MacMillan, 1997). Siperstein (1992) quoting Dunn (1968) suggested that special educators have long recognised that the ability of a “handicapped [sic]” person to succeed in society depends, in large measure, on the skill to get along with other people. Further, Edgerton (1967) in his ethnographic sketches showed that social incompetence was the major factor by which the community identified that a person had an intellectual disability. The literature clearly shows that many students with specific learning disabilities exhibit substantial deficits in social competence. Thus the study of social competence is crucial.

*Theoretical Background/Theoretical Issues*

*Conceptualisations of social competence and social skills.* There are many definitions and conceptualisations of social competence and social skills in the literature. These two constructs often overlap and can lead to confusion due to the apparent interchangeability of the two concepts. Social competence has been defined by Vaughn and Haager as “multidimensional construct analogous to intelligence in its higher order and elusive nature” (1994, p. 254). It “is best conceptualised as fluid, and as having multiple related correlates”. Social competence “is the ability to establish and maintain satisfactory interpersonal relationships, gain peer acceptance,
establish and maintain friendships, and terminate negative or pernicious interpersonal relationships” (Vaughn & Haager, 1994, p. 331).

To date, researchers have not reached a consensus of a general definition of social skills. There are no social skills definitions that are universally accepted or applicable in all situations. Social skills definitions have been criticised for being broad and non-specific (Huang & Cuvo, 1997). These authors found that social skills definitions either relied on a broad reference to the social competence domain or identified discrete, situation-specific responses. McFall (1982) identified two major ways in which the concept of social skills has been used: (a) the trait model, which views social skills as underlying characteristics and, (b) the molecular model, which views social skills as discrete situation-specific behaviours. McFall believed that both of these conceptualisations were inadequate and proposed a two-tier model of social competence and social skills, effectively combining the two concepts. Social competence involves a value-based judgment by an observer concerning the effectiveness of an individual’s performance on a specific task. Social skills are the specific component processes that enable an individual to behave in a manner that will be judged as competent (Schlundt & McFall, 1985).

Gresham (1982) has a useful social validity conceptualisation that is very closely aligned to McFall’s. The social validity conceptualisation defines social skills as socially significant behaviours that predict important social outcomes for individuals. An important distinction in this definition is made between social skills and social competence. In this view, social skills are the specific behaviours that an individual uses to perform competently on particular social tasks, (e.g., starting a conversation). Social competence, by comparison, is an evaluative term based on others’ judgements that an individual has performed competently on social tasks (McFall, 1982 in Gresham et al., 2001). Social skills must be taught, learnt and performed, whereas social competence represents judgments or evaluations of these behaviours within and across situations. Others have felt that “social skills are the overt manifestation of social competence” (Vaughn & Haager, 1994, p. 262).

Therefore, the definition proposed by McFall (1982) that combines the social skills and the social competence components is used extensively in the field for
people with mild intellectual disabilities. Social competence is used as a higher-order, general evaluative term, and refers to the adequacy of a person’s overall performance in a particular task, whereas social skills are the specific abilities required to perform competently at this task. This is the conceptualisation that dominates the field and therefore this is the conceptualisation that will be used in this study.

**Definition of social skills.** Following on from this conceptualisation, Chadsey-Rusch (1992) defined social skills as goal-oriented, rule-governed, and learnt behaviours that are situation specific and vary according to social context. They also involve both observable and nonobservable cognitive and affective elements. These assist in evoking positive or neutral responses and avoiding negative responses from others. There are five main components in Chadsey-Rusch’s (1992, p.85) definition that are stressed:

1. There are acceptable and non acceptable social skills, that social skills are learnt and that success in using these skills is judged by others. This implies that if social skills are learnt then they can be taught.
2. Social skills are used for a reason: they are used to achieve goals and purposes and these goals are determined by the individual. It is important that people understand that their social behaviours can effect environmental and personal change.
3. The types of skills that are exhibited by individuals will vary, depending upon the physical setting: the people in the setting and the social context or occasion for the interaction. Setting accounts for a major portion of the variance found in judgments of social performance.
4. Social skills involve both specific and observable and nonobservable cognitive and affective elements. Specific behaviours used to exhibit social skills are both observable and nonobservable and these are based on peoples’ abilities to make fine discriminations and solve problems.
5. There are behaviours that are not observable but thought to be used. These are decoding social contexts, making decisions about observable behaviour and problem solving. Although it is difficult to measure this problem-solving process, there are suggestions that this process can be trained and result in improved social skills.
Measurement Issues

There has always been difficulty measuring some of these constructs in generalisation settings such as the workplace. Chadsey-Rusch (1992), in a seminal article, has criticised the current measurement strategies employed with people with intellectual disabilities in employment settings. She claims that three issues must be addressed. These are:

1. The perceptions and judgments of significant others in the work settings.
2. The perceptions and social goals of the participants.
3. The performance of the behaviours and whether they were performed in the “right time” with the “right person” and in an “effective manner” that resulted in positive or neutral consequences (p. 409).

Assessing the perceptions of others has a long history in social skill studies. In several studies, the perceptions of others (employers, supervisors and co-workers) have been measured to provide social validation data, but they have also been sensitive to the impact of interventions. Usually, the measures are not standardised or validated but are designed for that particular piece of research which may explain why they are able to detect changes (Chadsey-Rusch, 1992). Agran et al. (1987), Rusch and Menchetti (1981), Park and Gaylord-Ross (1989) and Chadsey-Rusch, Karlan, Riva and Rusch (1984) all used perceptions of others as integral measures of the effectiveness of their interventions. All used non-standardised rating forms.

There is very little indication from the literature as to how to measure social goals and perceptions in people with intellectual disabilities. There is very little research that has examined the goals of people with and without disabilities and there appear to be no reliable and valid measures. The social goals of people with disabilities need to be measured as they could have an important influence on the motivational aspects of training. However, at the moment there appear to be few valid assessment tools or techniques.

Measuring the performance of social behaviour in the natural setting. As yet there are no standardised measurement techniques. The measurement of
generalisation to the appropriate setting is quite undetermined. Usually behaviours are expressed in behavioural terms and frequency counts are made of the behaviour within a specified time. Chadsey-Rusch (1992) has outlined criteria for measuring behaviours in these settings that go far beyond the frequency counts usually reported in the literature. Contextual variables that need recording are the appropriate physical setting, the appropriate social occasion, the right time, with an appropriate person. Very few reports record contextual data. Agran et al. (1987) recorded specific stimulus conditions but these conditions were contrived, as were those of Collett-Klingenberg and Chadsey-Rusch (1991).

Chadsey-Rusch (1992) acknowledges that it can be difficult to predetermine the most important contextual variables before the research has commenced. Collett-Klingenberg and Chadsey-Rusch (1991) attached microcassettes to their participants in the employment setting and then rated the tapes in an effort to assess generalisation. This could be seen as an intrusive/reactive measure and could not be easily adopted in all studies because of the difficulty in obtaining consent from different workplaces with large numbers of workers. Also, covert behaviours such as internal cognitive processes cannot be easily assessed. Both Agran et al. (1987) and Park and Gaylord-Ross (1989) could only infer that participants were using cognitive-processing methods as their participants did not emit observable self-instructions.

Breen, Haring, Pitts-Conway and Gaylord-Ross (1985) used anecdotal qualitative methods of research to describe interactions between young people with and without handicaps. Anecdotal qualitative methods are the data collection techniques that seem to have the greatest validity in the literature. They are fairly unobtrusive, do not stigmatise the worker and can suggest context variables that are important for replications of this research.

*Implications for the Current Investigation*

For this investigation, McFall’s conceptual outline of the relationship between social competence and social skills is used. Social competence will be inferred from observable social skills and standardised measures that report on improvements in socialisation, problem-solving and self-esteem. Following on from the discussion of
the measurement issues above, behavioural counts of behaviour within specified times will be made. However, this investigation will also use anecdotal qualitative methods as a data collection technique. Both of these data collection techniques will be collected by personal care workers who have close contact with the participants. They will also provide social validation data and report on contextual variables.

**Summary of Social Competence**

Social competence is an important construct for adults with intellectual disability who wish to live in the community. Social competence is a complex concept that has been operationalised in the field of intellectual disabilities as a two-tier construct where social competence is an overarching evaluation of specific social skill performance. Although there is no accepted definition of what social skills actually are, Chadsey-Rusch’s delineation of social skills has promise and suggests that social skills have both cognitive and affective elements and that the cognitive elements can be improved through training. Measurement of social skills seems to be an area fraught with difficulties. Few standardised techniques are available beyond the frequency counts of behaviour over time. Anecdotal qualitative measures by significant others in the naturalistic setting seems to be the approach that has the greatest validity in the literature.

**Summary**

This chapter has presented the conceptual and measurement issues for the major affective variables that may have an impact on social integration on people with intellectual disability who have been deinstitutionalised. These affective variables are multidimensional self-concept, self-esteem, locus of control, multidimensional quality of life and adaptive behaviour. Social competence and social skills were included as crucial for people with intellectual disabilities who want to live in the community. The theoretical basis of each of these variables was examined with a particular emphasis on the importance of these concepts for people with mild intellectual disabilities. The examination of the constructs was combined with the conceptual and measurement dilemmas that exist in this field. A strong justification for the choice of instrumentation for each affective variable was provided as weak unidimensional instrumentation has been a feature of research for people with mild intellectual
disabilities in the area of social integration. The majority of the instrumentation chosen for this study is multi-variate in nature. The choice of the data collection techniques for the social skills intervention was justified. Combined, the instrumentation for the affective variables and the data collection techniques for the intervention may allow for the complexity of social integration to be explored.
CHAPTER 4
Research Outcomes:
Affective Variables, Social Competence and Social Skills
Interventions

Introduction

Quality of life and adaptive functioning have been traditionally seen as key evaluation measures of deinstitutionalisation. However, the extent of social integration after deinstitutionalisation of adults with intellectual disability is unsatisfactory and, therefore, as this chapter substantiates it seems that traditional constructs must be examined conjointly with interpersonal variables such as self-esteem, self-concept and locus of control to provide a more complete picture of the impact of deinstitutionalisation. This chapter aims to establish the importance of four affective variables (self-concept, self-esteem, locus of control, adaptive behaviour and quality of life) in assessing the success of deinstitutionalisation for people with intellectual disabilities. First, this chapter discusses self-concept and self-esteem. The specific literature for self-concept on deinstitutionalisation and adults with mild intellectual disabilities is limited and therefore the effects on self-concept and self-esteem in educational and vocational placements are also discussed. Secondly, the importance of the locus of control construct for assessing the impact of deinstitutionalisation is discussed. Thirdly, the findings of recent reviews and relevant empirical literature that have assessed quality of life and adaptive functioning are outlined. Fourthly, the literature that relates to interpersonal cognitive problem-solving interventions is reviewed. Finally, the limitations of the available research literature and the implications for the present study are delineated. Discussion in this chapter supports the view that assessment of affective variables is important when evaluating the impact of deinstitutionalisation, and that interpersonal cognitive problem-solving techniques offer an approach to ameliorate the social skill deficits often exhibited by people with mild intellectual disabilities.
The Impact of Deinstitutionalisation upon the Self-Concepts of Adults with Mild Intellectual Disabilities

There is a paucity of research examining the impact of deinstitutionalisation upon the self-esteem/self-concept of people with mild intellectual disabilities and it has yielded mixed results. Research has examined the self-concept/self-esteem of people with mild intellectual disabilities who were living in institutions. In a study that supports social comparison theory (see chapter 2), Gibbons (1985) found that people with an intellectual disability living in an institution were more likely to rate themselves as smart and attractive than those people with an intellectual disability living in the community. The author concluded that it was the community group’s exposure to and comparison with non-disabled people that accounted for this difference. In another study, young adults who were resident, either in an institution or had moved from an institution to the community, were studied (Barlow & Kirby, 1991). Barlow and Kirby used an unspecified and nonnormed 14 item scale to assess self-concept/self-esteem. No differences were found in self-esteem between the two groups. The residents who were living in the community were less socially satisfied but they all said they preferred living in the community because of the greater independence. These results, at first glance, do not support social comparison theory. However, perhaps the lack of difference could be accounted for by the fact that both of these groups of people were working in the same sheltered workshop whereby the community group in this study could have utilised the people they mix with in the sheltered workshop as their social comparison group. Therefore, it is not surprising that there was no significant difference in their self-esteem. In addition, the lack of discrimination of the unspecified self-esteem scale could have also accounted for these results. Furthermore, Barlow and Kirby (1991) note that both groups scored close to the top of this scale, hence there is also a possibility that a ceiling effect could have masked the results.

In an interesting study, Brown and Goldenberg (1993) assessed changes in self-esteem after interventions. All of their participants with intellectual disabilities had been resident in the community for three years prior to the intervention. Self-esteem had not changed over that time. They observed a major improvement in the self-image of clients who received new individualised interventions based on
consumer choice. Other clients who had not received the intervention did not increase their self-esteem. The intervention affirmed that participants valued their rights as adults, as people first with an equal right to a quality of life. The post-intervention change was assessed using client self-reports, as well as data from parents/sponsors and workers. No standardised measures of self-esteem were used. Self-esteem was inferred from questions on quality of life and skills measures. This study, along with the others discussed above, has implications for the field whereby it is not just the address that must change if changes in the self-esteem of people with intellectual disabilities are to be observed; rather it seems imperative that the programs and quality of interactions need to change as well.

Some of the research has been investigated using social comparison theory, that is, self-concept is dependent on the comparison of a given social group. Thus, the self-concept of a person in an institution may be higher than the person in the community (for a fuller explanation see chapter 2). This hypothesis is in direct opposition to that posited by the normalisation movement that derives from stigma theory. Despite the euphoria from the initial move to the community, it might be logical to assume that over time there would be a decrease in self-concept as the major social comparison group may have changed to that of the mainstream community. However, the research of Sziros-Bach (1993), in relation to educational integration, and research from the related field of employment, has implied that the relationship between self-esteem, self-concept and integration into the community may not support one theoretical perspective over another. For example, in the only large-scale study to date, Griffin et al. (1996) randomly allocated two groups of 100 people who were either in supported or workshop employment. These participants were assessed overall for job satisfaction and self-esteem using the Coopersmith Self-esteem Inventory Adult Form (Coopersmith, 1981). Participants who worked in supported employment (partially integrated setting) reported significantly higher levels of job satisfaction and self esteem. Participants living in semi-independent homes had much higher self-esteem than those living in group or family homes. There was also an interesting interaction effect. Those participants who lived semi-independently and worked in supported employment reported the highest levels of self-esteem. From this study it can be seen that exposure to two integrated settings where social comparisons could potentially lead to an even more significant decrease
did not result in such a decrease. In fact, the findings were in the opposite direction. The authors concluded that self-esteem as measured by the Coopersmith SEI was bolstered by feelings of autonomy and self-determination. This study, at first, seems to disagree with social comparison theory. However, as the participants in question were in supported (partially integrated) and not competitive (fully integrated) employment, they still could be using their fellow workers with a disability as their primary reference group.

Another study examining the job satisfaction and psychological well-being of young adults with intellectual disabilities used a modified version of the Rosenberg Self-Esteem Scale (Rosenberg, 1965) to assess adults with mild intellectual disability who had moved to competitive employment from a sheltered workshop (Jiranek & Kirby, 1990). Results for participants with intellectual disability were compared with an employed and unemployed group of “non-disabled” adults. It was found that there was a difference between those who were employed and those who were unemployed in the area of self-esteem. Overall, the level of self-esteem of the adults with intellectual disabilities did not reach the level of the participants without disability whether they were employed or not. Although job satisfaction was higher for workers in competitive employment, it was found that overall psychological well-being was higher in sheltered employment, although self-esteem only discriminated between the participants with intellectual disabilities who were employed or unemployed. This, perhaps, suggests again that social comparison processes are operating in this context. If the workers in competitive employment were using upward comparison with their fellow workers, they may have been subject to negative contrast effects which can have a negative impact on self-esteem. However, the authors of this study noted that the sheltered workshop in their study was large, modern and offered a wide range of options, and had a commitment to normalised practices and policies. The workers in competitive employment had also only moved from the sheltered workshop within the last three months.

In conclusion, it seems that research that has examined the impact on self-concept and self-esteem of deinstitutionalisation on adults with mild intellectual disabilities is equivocal. As such, the research literature does not allow confident hypotheses to be made about the impact of deinstitutionalisation on self-concept and
therefore, does not support the use of one competing theoretical paradigm over the other. Different studies have found completely opposing results. Further confounding this issue is that the vast majority of research is plagued by weak research methodology.

**Limitations of Past Research**

The previous literature in relation to self-concept self-esteem and deinstitutionalisation is flawed as it includes studies that do not capitalise on recent advances in self-concept theory (see chapter 3), incorporates poor self-concept measurement instruments that have not been demonstrated to be psychometrically sound for the population examined, and uses weak methodologies, such as correlational studies and comparison of non-equivalent groups. A major problem for the majority of research in this area is small sample size and an emphasis on qualitative methods of research.

**Instrumentation issues.** There have been immense changes in the conceptualisation and measurement of self-concept and self-esteem (see chapter 3), however, these changes have not been reflected in the assessment of the self with people with mild intellectual disability. Most of the research has assessed the self as a unidimensional construct, and the only area where there has been some divergence from this are the studies that have used the *Self Description Questionnaires* (SDQ) with children with intellectual disabilities (Johnston, 2001; Marsh & Craven, 2002; Tracey, 2002).

Many of the studies that have used measurement questionnaires to report on self-esteem must be questioned as to their appropriateness. Investigators have adapted the administration, wording and response formats for many scales without assessing the impact these changes had on the reliability and validity of these measures (see chapter 3). Much of the research in the area of self-concept of adults with intellectual disability relies on the assessment of general self-esteem as assessed by the *Rosenberg Self-esteem Scale* (Rosenberg, 1965) (see chapter 3). However, modifications of this scale were used to make the scale easier for adults with intellectual disability and the
psychometric properties of neither the original instrument nor modified versions have been demonstrated for this population group.

In summary, the vast majority of self-concept research undertaken with people with intellectual disabilities has been underpinned by a unidimensional theoretical model of self-concept and self-esteem and has often employed measures that are idiosyncratic adaptations of unidimensional self-esteem measures. Research based on older instruments and the data they gathered are no longer appropriate as they were based on theory that has been superseded by advances in self-concept theory, measurement and research (see chapter 3). It seems then, that the widespread use of questionable measures must bring into contention the conclusions of previous research.

**Study design issues.** Quality of research in this area has been reduced by weak research design. Some studies have used correlational data to infer relations between the self and other variables with adults with intellectual disability. For example, Dagnan and Sandhu (1999), in a study based upon one group of participants, found that depression was highly correlated with negative self-concept in people with intellectual disabilities. Other studies have investigated the self and the impact of different (integrated versus segregated) vocational, and living arrangements in adults with intellectual disabilities. Most of these studies suffer from designs that would now be considered weak and have used non-equivalent comparison groups to explore the impact of different settings, as opposed to equivalent control groups and longitudinal research (Szivos, 1990; Jiranek & Kirby, 1990; Griffin et al., 1996). Irrespective of the study design, however, correlation cannot infer causality. In addition, small sample sizes inherent in this area of research confound the results. For example, Jahoda et al. (1988) used 12 participants in a total of three groups and used the observations of their mothers and staff members for their study.

Whilst some studies have employed robust research designs, they have used weak instrumentation. For example, Brown and Goldenberg (1993) assessed the impact on self-esteem of a change in programming for residents who were already living in the community. This was a pre-test post-test intervention with a comparison group. The results showed no change in self-esteem occurred after the intervention,
however, as mentioned previously, self-esteem was inferred from three questions in
the quality of life measure utilised in this study rather than measured by an instrument
specifically designed for this construct. Hence, much of the previous research that has
examined the impact of deinstitutionalisation upon the self-concepts of adults with
mild intellectual disabilities has been characterised by weak research designs with an
overreliance on correlational, non-equivalent comparison group designs. Because of
the dynamic changes possible to the self-concept of adults with intellectual disabilities
who are undergoing transition, these study designs cannot adequately describe the
impact of a move to the community on their self-concepts.

**Qualitative studies.** The disenchantment with the measuring of self-concept
using standardised rating scales (Sternlicht & Deutsch, 1972; Zetlin, et al., 1985), the
design and methodological problems outlined above, and the dominance of the
sociological stigma paradigm, has led many studies to use qualitative methodologies.
This approach attempts to investigate the way that stigma and social comparisons
operate to influence the development of the self for people with intellectual
disabilities (Jahoda et al., 1988; Szivos & Griffiths, 1990; Zetlin & Hosseini, 1989).
These studies have been of heuristic value but have often suffered from the same
problems in that they have a unidimensional theoretical basis. Therefore, there is a
need for qualitative studies that explore the multidimensional theory of self-concept
and give a unique blend of data that could lead to further developments in the field. A
blend of both empirical and qualitative studies is necessary to explore these
dimensions further.

**Summary**

Instruments and study designs used in previous research have limited the
validity of the interpretation of results into the self-concept of adults with intellectual
disabilities. With the need to focus on the deinstitutionalisation of people, and the
change that may occur in their self-concept as a result of their transition to the
community, further research is necessary to provide better outcomes from this
process. Blending both qualitative and quantitative assessments is a heuristically
tactical approach to further advance our knowledge in this area.
The Impact of Deinstitutionalisation upon Locus of Control of People with Intellectual Disability

Even though there has been considerable interest in the psychological literature in the locus of control construct, little research has been conducted with adults with intellectual disabilities. Until ten years ago this construct was not applied to people with intellectual disabilities despite its heuristic utility with other populations. There is now a research base with most of the recent research emanating from the work of Wehmeyer and colleagues (see chapter 3). Locus of control is important because people with disabilities continue to stress the need for more control to improve their quality of life, and there is emerging evidence that self-determination skills are important for more successful outcomes in quality of life (Wehmeyer & Schwartz, 1998). The results from these few studies have been consistent, that is, people with intellectual disabilities have external control orientations. With the move to deinstitutionalisation there has been an upsurge in the psychological literature testing the impact of deinstitutionalisation on locus of control (Sands & Wehmeyer, 1995).

Research Evidence

Wehmeyer and Schwartz (1998) studied 50 adults with mild intellectual disabilities who lived in group homes and who were employed outside. The participants were placed into comparison groups, one group had a high quality of life and the other had a low quality of life. Locus of control was assessed as part of a self-determination measure developed by the Wehmeyer group. They found that higher scores on the self-determination measure contributed to a higher quality of life. This study controlled for impact of living situation, but the researchers acknowledged that there could be considerable overlap between the constructs of quality of life and self-determination. In a further refinement, Wehmeyer and Bolding (1999) tried to control for the confounding impact of the level of disability. They conducted a matched samples design study that compared three groups of people who lived and worked in the community (integrated setting), community based but congregate setting (group home sheltered workshop) and non-community based congregate setting (institution or nursing home and day program). Research participants were grouped into sets of
three individuals, one person per setting each matched according to IQ, age and gender. There were 91 matched groups with a total of 273 people. All of the participants were in the mild range of intellectual functioning. As expected those participants who showed the most internal locus of control lived in the community and worked in the competitive workforce. Although this study used a large number of participants and controlled for confounding variables of the previous research, the study was based on correlational data, and to date, there has been no longitudinal research study conducted that examines locus of control and deinstitutionalisation.

Summary

While there is a typical developmental trend for people to become increasingly internal, this trend does not occur for children and youth with intellectual disabilities (Wehmeyer, 1994a). It may be that deinstitutionalisation will not have a great impact on locus of control as this construct seems to remain external for people with intellectual disability. Wehmeyer feels that the perceptions of adolescents and adults with intellectual disabilities remain external across the life span whereby people with intellectual disabilities score in a more external direction on locus of control scales than people without disabilities (Wehmeyer, 1993b, 1994a; Wehmeyer et al., 1996) even when inflation of scores for acquiescence are taken into account (Wehmeyer, 1994a). Consistent findings emanating from the locus of control literature with people with intellectual disabilities contrasts with the findings in the self-esteem/self-concept literature where there seems to be little consistency.

The Impact of Deinstitutionalisation upon the Quality of Life of Adults with Mild Intellectual Disabilities

The quality of life construct has overtaken adaptive behaviour as the defining principle for the provision of services for people with intellectual disability, although there is still considerable debate about its conceptualisation and measurement (see chapter 3). The theoretical orientation for this construct emanates from the work of Nirje (1985) and concentrates more on the person’s rights and need for personal
autonomy as opposed to Wolfensberger’s (2000) emphasis on social role valorisation. Quality of life is now seen as a sensitising notion and an overarching principle for service delivery (Schalock, 2000). In fact, the concept of quality of life is a social construct that is affecting program development and service delivery in a number of areas including education (Halpern, 1993), health care (Coulter, 1997, Renwick, Brown & Nagler 1996), mental health (Lehman, Rachuba & Postrado, 1995) and intellectual disability (Brown, 1997b; Schalock, 1996b, 1996c). This construct is also being used as the criterion for assessing the effectiveness of services to people with a range of disabilities (Felce & Perry, 1996a; Gardner, Nudler & Chapman, 1997; Perry & Felce, 1995a; Rapley & Hopgood, 1997; Schalock, 1996b).

**Research Evidence**

Over the past few decades there have been a large number of studies examining the effects of deinstitutionalisation on a variety of quality of life parameters (Emerson, 1985). As deinstitutionalisation has been accepted policy for many years, there are now reviews which have summarised the literature from North America (Larson & Lakin, 1989, 1991; Kim, Larson & Lakin, 2001), the UK (Emerson & Hatton, 1994, 1996) and Australasia (Young et al., 1998). The literature is vast, but the following demonstrates the fairly consistent outcomes from the overseas and local literature and highlights research that is relevant for this study.

**UK research.** Emerson and Hatton (1994, 1996) analysed the UK deinstitutionalisation literature and found that the most frequently assessed quality of life dimensions were resident engagement in activity, resident developmental growth, use of community amenities, staff-student interaction, opportunities for choice, residence management practices and social affiliation. The studies in these two reviews showed a wide range of approaches to measuring the impact of deinstitutionalisation on quality of life. To provide a basis for comparison, measures of outcome were categorised according to a number of domains. These included social indicators concerning the person’s physical environment, possessions and disposable income, and user satisfaction with regard to their overall quality of life or the services they were receiving. These measures are traditionally utilised to evaluate quality of life (Emerson, 1985; Felce & Perry, 1995; Hughes et al., 1995; Parmenter,
1992). For each study, results were categorised as significant improvements, no change, or significant deterioration. For comparison group studies and longitudinal studies, results were pooled because the authors thought the findings were very similar. Overall, the majority of studies found an improvement in satisfaction with services, with lifestyle and with life in general. Specifically, Emerson and Hatton (1994, 1996) concluded that deinstitutionalisation had impacted positively on quality of life: residents who lived in community services lived in physically better circumstances, had more personal possessions, had greater opportunities for choice, had more contact with family and friends, made greater use of community amenities, and received more attention from staff. Emerson and Hatton (1994, 1996) also highlighted some of the problems inherent in this area of research. Specifically, they identified the selection of outcome measures, the use of measures of unknown reliability and validity, the use of weak evaluative designs, the failure to measure for potentially important characteristics of settings and participants, and the failure to evaluate the impact over significant periods of time.

Only a few specific instruments have been employed in longitudinal studies examining the impact of deinstitutionalisation. Much of the UK literature used the *Questionnaire on Quality of Life* (Cragg & Harrison, 1986; Donegan & Potts, 1988; Fleming & Stenfert-Kroese, 1990; Dagnan, Look, Ruddick & Jones 1995). This measure uses both subjective and objective indicators of quality of life based upon the principles of normalisation. It does not consider subjective indicators of preference from the clients. Subjectivity comes from observer’s impressions of the environment, not from individual’s ratings. In other words, the emphasis in the UK literature is on proxy responding and observational data by impartial observers. Emerson and Hatton (1996) consider that this emphasis on observational data as opposed to subjective data from participants is a strength of the UK literature. However, this is a point of contention in this field (see chapter 3).

Several significant longitudinal studies have been reported. Fleming and Stenfert-Kroese (1990) assessed the move of 17 people with intellectual disability from hospital and hostel to community-based care, taking measures before and then one year after the move. These authors used a variety of measures including the *Questionnaire on Quality of Life* (Cragg & Harrison, 1986). They compared small
homes with the hostel and hospital and showed an improvement in all domains for the community homes only. Similarly, in a study that examined the move of 36 older people from hospital to community-based homes, Dagnan et al. (1995) also used the Questionnaire on Quality of Life (Cragg & Harrison, 1986). They found that quality of life significantly improved three years after the move across all eight domains measured by this instrument. However, as has been found with other studies, access to the community and social interactions had not increased. In a later study by the same research group, Dagnan, Ruddick and Jones (1998) used a shortened version of the Questionnaire on Quality of Life for 29 older people with intellectual disability. The group were assessed before they left the hospital and then three times during their first 53 months in the community. The data showed a consistent increase for the first 41 months and then a levelling off at 53 months. The authors found that clients had reached a fairly high level of quality of life and suggested that there was a ceiling effect. However, it needs to be noted that all three of these studies did not employ a matched comparison group.

In a study that did use a matched group and is widely cited, Cullen, Whoriskey, Mackenzie, Mitchell, et al. (1995) used a measure derived from the Improving the Quality of Services for Mentally Handicapped People: a Checklist of Standards to measure aspects of people’s behaviour. The study compared a group of people who left hospital with a matched group who stayed in the institution for 30 months. For the group who had left the institution, quality of life improved over baseline scores for six months and remained significantly improved at each of four subsequent, 6-monthly data collection points. No changes were observed for the comparison group.

North American research. Similar outcomes have been found in the US. Schalock and his collaborators have reported longitudinal studies of placement outcomes for people with intellectual disability. Schalock, Harper and Carver (1981) investigated the placement success of people who had been placed five years previously into independent living and competitive employment. Five years later the status of these people was re-evaluated and they expanded their data to measure quality of life (Schalock & Lilley, 1986). They found that quality of life had improved for people who were successfully placed. In another study, the quality of life of
people with mild to moderate disability in three different living environments was evaluated by Burchard, Hasazi, Gordon, and Yoe (1991). These environments were supportive apartments, small group homes with continuous staff supervision and family homes in which people were residing with their families. The participants were followed for three years, information was obtained from knowledgeable informants (usually carers) and structured interviews with participants. Various measures were used including the Community Adjustment Scale (Seltzer & Seltzer, 1976). The study found differences that favoured people who were residing in supported apartments over those residing in group homes as there were more behavioural problems in group homes. Most gains in community adjustment including community integration were not lost, as some research has suggested, and this study found that positive changes in quality of life can occur after the initial experience of being in the community. Most measures of life-style and satisfaction were consistent across the three years within the residence types, and where changes in outcomes occurred they were in the positive direction. For all outcomes though, people living in the most independent accommodation (i.e., supported apartments), even when disability level was kept constant, were far more active, autonomous, normalised and integrated into the community.

In Canada, another small study (Kelly & Walsh, 1998) compared matched groups of 10 people, five years after a move to the community, and found that the participants who were living in the community were more satisfied with their lives and were better psychologically adjusted. The community residence also provided a more normalised existence.

A number of studies have utilised a comparison group design, where deinstitutionalised participants were compared with non-deinstitutionalised groups. In general, positive outcomes for quality of life were observed for deinstitutionalised participants, although the inherent nature of this design could not assess the dynamics of change. Crapps, Langone and Swaim (1985) utilised a quality of life measurement in the evaluation of community-based group home placement. This study focussed on two aspects of quality of life which have been hypothesised to be more predominant in smaller community-based residences than larger congregate facilities: active participation in integration activities and choice of activities. They concluded that
placement in group homes by itself did not seem to contribute to an overall increase in quality of life. Placement needed to be linked to specific programming to achieve this goal of improved quality of life.

One such programming issue relates to social integration which has emerged as an important theme. Many people were successful in the community, but their social integration was minimal. Donegan and Potts (1988) found that their participants were still living on the fringes of society because of their limited ability to cope with social and interpersonal aspects of their lives. The authors suggested that further improvement in quality of life would depend largely on the acquisition of social and interpersonal skills.

It has also been suggested that living in the community without using the residential facilities of an institution seems to be needed to improve quality of life. For example, Janssen, Vreeke, Resnick and Stolk (1999) in a study using a self-designed instrument, examined the differences in quality of life between a range of people from institutions and people in group homes using proxy responding. They compared two matched groups of residents: those living on the edge of the institution and those in the community. Those living in the community had a much better quality of life even though their care needs were the same. In a large study, Stancliffe and Lakin (1998) examined 187 participants with severe to profound disability. Of these 116 were living in community residences and 71 were still institutionalised. The consistent pattern that emerged was that residents who remained in the institution had poorer personal outcomes than those who moved to community settings. It also needs to be noted that most of the research in this area has assessed the move to group homes, rather than individual flats or shared apartments. However, Burchard et al. (1991) in a previously mentioned comprehensive study found that self-contained apartments were far more conducive to personal satisfaction, personal autonomy and personal satisfaction far beyond those of the residents who were in agency-directed group homes.

**Australasian research.** Australian studies have been reviewed by Young et al. (1998). They identified 13 studies from eight projects to provide a comparative review with those undertaken in the US and UK. Although, this small number of
studies reflected the findings of the much larger databases from the UK and US, there is a dearth of studies that have used comprehensive quality of life measures and in-depth analyses. This is surprising given that Australian researchers have been at the forefront of conceptualisation and measurement issues for the past decade and, in particular, a considerable amount of work on the construct has been undertaken in relation to people with intellectual disability (Brown, 1997a; Cummins et al., 1997; Parmenter, 1994). It is also interesting to note that the review of Young et al. found only three research studies investigated the effects of deinstitutionalisation on the quality of life of people with intellectual disabilities. Young et al. examined nine classes of variables that equated with the variables used in Emerson and Hatton’s review of deinstitutionalisation in the UK. All of the studies were then rated as to whether the outcomes were positive, negative, no change or not applicable. Overall Young et al. identified only 10 reports that examined some aspects of the quality of life construct and six of these were from the St. Nicholas project. The authors of this review found that those studies that monitored community participation, such as increased social interaction, increased recreational and leisure activities and greater use of community resources all reported positive outcomes. Contact with family and friends were monitored in five studies and the results were all positive. Client satisfaction with community-based services was also reported positively by four studies. Young et al. (1998) describe only three research designs used in Australian research. Seven of the 10 studies reviewed involved pre-post designs, two of the studies employed post hoc analyses (Jones, 1986; Stanton & Cook, 1985), and one study (Barlow & Kirby, 1991) involved a comparative design. To date, no matching or random selection of participants has been reported in the Australian literature. A longitudinal design was utilised by Barber, Cooper and Owen (1994) to examine the quality of life of 15 residents with mild to severe intellectual disability. They used the Quality of Life Questionnaire (Schalock, Keith & Hoffman, 1990) and found no significant differences between Time1 and Time2 scores. However, their sample was very small, clients had only been in the community for one month at the retesting time and there was no comparison group incorporated into the research design. In a comparison group study, Yu, Jupp and Taylor (1996) used the Lifestyle Satisfaction Scale (Heal, Novak & Chadsey Rusch, 1981) with 49 clients with mild to moderate disabilities who were housed in three different locations. Eighteen people were resident in wards in a hospital, 13 people were situated in cottages on the same
congregate site, and 18 were living in group homes in the community. For community satisfaction there was a clear positive effect for participants living in group homes. They also found that living location had a significant effect on lifestyle satisfaction. More restriction in lifestyle was associated with less total satisfaction. People living in group homes were more satisfied with their residence and community setting and were more satisfied with the contact they had with friends than people living in the cottages. Those people who were living in cottages were more satisfied with the contact with friends than those living in the wards. In contrast, and as would be expected, there was more satisfaction for services by people from the wards or cottages than those living in group homes. This was because the services in the institution were provided on a 24 hour basis.

Australian studies also utilised different techniques used to collect the data. The primary data source of Jones (1986) was a review of existing documents; structured questionnaires were used to collect information from staff, parents and other relevant professionals in six of the 10 studies. Most of the studies used a combination of procedures. For example, the St. Nicholas project used observation and questionnaires and standardised rating scales. However, some studies used only one procedure (e.g., Jones, 1986).

Instrumentation utilised has also varied. Barlow and Kirby (1991) used an adapted version of the Satisfaction Questionnaire of the Community Adjustment Scale (Seltzer & Seltzer, 1976) to assess client satisfaction with residential setting, leisure and work environment. They adapted the scoring procedures to make it easier for the participants in their study. Cummins and Dunt (1990) developed questionnaires to assess changes client’s routines and activities. Relevant third parties completed these questionnaires. Direct and systematic observations were used in two projects to provide objective measures of client behaviour and activities (Barber, Cooper & Owen, 1994; Dunt & Cummins, 1990); a third study (Jones, 1985) used informal observations between staff and clients. Nevertheless, positive outcomes, to some degree, were observed in all studies. The St Nicholas Project (Cummins, Polzin & Theobald, 1990a, 1990b) assessed quality of life using the Residents Routines and Activities Questionnaire. This was completed on behalf of 56 residents who were in the severe to profound range of intellectual disability. After four years, residents had a
more normalised lifestyle, with increases in family contact, contact within the community and with friends plus personal development. All of these indicators were used to infer a higher quality of life. However, Cummins (1990b) commented that although the rate of contact improved it remained extremely low. Barlow and Kirby (1991) used a modification of the Satisfaction questionnaire of Seltzer and Seltzer’s (1976) Community Adjustment Scale to interview 16 clients living in the institution and 15 clients who had moved to the community from the institution about satisfaction with their lives. The community group scored lower than the institutional group because they were less happy with their social relationships. The community group was significantly more satisfied with their autonomy and preferred living in the community in spite of their dissatisfaction with their social relations.

There have been further studies post-dating the Young et al. (1998) review. Research by Rapley and Hopgood (1997) used the Quality of Life Questionnaire (Schalock and Keith, 1993) to assess differences in quality of life amongst rural and urban group homes. They found that on the Competence subscale residents in urban locations achieved significantly higher scores than those in rural locations. Quality of life was related to higher levels of community involvement. In addition, in a frequently cited study, Young, Ashman, Sigafous and Grevell (2000) used the Life Circumstances Questionnaire, a questionnaire developed specifically for their study. They measured life circumstances and choice making and found that scores increased dramatically over a 12 month period of the participants’ living in the community. There were significant increases in regards to choice making after deinstitutionalisation. However, although this measure covers some of the recognised domains in the quality of life literature, it has never been published, does not identify objective or subjective domains; it does not include any measure of individual satisfaction, has no known psychometric properties and yields only a total score. Most authors consider inclusion of the subjective-objective dichotomy as the hallmark of a valid measure (see chapter 3). Current developments in the field of quality of life have called for the abandonment of any total scores and the need for multidimensional reporting of results (Dixon, Marsh & Craven, 2003).

In 2001, Young et al. (2001) published the companion study that examined outcomes for people living in the community for 12 months. The measures were
administered after 1, 6 and 12 months in the community. At this time this was the only rigorous longitudinal study in Australia following a large (N= 95) group of mainly older adults within the Australian context. Even so, unlike the first study, there was no comparison group. The authors used the same instrumentation and assessed quality of life through a combination of choice-making which they claimed is an integral part of quality of life and life circumstances (objective quality of life). These constructs were assessed using the Life Circumstances Questionnaire developed by the authors that seeks information on many areas that are covered in the objective scales of other quality of life measures. The authors felt that, as most of their participants had severe and profound disability, a limited behavioural repertoire and/or no communication skills, it was deemed inappropriate to use validated quality of life assessments such as QOL-Q (Schalock & Keith, 1993) or Com-QOL (Cummins, 1993) as these require participation by individuals or proxy responding. The results showed an increase in the number of personal possessions, the variety and frequency of community outings and contact with family and friends. In this study the staff involved in direct care were respondents for objective information and completion of other standardised assessments. The use of proxy respondents has been shown to have both satisfactory (Schalock & Keith, 1993; Stancliffe, 1999) and questionable reliability (Rapley, Ridgway & Beyer, 1998; Reiter & Bendov, 1996). They are not a substitute for first-hand subjective information but they are accurate for objective issues related to quality of life (Cummins, 1998). Nevertheless, it also needs to be appreciated that people with profound intellectual disabilities do experience difficulty responding to certain measures.

In New Zealand, the first study of deinstitutionalisation by O’Brien, Thesing, Tuck and Capie (2001) examined the quality of life of 54 people who had been living in the community for nine years. Most of their participants had high support needs and exhibited challenging behaviours before deinstitutionalisation. They assessed quality of life using semi-structured interviews with care workers, family and nine verbal participants, asking the interviewees to compare the quality of life of the participants when they first met them or when they were in the institution nine years before, with their present quality of life. The interviews were designed to reflect the quality of life domains identified in the ComQol-ID (Cummins, 1997a). On the basis of the ratings on this unsophisticated and psychometrically unproven measure, they
found that the quality of life of their participants had significantly improved across all domains. As all but nine of the participants in this study were non-verbal, then proxy responding (i.e., using care workers and families to complete measures) was probably unavoidable. However, the authors do not explain why they adapted the ComQol-ID measure. This measure has been designed for people with intellectual disability and has response formats, which can be used for proxy reporting. Another weakness of this study is the use of retrospective data. This approach is not totally unusual in this field. Larson and Lakin (1991) in their overview of parents’ attitudes about deinstitutionalisation found that seven out of 27 studies used retrospective data. Of concern however, is that Larson and Lakin identified a trend for retrospective data to present a more positive view of transition than prospective data. Using retrospective data such as asking people to rate quality of life over a nine year gap must lead to questioning the validity of these results.

Summary

Australasian studies show results consistent with similar studies in other Western countries. The outcomes from these studies are generally positive and consistent with the trends found in larger databases overseas (Emerson & Hatton, 1996; Hatton, Emerson, Robertson, Henderson et al., 1995; Lakin et al., 1994; Larson & Lakin, 1989). However, there are concerns regarding the limited number and scope of these studies, and the methodologies used in design and in data collection. Very few Australian studies include control or comparison groups and there is only one study, that the author is aware of, that has used longitudinal and comparison groups (Young et al., 2000). This latter study used an unknown measure of lifestyle satisfaction that does not reflect the growing consensus in the field to utilise multidimensional quality of life scales. In addition, Australian research could be strengthened by collecting data from participants as a primary data source.

Community placement is associated with increased community participation, greater contact with family and friends and greater overall satisfaction. The overall conclusion from the reviews cited here is that quality of life improves for people with intellectual disability who have been deinstitutionalised. This applies across different countries, different types of residences and across all levels of disability.
The Impact of Deinstitutionalisation upon the Adaptive Behaviours of Adults with Mild Intellectual Disabilities

Until the middle of the 1980s, one of the most common outcome measures utilised to assess the impact of deinstitutionalisation was adaptive behaviour. The concept includes adaptive behaviour and maladaptive behaviour, the latter now referred to as challenging behaviour. Underpinning the popularity of this outcome measure was Wolfenberger’s (1972) version of the principle of normalisation that suggested that more normalised settings facilitate more normative and independent client behaviour (see chapter 3). Historically, the most consistent finding of investigators who have used adaptive behaviour measures (Conroy et al., 1982), notwithstanding the recognised methodological weaknesses of previous research (Emerson, 1985; Landesman and Butterfield, 1987; Larson & Lakin, 1989, 1991; see chapter 3), was that deinstitutionalised clients made gains in the areas of self-help, socialisation and communication. There was a consensus, at the time, that following deinstitutionalisation, people with intellectual disabilities demonstrated an improvement in adaptive skills that would stabilise over time. For challenging (maladaptive) behaviours, the relation of placement environment was thought to be very complex. Reductions in maladaptive behaviour may be independent of gains in adaptive behaviour. Some studies had found, particularly for participants with severe disabilities, that there may be an increase in challenging behaviours with deinstitutionalisation (Larson & Lakin, 1989). This finding was the basis of a key major argument against deinstitutionalisation.

Research Evidence

There is now a significant body of research that has examined changes in adaptive behaviour and maladaptive (challenging) behaviour associated with the move from institutions to the community. Reviews of this research note that, overall, adaptive behaviour was almost always found to improve with the move to community settings (Larson & Lakin, 1989, 1991; Emerson & Hatton, 1994, 1996; Kim, Larson & Lakin, 2001; Lynch, Kellow & Wilson, 1997; Young et al., 1998). Each of these reviews had a focus on studies pertinent to the country of origin, thus reflecting
individual national policies on deinstitutionalisation and their implementation and as such, offers cross-cultural support for findings demonstrating a positive impact of deinstitutionalisation on adaptive behaviour.

Kim et al. (2001) published a review that examined all identifiable studies conducted in the US that assessed changes in adaptive and challenging behaviour associated with deinstitutionalisation. The authors screened 250 studies based on specified selection criteria that resulted in only 33 studies being reviewed. The large exclusion rate reflects the paucity of sound methodological studies in the field. Of the selected studies, there were mainly two types of design: a longitudinal time series design or a longitudinal with a non-deinstitutionalised control group design. The vast majority of studies employed a time series design, whereas 12 compared participants who moved to the community with a control group who stayed in institutions. All of the studies found either a significant improvement in adaptive behaviour after the move to the community or that improvements had occurred, but that these improvements did not reach statistical significance. Similarly, an analogous pattern of results was also present for the findings of studies that examined outcomes in relation to the specific domains of adaptive behaviour (see chapter 3) among the contrast group studies. These studies showed that people who had moved from an institutional setting had either statistically significant improvements relative to the people who had stayed in an institution or had improvements that did not reach statistical significance (Lynch et al., 1997).

A meta-analysis by Lynch et al. (1997) examined the self-care or domestic skills domain of adaptive behaviour and showed the most consistent significant improvements occurred in these domains on deinstitutionalisation. In at least two separate studies, the domains evaluated were academic skills, community living skills, social skills and vocational skills. Only one study examined the subdomains of challenging behaviour. This study reported significant improvements in externalised challenging behaviour and improvements that did not reach statistical significance for internalised challenging behaviour (see Lynch et al., 1997).

Over 22 studies examined changes in overall adaptive behaviour, 13 reported significant improvements after the move to the community and two reported a
significant decline. Longitudinal studies of changes in challenging behaviour displayed the same pattern of results as the contrast group studies whereby 10 studies found improvements in challenging behaviour after the move. However, only three of these were statistically significant. Six studies reported increased levels of challenging behaviour, but again only two of these reported statistically significant increases. Fourteen longitudinal studies examined changes in specific domains of challenging behaviour. In the longitudinal studies, the most consistent pattern of improvements was in social skills. Six of the seven studies that measured social skills found statistically significant results and the seventh found improvements that did not reach statistical significance. Similarly consistent improvements were found for community living skills and vocational skills. Patterns within specific domains of challenging behaviour were not predictably associated with a move to the community. Of the significant changes, five were significant improvements, while two were significant declines. Whilst non-significant findings cannot be interpreted, it is interesting to note that all non-significant results were in the positive direction.

This synthesis of recent US literature continues to support the contention that people with intellectual disabilities living in the community usually benefit in terms of increases in adaptive behaviour. In 19 of the 21 studies, deinstitutionalisation was associated with statistically significant positive changes in adaptive behaviour as measured by standardised instruments. As such, the US literature suggests that deinstitutionalisation impacts positively on adaptive behaviour. In the area of challenging behaviour, somewhat different outcomes were noted for the studies published in the 1990s to those published in the 1980s. The studies of the 1980s reported that challenging behaviour increased. In the 1990s, studies show that challenging behaviour had either improved or was not statistically different as a result of deinstitutionalisation. Perhaps these improved outcomes are the result of improved behavioural support and community programs that are now addressing this issue (Kim et al., 2001).

Similarly, Emerson and Hatton (1996) reviewed the research from the UK and found similar results. However, unlike the US research where standardised measures were used, some of the UK studies considered used direct observation rather than, or in addition to, standardised instruments. Emerson and Hatton (1996) reported that
movement to small community homes was associated with gains in adaptive behaviour and there were a range of different results for challenging behaviours which the authors thought were highly related to whether standardised measures or direct observations were employed. Standardised measures were related to no increase in challenging behaviours whereas direct observations resulted in increases in challenging behaviours.

The same broad outcomes have been supported by Australian research reviewed by Young et al. (1998). In Victoria, the St. Nicholas project saw the transfer of 99 children and young people to community-based living arrangements. Dunt and Cummins (1990) evaluated the impact of deinstitutionalisation on adaptive behaviour, however, the sudden closure of the hospital without a transitional period meant that it was not possible to employ a control group to evaluate the impact of deinstitutionalisation. Nevertheless, Dunt and Cummins reported an overall increase in the level of self-help and socialisation skills after four years. In a follow-up study of the impact of deinstitutionalisation in relation to this group, Cummins et al. (1990a, 1990b) found that adaptive behaviour scores had increased some four years after deinstitutionalisation. The results of the Cummins et al. studies support the observation that life skill development can continue into adulthood, particularly in community settings.

Several Australian studies have assessed changes in both adaptive and maladaptive behaviours, and these studies have produced varying results. For adaptive behaviour, Bowen and Gerry (1995) found that no changes had occurred in adaptive behaviour but there were substantial increases in maladaptive behaviour. Their study involved a small population of people with severe or profound intellectual disability and involved an eight year follow-up examination of 10 clients who were relocated to community-based residences and were assessed using the AAMD-ABS (see chapter 3). In another study, Molony and Taplin (1990) studied a group of people deinstitutionalised from a hospital-based accommodation to group homes in the community. Molony and Taplin (1990) used the Vineland Adaptive Behavior Scale and found significant increases in adaptive functioning (daily living skills, communication skills and socialisation skills) and no changes in maladaptive behaviour for the group that moved to the community over time. There was no change
at all, over time, for the group who remained in the same institution. After the closure of the large institution with deinstitutionalisation in Queensland, Young et al. (2000, 2001) found that adaptive behaviour increased significantly. Challenging behaviour did not decrease. Most of their participants were in the severe range of functioning and these findings mirror the results from overseas for people in this range of functioning.

Summary

The vast majority of previous research examining adaptive behaviour, using matched control groups and longitudinal designs, has found that deinstitutionalisation led to increases in adaptive behaviours as well as possible increases in challenging behaviours, but these challenging behaviours were far more noticeable for clients with severe intellectual disabilities. These increases were sometimes, but not always, greater than those among institutionalised control participants. These reviews, along with sample studies discussed, present a robust set of findings that are remarkable for their consistency, across differing cultures, differing models of community provision and differing levels of disability. Whilst there is not unanimous support for the principle of deinstitutionalisation, the era of housing large numbers of people with intellectual disabilities in congregate care is over. Whatever differences were found in the research reviewed above, they were nearly always in favour of the participants who have moved to the community rather than those who have stayed in the original setting. However, the gains seem to be modest, and occur soon after moving and then become stable.

The Impact of Interpersonal Cognitive Social Skill Intervention Programs on People with Intellectual Disabilities

The importance of social competence in successful social integration into the community of people with intellectual disabilities was reviewed in chapter 2 and chapter 3. The failure to develop such competence puts these individuals at risk. As social competence is recognised as being crucial, this recognition has been translated into various service delivery and instructional approaches to remediate deficits in social competence functioning. One of the most frequently employed of these is social
skills training. Interestingly, the application of these programs to adults with intellectual disabilities who are in the process of deinstitutionalisation has not been reported to the author’s knowledge.

**Research Evidence**

**Social skills training.** Social skills training refers to interventions designed to increase behaviours absent from the individual’s interpersonal repertoire. Much of the focus for intervention in intellectual impairment has been on social skills training. Most studies have used a very traditional and rigid social skills training format that uses a combination of behaviour rehearsal and modelling. Usually this approach consists of:

1. A rationale for why the behaviour is important.
2. Examples of the behaviour.
3. An opportunity to practise the behaviour.

Research has also usually concentrated on enhancing one skill at a time and the same skill for every participant.

Kelly, Wildman, Urey and Berler (1998) investigated interviewing, Karlan and Rusch (1982) compliance, and Chadsey-Rusch, Karlan, Riva and Rusch (1984) question-asking in conversations. These studies have been criticised because the direct instruction methods they employ increase the likelihood that the behaviour will only be performed in the presence of the specialist (Alberto, Sharpton, Briggs & Stright, 1986; Hughes & Rusch, 1989). Agran et al. (1987) found that after reviewing the social skills literature, generalisation measures were either “absent or restricted” (p.132) and called for procedures that were capable of maintaining effects across people, tasks and settings.

In spite of its popularity, social skills training has not been shown to be a particularly strong intervention for people with mild intellectual disabilities. Two meta-analyses (Forness & Kavale, 1999; Mathur, Kavale, Quinn, Forness & Rutherford, 1998) found that social skills training did not provide large, socially important, long-term or generalisable changes in social competence for students with
high incidence disabilities. Meta-analyses with other populations and narrative reviews involving students with learning and behavioural disabilities have shown stronger effects for social skills training (McIntosh, Vaughn & Zaragoza, 1991; Zaragoza, Vaughn & McIntosh, 1991). In response to these criticisms, and in recognition of the importance of self-determination and self-regulated learning, interest has increased in the self-instructional problem-solving interventions.

**Self-instructional problem-solving.** In an interesting study, Foss, Auty and Irwin (1989) compared modelling, behaviour rehearsal and problem-solving. They concluded that problem-solving was not only the most effective in terms of increasing student knowledge but also one of the most time-efficient techniques. In the area of social skills most studies that have taught social skills through the use of various problem-solving techniques, particularly self-instructional problem-solving (Agran et al., 1987; Collett-Klingenberg & Chadsey-Rusch, 1991; Hughes & Rusch, 1989; Park & Gaylord-Ross, 1989) have been conducted in sheltered workshops or schools. Participants were withdrawn and provided with fairly specific and rigid training sessions on a one-to-one basis in a separate room and then generalisation was assessed in the workshop. Although this approach has been shown to be relatively effective, there is recognition that self-instruction may not be a sufficiently powerful technique to produce generalisation to other settings (Chadsey-Rusch, 1986). Agran et al. (1987) found that even though the technique was successful in increasing the target behaviour, their participants did not verbalise in any of the generalisation settings.

**Process training.** More recent studies have examined the impact of problem-solving training packages that enhance adaptive capacity and provide people with intellectual disabilities an executive strategy that can be applied across domains such as process training. Process training is closely related the use of self-instructional problem-solving strategies. With process training, individuals are taught a generative process of social behaviour rather than specific component behaviours (Hollin & Trower, 1988). Chadsey-Rusch (1992) and Park and Gaylord-Ross (1989) demonstrated that youth with mild “mental retardation” could learn the process for generating social behaviours and that the process did lead to the generalisation of behaviours across settings. Additionally, this study begins to suggest that the process approach may be more effective for training job-related social skills than the
traditional social skills training package. In a more recent review by Huang and Cuvo (1997), generalisation data was reported for a great majority of studies (O’Reilly & Chadsey-Rusch, 1992). However, the majority of studies did not actively program for maintenance. This is surprising as maintenance of the social skill is a basic requirement for social skills training (Huang & Cuvo, 1997). The lack of maintenance data severely limits the significance of the studies.

**Interpersonal cognitive problem-solving.** Social problem-solving has been defined as a meta-cognitive process (Elliot, Godshall, Shrout & Witty, 1990). Researchers directed their attention to “how a person thinks” rather than “what a person thinks” (Wehmeyer & Kelcher, 1994). Jahoda (1953) first identified the relationship between interpersonal problem-solving and positive mental health, and research in this area has confirmed that poor social problem-solving skills and maladjusted outcomes are linked. Subsequent research has validated the use of interventions incorporating training in interpersonal cognitive problem-solving skills to improve mental health and performance (Elliot et al., 1990).

Research on individual differences in social problem solving found relationships between effective problem-solving and measures of locus of control, self-efficacy and confidence (Wehmeyer & Kelchner, 1994). Theorists investigating locus of control and self-efficacy linked adaptive perceptions in these areas to effective problem solving and decision-making (Lefcourt, 1976). More recently, educational researchers have emphasised the interrelationship between self-regulated learning, interpersonal cognitive problem solving, self-concept and esteem, and perceptions of control and efficacy (Zimmerman & Martinez-Pons, 1992). It is evident that there is a great deal of reciprocity between these areas. Strong interpersonal cognitive problem-solving skills should contribute to adaptive perceptions of control and efficacy and, in turn, are strengthened and developed through opportunities to self-regulate and enhanced perceptions of control and efficacy.
Researchers examining individual differences in cognitive problem-solving have, during the last decade, provided evidence that people with intellectual disabilities exhibit inflexible patterns of problem-solving (Ferretti & Butterfield, 1989; Ferretti & Cavalier, 1991). This pattern labelled cognitive rigidity by Gestalt psychologists is characterised by repetition of past strategies to solve current problems without adapting to new stimuli or new task demands (Ferretti & Butterfield, 1989). Other shortcomings have been the inability to represent problems, the flexibility to use different strategies and the application of background knowledge for problem-solving (Gresham et al., 2001). It was at first thought that this approach would not be suitable for people with intellectual disabilities because of the previously mentioned problems they may have with problem-solving (i.e., inflexibility and rigidity in strategy selection due to an inability to represent problems and apply background knowledge to the situation). It has now been shown, particularly for people with mild intellectual disability, that social cognitive problem-solving may be linked to successful integration and deinstitutionalisation, as two of the most frequently cited barriers to successful adult outcomes were poor social skills and ineffective problem-solving abilities (Wehmeyer & Kelchner, 1994).

Healey and Masterpasqua (1992) examined interpersonal cognitive problem-solving skills to determine if they could distinguish adjusted from nonadjusted classroom behaviour of children with intellectual impairment. Specifically, they hypothesised that the interpersonal cognitive problem-solving skills of children with intellectual impairment would mediate positive peer relations and behavioural adjustment in the classroom. They found that classroom adjustment could be predicted by interpersonal cognitive problem-solving abilities. They thought that the development of these skills may be critical to successful integration and to eventual adult adjustment. Castles and Glass (1986) examined social skills and interpersonal problem-solving for youth with mild intellectual disabilities and found that training improved interpersonal problem-solving ability. Recent research has determined that the problem-solving approach is seen as an effective strategy with people with mild and moderate levels of intellectual disability (O’Reilly & Glynn, 1995; O’Reilly et al., 2000a, 2000b).
Summary

It can be concluded then, that although increasing attention is being given to social skills training, problems still exist and there are limitations in the research base. Social skills training packages have not been shown to be effective in maintenance and generalisation as they rely too much on external agents. Interpersonal cognitive problem-solving would seem to hold more promise for meeting the needs of people who wish to live independently in the community. There is now a substantial body of empirical literature that shows the benefits of self-instructional training for people with intellectual disability. However, there is also very little evidence for the generalisation effects of interpersonal cognitive problem-solving, even though it is the most widely sought after outcome (Ferretti, Cavalier, Murphy, & Murphy, 1993) and there is little evidence of planning for maintenance (Huang & Cuvo, 1997).

Another area in which the importance of interpersonal problem-solving skills is the use of self-management strategies for learners with intellectual disabilities. Agran, Fodor-Davies and Moore (1986) used a self-instructional technique to promote a problem-solving strategy that then facilitated performance in job related activities. Agran et al. (1987) used self-instructions to improve social skills of individuals with severe disabilities in a work setting. Group home residents with severe intellectual impairment were taught to use self-instruction in combination with multiple exemplars to solve daily living task-related problems (Hughes, 1992). In addition to the increased use of self-management techniques for behaviour change, the importance of interpersonal cognitive problem-solving has been emphasised in research with youth with intellectual disabilities.

Self-determination refers to the attitudes and abilities necessary to act as the primary causal agent in one’s life and to make choices and decisions regarding one’s quality of life, free from undue external influence or interference (Wehmeyer & Kelchner 1994). There is a consensus that specific elements of self-determination require active, effective interpersonal cognitive problem-solving skills (Wehmeyer & Kelchner, 1994). Research into the interpersonal problem-solving skills of individuals with intellectual disabilities who are being deinstitutionalised could lead to procedures
that augment social skills training, self-management and self-determination and consequently, improve the social integration of this population. There has not been as much application of this to the field, as would be expected, because of lack of assessment methods.

Research Outcomes:

Affective Variables, Social Competence and Social Skills Interventions:
Implications for the Present Investigation

The literature discussed above implies that it is useful to examine the impact of deinstitutionalisation on psychological constructs. As such the present investigation was designed to test the impact of deinstitutionalisation upon the self-concept, locus of control, adaptive behaviour and quality of life of people with mild intellectual disabilities. The present investigation also capitalised upon recent advances in theory, research and practice in order to avoid methodological flaws prevalent in previous research. A number of additional issues emerge from the literature on the social competence and affective characteristics of people with mild intellectual disabilities of relevance to the present investigation.

Self-Concept and Self-Esteem

The research conducted thus far on the self-concept/self-esteem of people with mild intellectual disabilities who are in transition (through community living, and/or vocational placement) has yielded mixed results. Some of the studies have reported lower self-concepts, some higher and some with no difference. It is nearly impossible also to conclude if a deinstitutionalisation will produce an increase or a decrease in self-esteem/self-concept. This situation has been caused by a paucity of conceptualisation, methodological problems plaguing this area of research with respect to theory, weak research designs that do not use a comparison group, and a failure to demonstrate the psychometric properties of measurement instruments employed in regards to the population of participants. Although there has been some research describing the self-concept of adults with mild intellectual disability in different living situations, most of it is cross-sectional. This does not allow policy
makers to know how affective characteristics may interact with changes in program and living arrangements to influence the interpersonal growth of people with intellectual disability. Therefore, one of the major problems, which has been highlighted by several authors, is the lack of longitudinal research. It is not possible in this field to randomly assign groups to different placements and often it is difficult to identify an appropriate control group; however pre test, post test designs would seem to overcome problems of the correlational, cross-sectional and between-groups designs that predominate in the area.

There have been some studies that have employed regression models to examine the influence of factors as they interact with the independent variables, but none that have included interpersonal variables such as self-concept, locus of control and self-esteem. Yet, as the review above suggests, these are potentially important constructs to consider when evaluating the impact of deinstitutionalisation.

At present, there is insufficient data to explain the deficits in social competence and affective characteristics of people with mild intellectual disabilities. We know that deficits exist, but we do not know why. The research does not tell us which paradigms are influencing the development of the self for adults with intellectual disabilities (see chapter 2).

These mixed outcomes for self-concept and self-esteem need to be further investigated in the Australian context, as the scope of Australian studies is very limited. Although a variety of data collection procedures were reported, little direct observation was used. Direct observation is a distinctive feature of the UK literature. Instead, Australian research has relied on proxy or third person responding, along with the use of informal scales with unknown psychometric properties. Many studies were also limited in the range of dependent variables studied. In general then, the research designs used in the Australian studies have been relatively weak. Most use a pre-post component and only one used a control group; only the St. Nicholas project is exemplary in the Australian literature in that it used multi-occasion longitudinal research design over an extended period, it used psychometrically sound instrumentation, and reported multidimensional scales.
The present investigation was designed to avoid the methodological pitfalls present in previous research by incorporating a longitudinal research design with a comparison group, utilising psychometrically sound instruments with demonstrated reliability and validity for adults with intellectual disabilities, measuring multidimensional facets of self-concept, and focussing on adults with mild intellectual disabilities to avoid the confounding effect of different levels of disability.

Locus of Control

There have been problems with the designs of locus of control research, which must bring into question some of the findings. Problems acknowledged by researchers include small sample sizes, cross-sectional research designs, the confounding impact of level of disability which was not always controlled for, and an emphasis on correlational designs that may be measuring overlapping constructs. Wehmeyer and his co-workers have elucidated some aspects of the nature of locus of control for people with intellectual disabilities. However, they do not appear to recognise the multidimensional nature of locus of control and their reliance on a unidimensional scale does not reflect some of the developments in the field. It is now recognised in groups without disabilities that self-attributions do not generalise over success and failure perceptions of control (Marsh & Richards, 1986). In fact, in other populations such as those people with learning disabilities, (Chapman & Boersmsa, 1991), these attributions may be asymmetrical whereby these people externalise success outcomes and internalise failure outcomes. There is a well-established pattern in the general population, but that the pattern apparently differs for special populations.

In relation to adults with intellectual disabilities, there seems to have been little recognition of this research development. For example, Wehmeyer and colleagues report global locus of control scores in all of their studies with adults. This probably reflects the instrumentation that is usually used for adults (either the Rotter or Nowicki-Strickland scale) which does not separate success and failure outcomes, and does not balance causal attributions for internality and externality. Given the limitations of the instrumentation, it cannot be determined if adults with intellectual disabilities use self-serving bias that is prevalent in the general population. That is, it cannot be determined whether persons with intellectual disabilities are more likely to
attribute their successes to internal causes and attribute their failures to external causes similarly to the regular population who utilise this self-serving bias to enhance their self-esteem. The results of previous research (Marsh & Richards, 1986) suggests that as people with intellectual disabilities have such a long history of failure, they may be less able to use this effect and are, therefore, less able to enhance their self-esteem.

Research has found that adults with intellectual disabilities have a high external orientation in perceptions of locus of control. An emphasis on cross-sectional and correlational designs and the confounding of the results with level of disability, whilst establishing the importance of this construct for people with intellectual disabilities, has resulted in serious flaws in a number of studies. Often instrumentation utilised has not allowed predictions to be made separating success and failure outcomes, hence it is not known whether adults with intellectual disabilities respond differentially in the context of these outcomes. Results from some studies have shown that people with intellectual disabilities’ perception of locus of control seemed to have responded to changes in environment and placement, particularly where people are given more autonomy and choice. There have been no longitudinal studies that have examined the impact on locus of control by a change in placement and a change in program for adults with mild intellectual disabilities.

The present investigation will address some of the concerns described above by employing the first Australian longitudinal study of the impact of deinstitutionalisation on locus of control for people with intellectual disabilities. This avoids the pitfalls of the correlational-only studies that have predominated in this area. All the participants are in the mild to moderate range of intellectual disability. This controls for the confounding effect of the level of disability that has been a feature of the research in this construct to date. The same instrument used by Wehmeyer and his colleagues will also be used.

Quality of Life

At the inception of this research, Cummin’s ComQol-I5 (1997a) was considered to be the instrument of choice for Australian populations. Cummins
(1997a, 1997b) argues that the whole deinstitutionalisation movement, particularly in the UK, has concentrated far too much on objective data and third party responding. However, the ComQol-I5 has not been implemented in any of the research studies that have assessed quality of life and deinstitutionalisation to date.

No study the author is aware of has used the Cummins instrument for longitudinal assessment. It includes subjective and objective axes; it is multidimensional and includes a measure of satisfaction. The one other study using a longitudinal/comparison group methodology to assess objective quality of life (Young et al., 2000) employed a measure of lifestyle satisfaction that measured objective quality of life but used proxy responding and as such this measure does not fulfil the growing consensus in the field in regards to the need to report objective and subjective scores from the viewpoint of the participants. The authors also used sum scores. There is considerable agreement that quality of life is a multidimensional concept and that precludes reducing it to a single sum score (Schalock, 2000).

The present study is designed to address these issues by using a valid, reliable instrument that assesses both objective and subjective multidimensional scales of quality of life, using a strong longitudinal design with a comparison group, and using participants’ ratings rather than proxy responding.

Adaptive Behaviour

The effects on adaptive behaviour from deinstitutionalisation have varied. Positive outcomes have mostly been reported for adaptive behaviour. However, with challenging (maladaptive behaviour) the results are quite different. The latest Australian research (Young et al., 2001) has found the classic pattern of improvements in adaptive behaviour, but no decrease in challenging behaviour for people with severe intellectual disabilities. Few studies have examined changes due to deinstitutionalisation using the factor scores that the authors recommended for research purposes (see chapter 3). Instead
the studies have focussed on sub-scale scores and summative scores that are recommended for programming and individual assessment. This might explain why there has been some inconsistency in the results and why greater changes have not been reported. This study will use a longitudinal design, a comparison group and analysis will focus on factor scores of the AAMD-ABS instrument.

**Interpersonal Cognitive Social Skills Interventions**

Social skills programs have been successfully implemented with people with intellectual disabilities, however most studies have not demonstrated generalisation or maintenance of the improvements once the intervention has been withdrawn. Interpersonal cognitive social skills interventions appear to be a useful technique for enhancing the generalisation and maintenance. Generalisation and maintenance will be particularly important for adults who are living in the community.

**Summary**

This chapter has provided a review of the literature in relation to the impact of deinstitutionalisation on four key affective variables, social competence and social skills interventions. Methodological flaws prevalent in previous research were identified and the findings emanating from recent methodologically sound studies were outlined. This review suggested that the constructs of self-concept/self-esteem, locus of control, adaptive behaviour and quality of life are critical to examine when evaluating the impact of deinstitutionalisation. Social competence and social skills interventions were highlighted because of their importance for people who are living in the community. Difficulties found in previous research in relation to these four major variables and social skills intervention were discussed. Implications of this analysis were discussed and key features of the present investigation that address identified research directions were presented.

It was emphasised that promising features of the present investigation are incorporating measures of the four affective variables reviewed in this chapter, implementation of a strong longitudinal design, and utilisation of valid and reliable instruments with demonstrated reliability and validity for the population under
consideration and the use of interpersonal cognitive social skills intervention to enhance generalisation and maintenance. In addition, the combination of two constructs that are traditionally used to evaluate deinstitutionalisation (adaptive behaviour and quality of life) with two interpersonal constructs (self-concept and locus of control) ensure the present investigation examines issues that have been acknowledged as important from a philosophical viewpoint, but are rarely addressed simultaneously in empirical research in this area. This may more fully elucidate the impact of deinstitutionalisation on adults with mild intellectual disabilities. Also research was reviewed relating to social skills interventions. In the empirical literature, the lack of generalisation and maintenance was highlighted as significant. Interpersonal cognitive problem-solving social skills interventions were suggested as a promising approach to overcome these problems. Hence, the present investigation utilised previous reviews to develop a promising study founded upon a sound research design to explore social and interpersonal outcomes for deinstitutionalised people with intellectual disabilities.
CHAPTER 5

Aims, Hypotheses and Predictions and Their Rationale

Introduction

The empirical evidence on the impact of deinstitutionalisation of adults with intellectual disabilities in Australia is sparse. To provide new data on the effect of deinstitutionalisation on a number of affective variables, social competence and social skills, the present investigation comprised three interrelated studies. Study 1 sought to assess the impact of deinstitutionalisation on multidimensional self-concept, self-esteem, locus of control, quality of life and adaptive behaviour of people with mild intellectual disability. This study employed both a longitudinal and comparative design and instrumentation that allowed conclusions to be made about the impact of the deinstitutionalisation process on salient affective variables. Study 2 used a qualitative methodology to assess the development of the self, socialisation experiences and social competencies from a subgroup of participants from Study 1. The aim of this study was to ascertain which of two paradigms of the development of the self had more saliency: stigma or social comparison. Another purpose was to elucidate what coping or self-enhancement strategies were employed by socially competent participants to maintain self-concept and feelings of social competence. Finally, Study 3 tested the impact of a social skills intervention on the self-concept, socialisation, self-direction and social skills of adults with mild intellectual disabilities who were going to be deinstitutionalised. The intent of this chapter is to present for each of these studies (a) the aims; (b) the research problem; (c) the hypotheses, research questions and predictions; and (d) provide a rationale for the hypotheses, research questions and predictions.
Study 1: The Impact of Moving into the Community:  
a Longitudinal Study of Salient Affective Variables

Statement of the Problem

Does deinstitutionalisation of adults with mild intellectual disability impact upon their self-concept, self-esteem, locus of control, quality of life and adaptive behaviour?

Aim

The aim of this component of the present investigation was to:

1. Assess the impact of moving into the community on adults with intellectual disability’s multi-dimensional self-concept, self-esteem, locus of control, quality of life and adaptive behaviour in comparison with a group who stayed in an institution.

2. Test whether the predictions suggested by stigma theory or social comparison theory are supported in relation to a deinstitutionalised group of adults with intellectual disabilities and in comparison to a control group of adults who were not deinstitutionalised.

Statement of Research Questions

Given that stigma theory and social comparison theory (see chapter 2) cast opposing predictions, it is not possible to predict what the impact of deinstitutionalisation is likely to be on facets of self-concept and self-esteem. Therefore, research questions have been proposed, instead of hypotheses, in relation to the constructs of self-concept and self-esteem.

Research question 1.1: multidimensional self-concept. Do multi-dimensional facets of self-concept as measured by the SDQIII for adults with mild intellectual disabilities change after being housed in the community for 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutional setting during this time?
Research question 1.2: self-esteem. Does self-esteem change for adults with mild intellectual disability who have moved to the community as measured by the Coppersmith Self-esteem Inventory after being housed in the community for 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this period?

Statement of Hypotheses

Hypothesis 1.1: locus of control. Adults with a mild intellectual disability who have moved to the community will have greater internal locus of control scores as measured by the Nowicki-Strickland Adult Internal-External Scale after being housed in the community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time.

Hypothesis 1.2: quality of life. Adults with mild intellectual disability who have moved to the community will have a better quality of life, specifically in the community and material domains as measured by the ComQol-I5 after being housed in the community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time.

Hypothesis 1.3: adaptive behaviour. Adults with mild intellectual disability who have moved to the community will have an increase in Adaptive Behaviour particularly in Factor 1 (Personal Self-sufficiency), Factor 2 (Community Self-sufficiency) and Factor 3 (Personal-Social Responsibility) as measured by AAMD-ABS after being housed in the community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time.

Hypothesis 1.4: Adaptive behaviour. Adults with mild intellectual disability who have moved to the community will have no increase in Challenging Behaviour particularly in Factor 4 (Social Challenging Behaviour), Factor 5 (Personal Challenging Behaviour) as measured by AAMD-ABS after being housed in the
community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time.

**Rationale for Research Questions and Hypotheses**

*Research questions 1.1 and 1.2: multi-dimensional self-concept.* There is a paucity of research that has examined the impact of deinstitutionalisation on multidimensional self-concept facets of adults with mild intellectual disabilities. Two competing theoretical predictions have been proposed. Stigma theory suggests that self-concept and self-esteem would increase after deinstitutionalisation. In contrast, social comparison theory would suggest that self-concept and self-esteem would decrease after deinstitutionalisation (see chapter 2). Therefore research questions were developed rather than hypotheses to test these opposing theoretical predictions in relation to the sample under consideration.

*Hypothesis 1.1: locus of control.* There has been some previous research support for the contention that locus of control would be enhanced after deinstitutionalisation (Tossebro, 1995; Wehmeyer & Metzler, 1995). The limited available literature suggests that adults who have been living independently in the community would be experiencing greater personal autonomy than when they were institutionalised (Stancliffe & Wehmeyer, 1995). It also follows that deinstitutionalised adults would have experienced greater opportunities to make choices and would be encouraged to take more initiative for their lives. Therefore, after 30 months in the community, their locus of control was predicted to become more internal.

*Hypothesis 1.2: quality of life.* Previous research suggests (see chapter 4) that the quality of life of people with intellectual disabilities should improve on a move to the community. Reviews of the literature both in Australia (Young et al., 1998) and overseas (Schalock, 2000; Emerson & Hatton, 1996) have concluded that deinstitutionalisation has had a positive impact on quality of life. Research has predicted that, apart from overall improvement there should be significant increases in the two domains of quality of life (Community Involvement and Material Possessions) most closely related to the move to the community.
**Hypothesis 1.3 and Hypothesis 1.4: adaptive behaviour.** Increases in adaptive behaviour upon deinstitutionalisation have been reported in the literature (Kim et al., 2001; Lynch et al., 1997; Young et al., 1998), but paradoxically increases in maladaptive behaviour have also been reported as a result of deinstitutionalisation (e.g. Larson & Lakin, 1991; see chapter 4). However, recent studies using advances in research methodology (e.g., Kim et al., 2001) have found significant increases in adaptive behaviour, but no increases in maladaptive or challenging behaviours (see chapter 4). Given that this study capitalises on advances in methodology utilised in the recent literature, it is predicted that the factors of Personal Self-sufficiency and Community Self-sufficiency and Personal-Social Responsibility will be positively affected and no statistically significant differences will be present for the maladaptive (challenging) factors of Social Challenging Behaviour and Personal Challenging Behaviour.

**Study 2: The Impact of Deinstitutionalisation on the Self-Esteem of Adults with Mild Intellectual Disability—A Qualitative Analysis**

**Statement of the Problem**

Does social comparison or stigma theory have the greater explanatory power in the examination of the impact of deinstitutionalisation on the self-concept and identity of people with mild intellectual disabilities?

**Aim**

Study 2 aimed to:

1. Identify the psychological and external factors that impact upon the perceived social competence of adults with intellectual disabilities who have recently moved to the community.

2. Elucidate which of two competing paradigms—stigma or social comparison theory—had greater saliency in relation to the impact of deinstitutionalisation upon the self-concepts and identity of adults with mild intellectual disabilities.
**Statement of Research Questions**

**Research question 2.1.** What are the external factors (socialisation, life experiences with significant others and carers) that have impacted on the skills and attitudes of adults with mild intellectual disability?

**Research question 2.2.** What is the nature of the self-concept of adults with mild intellectual disability who have recently moved to the community and have been assessed as showing competence in social settings?

**Research question 2.3.** Are people with an intellectual disability who have moved to the community aware of a stigmatised identity?

**Research question 2.4.** What is the nature of the coping strategies that people with an intellectual disability have used in the past and have these changed now that they have moved to the community?

**Research question 2.5.** What are the overall patterns of the social comparisons people with an intellectual disability who have moved to the community make, and do people with intellectual disabilities categorise themselves through these social comparisons?

**Research question 2.6.** Does social comparison or stigma theory have the greater explanatory power in the examination of the impact of deinstitutionalisation on the self-esteem of people with mild intellectual disabilities?

**Research question 2.7.** Is the typology of reactions to the stigma of being labelled intellectually impaired proposed by Zetlin and Turner (1984) valid for long term institutionalised women who have moved to the community?

**Rationale for the Research Questions**

**Research questions 2.1 and 2.2.** There is a dearth of literature that has examined the impact of deinstitutionalisation on the self-concept from the viewpoints of the participants themselves; there is also a dearth of literature that has examined
socially competent people within this reference group. As competing theoretical predictions are posed in relation to the impact of deinstitutionalisation on self-concept and identity, research questions are posed to elucidate psychological factors that may be affected by deinstitutionalisation. Choosing a group of people who are socially competent in their social category is a novel approach, which moves away from the deficit focus of people with intellectual disability.

**Research questions 2.3 and 2.4.** These questions derive from stigma theory which is the most influential paradigm in the area of the development of the self. Previous research (see chapter 4) indicates that stigmatisation is not inevitable and that even when people with intellectual disabilities are aware of their membership of a stigmatised group they may be able to use strategies which will help them maintain their identity and aid in the development of the self (Zetlin & Turner, 1984). In order to test the saliency of stigma theory, the posed questions are aimed at elucidating whether the participants in this study are aware of their membership of a stigmatised group, what coping strategies have they used to manage a stigmatised identity in the past and whether they are still using these same strategies after deinstitutionalisation.

**Research questions 2.5 and 2.6.** These questions derive from social comparison theory (Gibbons, 1986; Szivos-Bach, 1993), which suggests predictions that are diametrically opposed to stigma theory for adults with intellectual disability who have moved to the community. Social comparison theory, in contrast to stigma theory, would predict that deinstitutionalised adults make comparisons with “normal” groups and as such their self-concept will decrease because of negative frame of reference effects. Social comparisons also might be more complex than has been conceptualised thus far. There is recognition that the participants may view context in different ways (Haslam & Turner, 1992). For example, people may choose to make either upward or downward comparisons and be quite selective as to which groups they use for comparison. Hence, these research questions were devised to test the relevance of social comparison theory.

**Research question 2.7.** This study is one of the few to use this typology for people with intellectual disabilities who have been deinstitutionalised. Although it has been supported by other studies in the field (Angrosino, 1992) the validity of the
typology needed to be investigated with the participants in this study to see whether it was a suitable vehicle for the analysis of the results.

**Study 3: Social Skills Intervention**

*Statement of the Problem*

Will a cognitive problem-solving intervention improve the social skills of adults who wish to be deinstitutionalised and will these effects be maintained over time and in different settings?

*Aim*

The aim of Study 3 is to evaluate the effectiveness of an interpersonal cognitive problem-solving intervention as a means of enhancing social skills of long-term institutionalised adults with intellectual disability.

*Statement of Hypotheses*

**Hypothesis 3.1.** Adults with mild intellectual disabilities who prior to deinstitutionalisation have participated in a cognitive problem-solving social skills training program will have acquired the problem-solving process in comparison to baseline scores and will maintain these skills for up to six months following the withdrawal of the intervention.

**Hypothesis 3.2.** Adults with mild intellectual disability who have participated in a cognitive problem-solving social skills intervention will generalise the skills to two different contexts outside of the training milieu, one in the community and one in the residential service, in relation to criterion set for individual target behaviours. The changes in target behaviours will be maintained for six months after the withdrawal of the intervention.

**Hypothesis 3.3.** Adults with mild intellectual disability who participated in a cognitive problem-solving social skills training program prior to deinstitutionalisation
will display higher scores at the post-test compared to pre-test scores in the problem-solving subscale of the SDQ-III, global self-esteem, socialisation and self-direction subscale scores of the AAMD-ABS. These increases will be maintained for up to six months.

**Rationale for the Hypotheses**

**Hypothesis 3.1-3.2.** There is a need to develop powerful social skills programs that can aid in the acquisition of social skills. Social skills programs have often displayed positive improvements in targeted behaviours (Huang & Cuvo, 1997), but most of these interventions have failed to maintain social skills over time and generalise them to other contexts. The interpersonal cognitive social skills program is a technique which can be adapted to incorporate features that can enhance generalisation and maintenance.

**Hypothesis 3.3.** It is assumed that people who have acquired problem-solving techniques and social skills in relation to challenging target behaviours may enhance their feeling of themselves. Also, they will have acquired the skill to control targeted behaviours in their living situation and in the community and as such their socialisation should increase (Castles & Glass, 1986). Hence, it is predicted that after experiencing a problem-solving intervention, adults will display higher problem-solving self-concept, global self-esteem, socialisation and self-direction scores.

**Summary**

This chapter presented the aims, research questions, and hypotheses that relate to each of the three studies that comprise this research. A rationale was presented for each of the hypotheses and research questions based on previous theory and research.
CHAPTER 6

Overview of the Methodology

Introduction

This chapter provides an overview of the methodology designed to address the aims, hypotheses and research questions for this thesis. A more detailed description of the methodology pertaining to specific hypotheses and research questions is presented in later chapters of this thesis which present the results for each study. Using a multimethod approach, three distinct yet innovative studies were developed. Study 1, a longitudinal, comparative study based on a quantitative approach, aimed to determine the impact of deinstitutionalisation on multi-dimensional self-concept, self-esteem, locus of control, quality of life and adaptive behaviour and used a longitudinal/comparison group methodology. Study 2 used an ethnographic methodology, and aimed to identify the external factors that had impacted on the social competence of adults with intellectual disabilities. It also aimed to elucidate whether stigma theory or social comparison theory had greater saliency in relation to the impact of deinstitutionalisation upon the self-esteem and identity of adults with mild intellectual disabilities. Study 3, using a multiple baseline methodology, described the acquisition, maintenance and generalisation of an interpersonal cognitive problem-solving intervention that was designed to enhance real-life social behaviours and self-esteem. In this chapter an overview of the methodology employed in all three studies is presented. A detailed description of the participants, the measures employed, the administration procedures, and the research design for distinct study components are described.
Study 1:
A Longitudinal and Comparative Analysis of the Impact of Deinstitutionalisation upon the Multidimensional Self-concepts, Global Self-esteem, Locus of Control, Quality of Life and Adaptive Behaviour of Adults with Mild Intellectual Disability

Participants

All adults participating in these studies had previously been identified by the Queensland Department of Social Security as having a mild or a mild-moderate intellectual disability. All of the participants had an IQ within the range of 56-75 for those with mild intellectual disability and within the range of 45-56 for those with mild-moderate intellectual disability. All participants had been individually administered tests of intelligence by a psychologist, and had impairments in adaptive functioning. These criteria were needed for placement in the institution and for the receipt of the disability pension. For Study 1, two groups of adults with intellectual disabilities were chosen from two institutions.

**Movers—Group 1.** Group 1 (see Table 6.1) consisted of 25 adults who all resided in a residential service established for people with intellectual disabilities. All of these participants moved to the community after Time1 testing. These residents ranged in age from 32 to 65 (with a mean age of 47.9 years and a SD 9.7 years), but the great majority were under 60 years of age. Eighteen of the participants were female and seven were male. Eighteen were in the mild range of intellectual disability and seven were in the mild/moderate range of intellectual disability. There were four people with additional disabilities and eleven had a dual diagnosis (i.e. they had a diagnosis of intellectual impairment and a diagnosis of a psychiatric condition).

**Stayers—Group 2.** Group 2 (see Table 6.2) was a comparison group of 27 residents with intellectual disabilities who were not moving to the community. These participants were living in a different residential facility and ranged in age from 18 to 55 years of age (with a mean age of 36.1 years and a SD of 8.1 years). Twenty-one of the participants were in the mild range of intellectual disability and six were in the mild/moderate range of intellectual disability. There were three participants with additional disabilities and 10 participants had a dual diagnosis (i.e., they had a diagnosis of intellectual impairment and a diagnosis of a psychiatric condition).
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*Note.* Mod. = moderate; Downs = Downs Syndrome; HI = Hearing Impairment; VI = Visual Impairment.
Table 6.2
Demographic Information for Stayers (Group 2)

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<th>Participant Number</th>
<th>Age</th>
<th>Sex</th>
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<th>Additional Disabilities</th>
<th>Dual Diagnosis</th>
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</table>

*Note.* Mod. = moderate; Downs = Downs Syndrome; HI = Hearing Impairment.
The institutions were located in the same geographical area and run by the same non-government organisation. The two institutions were quite separate and provided residential services to people with mild and mild/moderate intellectual disabilities.

**Measures**

**Multi-dimensional self-concept.** The instrument chosen to assess multidimensional self-concept facets was the *Self Description Questionnaire-III* (SDQ-III) (Marsh, 1989b; Marsh & Craven, 1997). The SDQ-III is a multidimensional instrument with 11 subscales. The SDQ-III self-concept instrument was based on the Shavelson-Marsh multidimensional model of self-concept (see chapter 3). The SDQ-III has excellent psychometric properties and is widely regarded internationally as the best available self-concept instrument (see chapter 3). The SDQ III was originally designed for use with late adolescents and young adults. Each dimension was measured using 10-12 items. Participants respond using an 8-point Likert type scale. The subscales are Physical Appearance, Physical Ability, Honesty, Emotional Stability, Problem-solving, Global Self-concept, Academic Self-concept, Maths Self-concept, Same Sex Relations, Opposite Sex Relations and Parent Relations.

Some changes were made to the administration procedure as a result of pilot testing (Dixon & Gow, 1994) with adults with intellectual disabilities. These included changing all items to positive wording, using a pictorial 5-point scale and reducing the number of items in each sub-scale by 3 (see Procedures) as people with intellectual disability were fatigued by repetition and thought that they had answered questions incorrectly.

The wording of the parental scale was adjusted for some participants as contact with parents had been minimal for many years. Although testing procedures were standardised, the one-to-one administration allowed the testing situation to accommodate participants’ specific needs so that valid responses were made to the questions. Tracey’s (2002) research has shown that the individualised administration procedure with SDQI was quite effective with children with special needs.
Self-esteem. The Coopersmith Self-esteem Inventory (SEI) (Adult Version)
Short Form (Coopersmith, 1981) was used to assess global self-esteem. The
Coopersmith (1981) SEI Short Form is a 25-question scale. Each question is answered
with either a “like me” or “unlike me” response. A total score was achieved by
summing the number of self-esteem items answered in the positive direction and then
multiplying by four. The maximum possible score is 100. This measure was designed
to evaluate attitudes towards the self in social, academic, family and personal areas of
experience (Coopersmith, 1981, p. 1). The term self-esteem was defined as “an
expression of approval or disapproval . . . [of] the extent that a person believes him-
or herself competent, successful, significant and worthy” (pp. 1-2). Studies conducted
with this instrument have found it to be reliable and valid (Maddona & Philpot, 1996),
with few differences found between males and females on the Short Form (Francis,
1998). However, relatively little psychometric data are available for the Adult Form
(Coopersmith, 1981).

In the original standardisation, Coopersmith (1981) administered the Adult
Form to 226 community college and state university students in northern California.
Coopersmith (1981) offered basic descriptive statistics for this college sample (means,
standard deviations and coefficient alphas). New normative data from Lall, Jain and
Johnson (1996) on a larger sample were remarkably similar to the normative data
reported by Coopersmith (1981). Therefore, it was decided to use the original
norming data. Coopersmith (1981) reported a mean score of 68.4 and standard
deviation of 18.5. The higher the score (i.e., the closer to 100), the higher the self-
esteeem. Coopersmith did not report any indications of high or low self-esteem but
suggested that scores below 25 be considered low self-esteem, those above 75 be
reported as high self-esteem.

Locus of control. Locus of Control was assessed using the Adult Nowicki-
Strickland Internal-External Control Scale (ANS-IE) (Nowicki & Duke, 1974). This
scale is widely used in assessing adult locus of control (Kearney & Kearney, 1983).
Most findings (Wehmeyer, 1994a,b,c) indicate that the ANS-IE is a dependable
instrument for assessing important facets of locus of control. Indeed it is this
instrument that is used in the most rigorous research studies that have employed this
construct with people with mild intellectual disabilities (see chapter 4). The scale consists of 40 items answered in a “yes or no” format. The scale includes questions pertaining to problem-solving style (e.g., Do you believe that most problems will solve themselves if you just don’t fool with them?), the role of luck or fate versus hard work and persistence (e.g., Do you think it is better to be smart or to be lucky?), and general perception of futility and helplessness versus control and choice (e.g., Do you feel you have a lot of choice in deciding who your friends are?). The scale has split-half reliability scores ranging from 0.74 to 0.86 with test-retest reliability scores ranging from 0.63 to 0.76 and was designed to be administered either individually or in group settings. The assessment yields a final score based on the number of items answered in the external direction, whereby the higher the score, the more external the person’s orientation. The highest score is 40, however typical scores range from 9-13 (Wehmeyer & Palmer, 1997). A score of over 13 is considered to represent an external orientation (Wehmeyer & Palmer, 1997).

Although normed with individuals without disabilities, the instrument has been used to determine locus of control orientation for individuals with intellectual impairments in previous research (Wehmeyer, 1993a). Wehmeyer (1993a) determined that the factor structure of the ANS-IE when used with adolescents and adults with intellectual disability was comparable to the factor structure for adolescents and adults without disabilities.

For Study 1, the wording of some items was modified to remove terms that were unfamiliar to Australian participants (e.g., the words “fool with” were changed to “worry about” and the word “grades” was changed to “marks”).

**Quality of life.** Quality of Life (QOL) was assessed using the Comprehensive Quality of Life Scale-I5 (Cummins, 1997a) (ComQol). The ComQol Scale was developed to measure the most contemporary understanding of the QOL construct. It exists in three parallel forms: one for the general adult population (ComQol-A) (Cummins, 1997a), one for the adolescent student attending school (ComQol-ST), and one for people with an intellectual disability (ComQol-I5). The ComQol is based on the following definitions: QOL is both objective and subjective, each axis being the aggregate of seven domains (material well-being, health,
productivity, intimacy, safety, place in community, and emotional well-being). Objective domains comprise culturally relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by their importance to the individual (see chapter 3).

The ComQol-I5 incorporates three additional features which have all been recommended to overcome some of the problems found in assessing QOL in people with intellectual disabilities. These are a pre-testing protocol, pictorial representation and provision of a parallel scale so a third-party can provide vicarious responses on behalf of the person with a disability. The latter was not used in this research because all of the participants were able to complete the pre-testing protocol. The ComQol-I5 has certain features that make it particularly appropriate for people with intellectual disabilities. It measures seven domains: material well-being, health, productivity, intimacy, safety, place in community and emotional well-being. It includes independent measures of objective and subjective components. Each subjective domain is rated in terms of its importance and satisfaction to the individual. In addition, the questions have been written in simple language. There are seven domains which each have an objective and a subjective scale. The subjective scale is made up of a satisfaction scale weighted by an importance score (subjective = importance x satisfaction). This yields 14 scores for each participant, seven objective scales and seven subjective scales.

There is an extensive pre-testing protocol that is designed to determine whether the interviewee can understand the kinds of abstract reasoning required by the subjective subscale and if they can, the maximum degree of scale complexity they can reliably utilise. The pre-testing protocol determines whether the person can complete the subjective axis. It involves three tasks. First, the person is asked to order five wooden blocks. Secondly, they are asked to match the blocks to a printed scale of importance and thirdly, they are asked to rank a personally-valued item to an importance scale. The first two parts of the protocol involve the person in a binary choice. If this completed successfully the task is increased to a 3-point and a 5-point scale. The participant must pass on all aspects of the pre-testing protocol and then the subjective questions are assessed at the highest level of complexity (2, 3 or 5) that the person was successful at. The use of this procedure eliminates those people who do
not have the cognitive capacity to make a valid response to this scale.

The test developer indicated that psychometric properties were adequate although Cummins (1997a) admitted that the psychometric data are limited. Cummins had found that 2, 3 or 5-point regimes were not significantly different and advised including data from all clients. All scores are converted to a standard scale provided by Cummins (1992a). The author presents some additional data in a more recent publication of the test (Cummins, 1997a). Cummins found no significant correlation between objective and client-subjective domain scores, except for objective health, which correlated positively with both importance and satisfaction. This relation was found in people without disabilities as well.

**Adaptive behaviour.** The adaptive behaviour of the participants was measured using the *American Association of Mental Deficiency - Adaptive Behaviour Scale* (AAMD-ABS; Nihira et al., 1974). The AAMD-ABS provides a criterion-referenced measure of individual’s effectiveness in coping with the natural and social demands of their environment (Nihira et al., 1974).

The AAMD-ABS is widely used to assess changes in adaptive behaviour for people with intellectual disability. There are two parts to the scale. Part A measures nine domains: independent functioning, physical development, economic activity, language development, numbers and time, vocational activity, self-direction, responsibility, and socialisation. Part B measures violent and destructive behaviour, antisocial behaviour, rebellious behaviour, untrustworthy behaviour, withdrawal, stereotyped behaviour and odd mannerisms, inappropriate interpersonal manners, unacceptable vocal habits, unacceptable or eccentric habits, hyperactive tendencies, psychological disturbances and use of medications. Parts A and B were completed by a personal care worker who had extensive daily contact with the participant. Test administration was undertaken over a period of 40 minutes to an hour.

The psychometric properties of the AAMD-ABS have almost been exclusively established on populations with mild intellectual disabilities. Spreat (1982) reported adequate test-retest reliability and interrater reliabilities for individual domains. With respect to validity, Foster and Nihira (1969) found that the AAMD-ABS

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discriminated between low and high functioning institutionalised individuals with intellectual disabilities. Eyman and Coll (1977) noted that profoundly mentally retarded individuals experienced more behaviour problems as assessed by the AAMD-ABS than did mildly retarded persons. The authors recommend that for research purposes the factor scores be used instead of the domain scores (Nihira et al., 1974). Nihira (1976) described the five factors measured as Personal Self-sufficiency, Community Self-sufficiency, Personal Social Responsibility, Maladaptive Behaviour towards others (now called Social Challenging Behaviour) and Maladaptive Behaviour towards oneself (now called Personal Challenging Behaviour).

The Personal Self-Sufficiency factor is defined by the variables of Eating, Toilet Use, Cleanliness, Dressing and Undressing and Motor Development. Eating represents the ability to feed oneself, which includes use of utensils, drinking from a cup or glass, table manners and use of public eating facilities. Toilet Use represents the degree of toilet training and self care at the toilet. Cleanliness relates to bathing, grooming, tooth brushing and general hygiene. Dressing and undressing represents skills in putting on and removing clothing and the handling of shoes. Motor development is assessed by ratings of gross and fine motor skills. The Personal Self-Sufficiency factor is considered by the authors of the instrument to be a developmental stage of the individual as an independent social being with the emphasis being on the ability to sustain themselves in the personal care sphere.

The second factor, Community Self-Sufficiency is defined by variables labeled Travel, General Independent Functioning, Money Handling and Budgeting, Shopping Skills, Expression, Comprehension, Social Language Development, Numbers and Time, Cleaning, Kitchen duties, and Other Domestic Activities. Travel, includes an individual’s sense of direction and the ability to use public transport. It indicates the geographical horizons of the person’s widening activities and locomotion. General Independent Functioning represents the variety of functional skills expected of an individual to maintain self-sufficiency in the community (e.g., use of the telephone, looking after personal health, and knowing how to use the post office and other public facilities). Money Handling and Budgeting and Shopping Skills represent awareness of the value of money and planning for its use, as well as skills for shopping and buying. Expression represents a wide range of expressive
abilities, including preverbal expression, articulation, vocabulary, the complexity of sentences used, writing, ability to comprehend verbal instructions, level of conversation and simple reading abilities. Numbers and Time, is a measure of the functional ability to use numbers and the understanding of time concepts. Cleaning, Kitchen Duties and Other Domestic Activities involve a variety of domestic activities that include room cleaning, laundry, table setting and clearing, cooking and other household activities. The authors of the instrument feel that these variables relate to the achievement of personal independence and self-sufficiency in relationships with other members of the social environment. The Community Self-sufficiency factor is considered to be a higher extension of the Personal Self-sufficiency Factor and indicates the attainment of self-sufficiency as an independent person in the sphere of community living.

The third factor, Personal-Social Responsibility is defined by the variables Initiative, Perseverance, Leisure time, Responsibility, Socialisation, Vocational Activity, Appearance and Care of Clothing. Initiative and Perseverance are the two leading variables for this factor. Initiative represents the degree to which the individual originates and engages him-/herself purposive activities of his/her own volition (Nihira, 1976). Perseverance involves attention span, and persistence to continue purposeful activities. These two variables represent the traditional notion of self-direction. Responsibility relates to dependable care of personal belongings and carrying out assigned activities. Socialisation consists of seven items designed to assess the individual’s degree of cooperation and interaction with others, consideration for others, and participation in group activities. The authors of the instrument feel that the Personal-Social Responsibility factor represents traditional notions of responsibility, and that the higher extension of this dimension may involve altruistic concerns for people’s associates, family, and society at large.

The fourth factor, Social (Challenging) Behaviour, is represented by violent and destructive rebellious behaviours, untrustworthy behaviours, and sexually aberrant behaviour and is characterized as destructive, violent behaviour exhibited outwards towards others.

The fifth factor, Personal (Challenging) Behaviour, is represented by
withdrawal, stereotyped behaviours and odd mannerisms, inappropriate interpersonal manners, unacceptable vocal habits, unacceptable or eccentric habits, self-abusive behaviour, hyperactive tendencies, and psychological disturbances.

The authors present data that the average correlation among the factors indicates an oblique factor structure and the average coefficient of congruence between all possible pairs of different factors was 0.36 which indicates that each factor was defined by reasonably unique sets of variables (Nihira, 1976). Spreat (1982) has found that the factor scores increased reliability and predictive validity and hence appeared to be a more appropriate unit of analysis than were domain scores for the AAMD-ABS. Therefore, for this investigation, the five factor scores as described by the authors were used for comparisons instead of domain scores.

**Procedures**

A battery of measures outlined above was administered to each participant. Testing people with intellectual disabilities has many problems. They are much more likely to answer acquiescently particularly if the questions are controversial, seek personal information, are too difficult, or the interviewer is perceived as being threatening. To minimise some of these problems certain procedures were introduced.

The literature was searched to find which standardised tests were being used most often in other studies with people with intellectual disabilities. These tests were then examined for simple language and response formats. A pilot study was conducted ($N = 8$) to determine the adequacy of the chosen tests, scoring procedures and questionnaire instructions. Changes were made to the administration of SDQ-III after this pilot. For example, the wording of all of the questions was made positive, as the pilot testing showed that participants with intellectual disabilities were confused by the negative wording. Other simplifications included reducing the 8-point scale to a 5-point scale, again as the pilot testing demonstrated that participants were much more willing to choose from a 5-point rather than an 8-point scale. A visual alternative was provided for the five choices in the form of a ladder. The number of items was also reduced by three, as some of participants in the pilot phase were fatigued by too many items.
All testing was completed by the researcher who visited people in their rooms before the beginning of testing. She explained the purpose of the research and emphasised the confidentiality of the results. The researcher participated in communal activities and outings for three days before any testing was begun and continued her involvement with the participants throughout the testing period.

A testing protocol was designed whereby the two longer tests (the ComQol-I5 and SDQ-III) were interspersed with the two shorter tests administered (the Coopersmith and the Nowicki-Strickland). The ComQol-I5 was administered first, the Coopersmith SEI was administered second, followed by the SDQ-III and the adult version of the Nowicki-Strickland. This arrangement allowed testing to be split in two if the participant exhibited fatigue. The ComQol-I5 was administered first because in the pilot testing respondents were able to answer this quite easily as it contained demographic information with which the respondents were very familiar.

The amount of time needed to administer the battery of tests varied as some residents required more time than others. Participants were encouraged to ask the researcher any questions they did not understand. As most of the participants had limited reading ability, all tests were administered in a one-to-one situation, with all questions being read out by the researcher. The researcher also filled in the answers. The presentation of the scales was fixed to meet the needs of people with intellectual disabilities. That is, there was a need to start with familiar information (as assessed by the ComQol-I5) then for two shorter tests which would maintain motivation, before the administration of the more sophisticated SDQ-111. There is a possibility of an impact of order effects, in that fatigue might have been a factor, however, the individual administration of the measures allowed testing to be split in two if the participant exhibited fatigue.

All of the participants included in the study were verbal and answered the instruments independently. Participants who were not sufficiently verbal to answer the instruments were not included in the study. The AAMD-Adaptive Behaviour Scale (ABS) was completed by personal care workers and scored by the investigator for all of the participants.
Research Design

Study 1 was a longitudinal/comparison group quasi-experimental design in that it utilised pre and post repeated measures on two matched intact groups. The two groups of people, the Movers (Group 1) and Stayers (Group 2) were administered the SDQ III, the Coopersmith Self-esteem Inventory, the ANS-IE Locus of Control Scale, the Com-Qol-I5 and the AAMD-ABS on two separate occasions over a period of 30 months. All participants were administered the battery at Time1 when they were living in the institutional setting; subsequently the Movers (Group 1) moved to living independently in the community. Measures were taken months before the move to the community, so a stable baseline could be assumed. The comparison group, Stayers (Group 2) did not move to the community and were still living in the other institution at the end of the research period.

Data Analysis

Data were analysed using SPSS for Windows. The data were analysed using repeated measures where time (two occasions) and two groups (Movers vs. Stayers) are the independent variables. The statistic of interest was a significant Group x Time interaction, indicating that change over time for one group differed from change over time for the other group and this was reported as a MANOVA. To determine the nature of the interactions post hoc analysis (simple main effects) were used to test a priori predictions. Product moment correlations were also computed in order to examine the relations between the variables.
Study 2:  
The Impact of Deinstitutionalisation on the Self-esteem of  
Adults with Mild Intellectual Disability—A Qualitative Analysis

Participants

A subsample of the participants who were the Movers participating in Study 1 took part in Study 2, the qualitative study. The age of the participants ranged from 39 to 58 years, one of these participants had a hearing impairment and one was on mood altering medication at the start of the research period. At the commencement of the 30 month study, three of these participants had just moved to transitional housing at a residence very close to the residential service. The other two participants were still resident in the service. At the end of the research period all of the participants were living in the community. The five participants in this study were chosen because they were assessed as being socially competent by their personal care workers, and were the first people chosen to move to living in the community.

Measures

Ethnographic measures that were employed in this study included literature review, in-depth life history interviews, interviews with personal care workers and administrators, perusal of case files and participant observation in different settings. A schedule was developed following the preliminary review of literature (see appendix A). The guide to developing the ethnographic interview recommended by Spradley (1979) was used to structure the interviews. The major documents were the extensive files maintained for each resident. The measures used in Study 2 are described in detail in Chapter 8.

Procedures

Participants were selected by administrators as being socially and verbally competent. The researcher approached the participants and asked them for their permission to be involved in the research. Once the participant agreed they were interviewed and asked to recount the story of their lives. If they agreed their personal case files were also accessed and personal care workers were interviewed. Tape recordings were made of the interviews and transcribed and, in addition, other memos
were kept of each contact that the researcher had with the participants. The resulting field notes were then developed into case studies (Edgerton, 1984).

**Research Design**

Study 2 was an ethnographic study where the researcher spent intensive periods of time over 30 months with the participants. This prolonged contact allowed the researcher to establish the emic (insider’s perspective). The study used measures outlined above. The study followed the principles outlined by Edgerton (1984), in that there should be multiple points of view, a longitudinal perspective and an ecological perspective. All of these perspectives were gained through using interviews, observation and document study, length of time and close contact with the participants and observing them in different settings.

**Data Analysis**

Data were analysed using Zetlin and Turner’s (1984) typology. Zetlin and Turner identified four distinct attitudes based on people’s willingness to discuss their disability, the salience they assigned their disability in day to day living, and the strategies they used to protect themselves from stigma and protect their self-esteem. The four categories they identified were (a) acceptance, (b) qualification, (c) vacillation and (d) denial. Once the participants were classified according to their initial attitude to their disability, then relations with other indices of socio-emotional adjustment including strategic goals, peer relations, involvement with delivery system, employment record, socialisation history and well-being were formulated.
**Study 3:**
*Interpersonal Cognitive Social Skills Intervention for Five Adults with Intellectual Disabilities*

**Participants**

A different subsample of the participants in Study 1 (to the subsample that took part in Study 2) of five participants was chosen by the administrator and personal care workers to participate in Study 3. The participants in this subsample were all female. They ranged in age from 32 to 50. Two of the participants had an additional disability of hearing impairment and one of the participants had a dual diagnosis (i.e., a diagnosis of intellectual impairment and a psychiatric condition). They were all assessed as having social skill problems that may preclude them from successful living in the community.

**Measures**

In multiple baseline methodology, there are two types of measures (dependent variables). These are standardised tests and behavioural observations with the second being the most common. Also, usually a range of tests is used and these strengthen the conclusions that can be made. In this study an extensive range of measures was chosen to assess the acquisition of the process and the generalisation and maintenance of target behaviours to different settings and real-life social behaviours. The measures relating to Study 3 are summarised in Table 6.3.

**Procedures**

The procedures for carrying out multiple baseline measures across subjects design were as follows. Initially, the researcher selected two different participants. All participants were observed concurrently in a baseline phase and their responses for each baseline were plotted on a graph. Next the investigator gave the intervention to two of the participants while continuing with baseline observations on the others, after changes were observed in the acquisition of the process, the intervention was started with the next two participants. After a
Table 6.3. Summary of the Pretraining, During Training and Post-Training Measures for Study 3

<table>
<thead>
<tr>
<th>Phase of Assessment</th>
<th>Assessment Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pretraining</strong></td>
<td>AAMD-ABS Part A Overall Score, Language Self-direction and Socialisation subscale scores, SDQ III-Problem-solving Subscale, Coopersmith Self Esteem Inventory, Adult Nowicki-Strickland Internal-External Locus of Control Problem solving abilities Measures of social skills in living situation Community observations of participants Daily anecdotal reports Baseline measures of specific program components and ability to apply them</td>
</tr>
<tr>
<td><strong>During Training</strong></td>
<td>Post session measures Probes to untrained scenarios Observations of acquisition and application of components of problem-solving process in training sessions Observations of social skills in near (living) and far (community) settings</td>
</tr>
<tr>
<td><strong>Post Training</strong></td>
<td>AAMD-ABS Self-direction subscales, and Socialisation Subscale and SDQ III Problem-solving Subscale Coopersmith Self-esteem Inventory Observations of target behaviours in near generalisation setting - living environment Observations of generalisation social skills in far generalisation setting - community Maintenance of acquisition and application of problem-solving process-training setting</td>
</tr>
</tbody>
</table>

given number of periods, the intervention was started with the second pair of participant and continued with the first pair of participants, while a baseline was continued for the other participant. Again after a number of baseline periods the intervention was commenced with the last participant and continued with the first two pairs of participants. This procedure was similar to that suggested by Morgan & Morgan (2001).

**Research Design**

For Study 3, a multiple-baseline design across participants was chosen to assess the effectiveness of an interpersonal cognitive social skills intervention. Single participant research is decidedly experimental in its approach. It is particularly well-suited to applied research and evaluation of novel interventions (Morgan & Morgan, 2001). In single participant research, individual differences usually make no contribution to the variance because no comparisons are made across individuals. A participant’s behaviour is compared with his or her behaviour in other phases, not with the behaviour of other participants.

Single participant research allows and is dependent on its emphasis on replication. The reliability of the independent variable manipulation often can be evaluated through simple intra-participant replication across several phase changes in a single experiment. Replication is achieved through reversal or ABA designs. However, reversal designs are not always feasible or ethical. Morgan and Morgan (2001) state that multiple baseline designs were introduced because in clinical situations the removal of the treatment is often considered unethical, especially if the treatment appears successful.

In multiple baseline studies many baselines may be recorded simultaneously. The responses may represent the responses of three different participants or the responses of the same participant in three different settings. The key to multiple baseline is that the researcher intervenes at a random time, and observes the effect on one of the baselines while the other baselines should be unchanged. Similar to participants in within-participants group designs, participants in single-participant
designs serve as their own controls with comparisons being made across experimental conditions. This design is also useful when it is not possible to use a reversal design. Many kinds of behaviour especially learnt behaviours, such as the problem-solving program and the social skills taught in this study cannot be removed by removal of the intervention. When this is the case, interparticipant replication is needed through multiple baseline design (Kazdin, 1994). Although there are several versions of multiple baseline designs, the most common is repeated implementation of treatment across several participants but with differing times so that the baseline is different for each participant. The staggered manner in which the baseline is implemented controls threats to internal validity (Kazdin, 1994). Thus the multiple baseline design employed in this study allowed for strong causal inferences to be made.

Data Analysis

The major tool for data presentation and analysis in single participant research is the graph. The dependent variable measures appear on the y-axis and the independent variable conditions (often depicted across time) appear on the x-axis. Individual data points in this study depict measures such as percentage of correct responding for the training data and tallies of behaviour for the generalisation data.

Single participant researchers argue that meaningful effects of an independent variable ought to be noticeable on visual inspection (Morgan & Morgan, 2001). Thus visual inspection of dependent measures during independent variable conditions, relative to baseline measures, represents the standard treatment of single-participant data. When evaluating a single subject design visually, the key is to look for patterns in the data, especially as the phases change from baseline to intervention. Kazdin (1994) discusses the use of certain criteria for visual inspection of single-subject designs. One criterion is level. This is the change from the last measurement in each phase to the first measurement in the next phase (e.g., from baseline to intervention). The other criterion is trend which looks at the direction of points within a phase. While visual analysis has been one of the strengths of single-subject designs, some investigators have used statistical methods. However, there is still disagreement over which statistical methods are the best to use (Gliner, Morgan & Harmon, 2000).
Visual analysis was chosen for data analysis in this study. Multilevel modelling would be an appropriate but the number of data points available for each participant was not available to make this feasible.

Single case research designs such as the one used in the study allow valid inferences about the efficacy of an intervention by comparing the same individuals over time, provided that a sufficient number of observations are available for each study phase (Kazdin, 1992; Morgan & Morgan, 2001). In the present study a minimum number of 18 data points were available for each participant, which is considered sufficient to establish a trend in data-time series (Jones, 1991).

Summary

This chapter has given an overview of the methods used in this investigation. The participants, measures, research design, procedures undertaken and the analysis techniques have been described for the three studies comprising the current investigation. These studies were designed to specifically address the research aims, hypotheses and research questions described in Chapter 5.

Some major methodological limitations that have been present in previous research were avoided by (a) utilising a multidimensional self-concept instrument with demonstrated construct validity to capitalise on recent advances in self-concept theory and research (see chapter 3), (b) implementing a strong longitudinal and comparative design (see chapter 7), (c) using instrumentation and testing protocols that allowed self-reporting of constructs and avoided proxy responding (see chapter 4), (d) implementing a potentially powerful intervention based on both theory and previous research (see chapter 9), (e) using a construct validity approach to compare the effects of the intervention in Study 3 on targeted specific facets of self-concept with effects on non-targeted areas, and (f) using a qualitative design that allowed people with intellectual disabilities views of the self to be assessed from their perspective.
CHAPTER 7

Results Study 1: A Longitudinal and Comparative Analysis of the Impact of Deinstitutionalisation Upon the MultiDimensional Self-Concepts, Global Self-Esteem, Locus of Control, Quality of Life and Adaptive Behaviour of Adults with Mild Intellectual Disability

Introduction

The lack of research which has addressed the impact of deinstitutionalisation on affective variables is a serious gap in the empirical literature. The first of the three studies (Study 1) investigated several hypotheses relating to the impact of deinstitutionalisation on a number of affective variables of adults with mild intellectual disabilities when they moved from an institutionalised to a community-based setting. The results presented in this chapter are based upon a methodology that employed a longitudinal and comparison group design. Two groups of people, Movers (Group 1) and Stayers (Group 2) were administered the SDQ-III, the Coopersmith Self-esteem Inventory, the ANS-IE Locus of Control Scale, the ComQol-I5 and the AAMD-Adaptive Behaviour Scale on two separate occasions over a period of 30 months (see chapter 6 for a full description of the instrumentation). All participants were administered the battery of measures at Time 1 when they were all living in the institutional setting, and again at Time 2, 30 months after the Movers (Group 1) moved to living independently within the regular community. The comparison group (Stayers-Group 2) did not move to the community and were still living in the other institution at the end of the research period.

This chapter presents the demographic results of the Movers and the Stayers and then reports the results of the data analyses using repeated measures where time (two occasions) and type of living placement (independent and institutional) are cast as independent variables. In presenting the results for each variable, the descriptive results will be presented first and then the repeated measures analysis of variance results relating to multidimensional self-concept, global self-esteem, locus of control, quality of life and adaptive behaviour. Finally
the results are discussed in relation to the research questions and specific hypothesis developed for this investigation.

**Comparison of Demographic Information of Movers and Stayers**

The current study employed a strong longitudinal/comparative design that examined the changes in two groups over a 30-month period. Therefore, an initial concern was the similarity of the demographic characteristics of the two groups. At the outset of the research the participant characteristics were gathered as part of the overall testing interview. Additional information such as the presence of psychiatric disability was gained after the participants agreed to have their personal files accessed. Independent samples t-tests were employed to measure the differences between the two groups on continuous variables and Pearson chi-square tests of significance were used for categorical variables. The participant characteristics of these two groups are presented in Table 7.1.

**Table 7.1**
**Demographic Characteristics of Movers and Stayers**

<table>
<thead>
<tr>
<th></th>
<th>Movers N=25</th>
<th>Stayers N=27</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td></td>
<td>47.9</td>
<td>9.7</td>
</tr>
<tr>
<td><strong>N %</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mild intellectual impairment</strong></td>
<td>18 72</td>
<td>21 78</td>
</tr>
<tr>
<td><strong>Mild/moderate intellectual impairment</strong></td>
<td>7 28</td>
<td>6 22</td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td>7 28</td>
<td>9 33</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>18 72</td>
<td>18 67</td>
</tr>
<tr>
<td><strong>Psychiatric disability</strong>*</td>
<td>11 44</td>
<td>10 37</td>
</tr>
</tbody>
</table>

Table 7.1 demonstrates that there were no significant mean differences between the groups in terms of numbers of participants with mild intellectual disability, numbers of participants with mild/moderate intellectual disability, ratio of males and females, and the number of participants with psychiatric conditions. Figure 7.1 also demonstrates that there
were no differences in the numbers of participants with additional disabilities. For the Movers there was one participant with Down Syndrome, two with hearing impairment and one with hearing impairment and visual impairment. For the Stayers there were two participants with Down Syndrome and one with hearing impairment. There was, however, a significant difference between the ages of the two groups with the Movers (Group 1, $M=47.3$, $SD=10.82$) being significantly older than the Stayers ($M=36.0$, $SD=9.2$ $p<.01$). Hence apart from age, the Movers and Stayers were demographically very similar (see Figure 7.1).

![Figure 7.1. Demographic Characteristics of Adults with Mild Intellectual Disability: Movers (Group 1) and Stayers (Group 2).](chart)

**Note.**

- **n:** number of participants
- **m:** no. of males
- **f:** no. of females
- **mi:** no. with mild intellectual impairment
- **mmiq:** no. with mild/moderate intellectual impairment
- **ad:** no. of additional disabilities
- **psyc:** no. with psychiatric disability
- **age:** in years
Time1 Differences of Movers and Stayers

In keeping with the design the two groups were evaluated for pretest differences on the range of outcome variables considered in this study. It was hypothesised that there would be no pretest (Time1) differences in the two groups. The results are presented in Table 7.2.

The results of the evaluation of Time1 differences demonstrate that overall there were very few differences between the two groups. As the Movers started out with lower scores, where there were differences, they mitigated against the hypotheses posed that there would be advantages associated with moving. These small initial differences were controlled for in the analysis by the longitudinal design. Any initial differences that were of importance are discussed in relation to the specific constructs below.

Evaluation of the Impact of Deinstitutionalisation on Movers and Stayers

It was the aim of this study to measure the impact of deinstitutionalisation on affective variables and multidimensional quality of life and adaptive behaviour. Repeated measures analysis of variance was used to investigate whether there would be any change in multidimensional self-concept facets as measured by the Self-Description Questionnaire III (Marsh, 1989b) (Research Question 1.1) and global self-esteem as measured by the Coopersmith Self-Esteem Inventory-Adult Form (Short Version; Coopersmith, 1981; Research Question 1.2). For Hypothesis 1.1, to determine whether there would be a shift to internality for locus of control, the Adult Nowicki-Strickland Internal-External Locus of Control Scale (Nowicki & Duke, 1973; Nowicki, 1981) was used. To determine whether there would be increases in some of the objective and subjective subscales of multidimensional quality of life for the Movers (Hypothesis 1.2), the ComQol-I5 (5th Edition; Cummins, 1997a) was used. Finally, for the Movers, whether there would be increases in Personal Self-sufficiency, Community Self-sufficiency, Personal-Social Responsibility factors, and no changes in Social (Challenging) Behaviour, and Personal (Challenging)
Behaviour (Hypotheses 1.3 and 1.4), adaptive behaviour was measured by the AAMD-Adaptive Behaviour Scale (Nihira et al., 1974).

The results for each of the measures are presented separately. The descriptive results are presented first, then the repeated measures analysis of variance. The statistic of interest is a significant Group x Time interaction, indicating that one group performed significantly better than the other from Time1/Time2. These are presented and graphed and significant main effects of time and group that relate to deinstitutionalisation are also presented. To determine the nature of the interactions post hoc analysis was used to test a priori predictions. Simple main effects sizes were also calculated and the results reported as F ratios.
Table 7.2
Tests for Pre-Existing Time1 Differences Between the Movers and Stayers on Variables Examined

<table>
<thead>
<tr>
<th></th>
<th>Movers</th>
<th>SD</th>
<th>Stayers</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SDQ-III</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Academic</td>
<td>3.36</td>
<td>1.70</td>
<td>5.4***</td>
<td>2.02</td>
</tr>
<tr>
<td>Emotion</td>
<td>4.28</td>
<td>1.88</td>
<td>5.33</td>
<td>1.75</td>
</tr>
<tr>
<td>General</td>
<td>5.88</td>
<td>1.66</td>
<td>5.60</td>
<td>1.53</td>
</tr>
<tr>
<td>Honesty</td>
<td>6.80</td>
<td>1.35</td>
<td>5.72</td>
<td>1.60</td>
</tr>
<tr>
<td>Maths</td>
<td>1.24</td>
<td>0.66</td>
<td>3.28***</td>
<td>2.79</td>
</tr>
<tr>
<td>Opposite Sex</td>
<td>4.24</td>
<td>2.02</td>
<td>3.74</td>
<td>2.26</td>
</tr>
<tr>
<td>Parents</td>
<td>5.92</td>
<td>1.89</td>
<td>5.23</td>
<td>2.04</td>
</tr>
<tr>
<td>Physical Ability</td>
<td>3.60</td>
<td>2.14</td>
<td>5.00*</td>
<td>2.38</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>5.24</td>
<td>1.51</td>
<td>5.81</td>
<td>2.02</td>
</tr>
<tr>
<td>Problem-solving</td>
<td>4.00</td>
<td>1.41</td>
<td>4.63</td>
<td>2.19</td>
</tr>
<tr>
<td>Religion</td>
<td>6.12</td>
<td>1.86</td>
<td>5.68</td>
<td>1.87</td>
</tr>
<tr>
<td>Same Sex</td>
<td>5.89</td>
<td>1.39</td>
<td>5.96</td>
<td>2.27</td>
</tr>
<tr>
<td>Verbal</td>
<td>4.04</td>
<td>1.81</td>
<td>3.62</td>
<td>2.59</td>
</tr>
<tr>
<td><strong>SDQ-III Total</strong></td>
<td>60.60</td>
<td>10.69</td>
<td>62.08</td>
<td>12.83</td>
</tr>
<tr>
<td><strong>Coopersmith Self-Esteem Inventory</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>52.48</td>
<td>14.48</td>
<td>49.96</td>
<td>16.50</td>
</tr>
<tr>
<td><strong>Adult Nowicki-Strickland Locus of Control Scale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Objective Community</td>
<td>7.12</td>
<td>1.94</td>
<td>6.5</td>
<td>2.11</td>
</tr>
<tr>
<td>Objective Emotion</td>
<td>9.7</td>
<td>2.56</td>
<td>8.44</td>
<td>2.53</td>
</tr>
<tr>
<td>Objective Health</td>
<td>9.56</td>
<td>2.5</td>
<td>8.96</td>
<td>2.37</td>
</tr>
<tr>
<td>Objective Intimacy</td>
<td>10.16</td>
<td>3.67</td>
<td>10.40</td>
<td>3.16</td>
</tr>
<tr>
<td>Objective Safety</td>
<td>11.52</td>
<td>2.08</td>
<td>10.16</td>
<td>3.36</td>
</tr>
<tr>
<td>Objective Material</td>
<td>5.12</td>
<td>1.20</td>
<td>5.24</td>
<td>0.88</td>
</tr>
<tr>
<td>Objective Productivity</td>
<td>7.40</td>
<td>2.48</td>
<td>10.08***</td>
<td>2.04</td>
</tr>
<tr>
<td>Subjective Community</td>
<td>6.12</td>
<td>11.11</td>
<td>9.48</td>
<td>9.32</td>
</tr>
<tr>
<td>Subjective Emotion</td>
<td>7.08</td>
<td>11.65</td>
<td>9.02</td>
<td>15.78</td>
</tr>
<tr>
<td>Subjective Health</td>
<td>5.32</td>
<td>11.26</td>
<td>6.08</td>
<td>14.67</td>
</tr>
<tr>
<td>Subjective Intimacy</td>
<td>2.67</td>
<td>14.94</td>
<td>3.66</td>
<td>14.82</td>
</tr>
<tr>
<td>Subjective Safety</td>
<td>5.08</td>
<td>10.65</td>
<td>9.38</td>
<td>10.62</td>
</tr>
<tr>
<td>Subjective Material</td>
<td>7.38</td>
<td>12.21</td>
<td>9.94</td>
<td>11.77</td>
</tr>
<tr>
<td>Subjective Productivity</td>
<td>8.24</td>
<td>7.35</td>
<td>10.18</td>
<td>9.53</td>
</tr>
<tr>
<td><strong>AAMD-Adaptive Behaviour Scale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal Self-Sufficiency</td>
<td>75.40</td>
<td>7.10</td>
<td>77.93</td>
<td>5.02</td>
</tr>
<tr>
<td>Community Self-Sufficiency</td>
<td>75.72</td>
<td>13.915</td>
<td>71.45</td>
<td>17.08</td>
</tr>
<tr>
<td>Personal Social Responsiblity</td>
<td>52.92</td>
<td>9.11</td>
<td>61.07***</td>
<td>11.33</td>
</tr>
<tr>
<td>Social Behaviour</td>
<td>36.12</td>
<td>26.59</td>
<td>25.24</td>
<td>28.32</td>
</tr>
<tr>
<td>Personal Behaviour</td>
<td>4.28</td>
<td>4.10</td>
<td>2.35</td>
<td>3.74</td>
</tr>
</tbody>
</table>

Significance determined by one-tailed t test* $p<.05$, **$p<.01$, ***$p<.001$
Results Research Question 1.1: Impact of Deinstitutionalisation on Multidimensional Self-concept Facets and Global Self-esteem

This section describes the multidimensional self-concept descriptive and Time1 differences between the groups. The repeated measures analysis of variance along with the simple main effects is also presented. No hypotheses were made about the differences on these measures between the Movers and the Stayers; because of the competing theoretical paradigms in this field, a research question was posed instead. Research Question 1.1 posed: Do multi-dimensional facets of self-concept as measured by the SDQ-III for adults with mild intellectual disabilities change after being housed in the community for 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutional setting during this time?

Pre-Test Self-Concept Differences Between Groups

The descriptive results based upon the multidimensional self-concept measure (SDQ-III) at Time1 are presented in Table 7.3. For the Movers the Academic subscale mean was low ($M = 3.87, SD = 1.8$), the Opposite Sex scale was low ($M = 4.2, SD = 2.1$) and the Maths subscale was very low ($M = 1.26, SD = 0.69$). Conversely, the Honesty subscale mean ($M = 6.87, SD = 1.3$) and the Parent subscale mean were quite high ($M = 6.04, SD = 1.9$).

Table 7.2 also reveals that at Time1 there were significant differences on some of the subscales between the two groups. There were differences on the SDQ-III Academic subscale and SDQ Maths subscale ($p<.01$) where the Stayers had significantly higher academic self-concept scores than the Movers, the SDQ Emotion and Physical Ability ($p<.05$) where the Stayers had higher scores in relation to these variables, and the Honesty subscale ($p<.05$) where the Movers had significantly higher Honesty scores compared to scores for the Stayers. These differences may be accounted for by the previously mentioned difference in mean age between these two groups. The Academic and Maths subscales could be explained by changes in educational practices for people with mild intellectual disability given that younger people have been exposed to more appropriate educational programs in comparison
<table>
<thead>
<tr>
<th>SDQ-III</th>
<th>Movers (N = 25)</th>
<th>Stayers (N = 27)</th>
<th>Effect F</th>
<th>Simple Main Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Total</td>
<td>60.2</td>
<td>11.1</td>
<td>60.2</td>
<td>12.9</td>
</tr>
<tr>
<td>Academic</td>
<td>3.30</td>
<td>1.66</td>
<td>5.0</td>
<td>1.91</td>
</tr>
<tr>
<td>Honesty</td>
<td>6.87</td>
<td>1.25</td>
<td>5.96</td>
<td>1.75</td>
</tr>
<tr>
<td>Emotion</td>
<td>4.28</td>
<td>1.89</td>
<td>5.56</td>
<td>1.90</td>
</tr>
<tr>
<td>Verbal</td>
<td>3.87</td>
<td>1.79</td>
<td>3.48</td>
<td>2.31</td>
</tr>
<tr>
<td>Opposite Sex</td>
<td>4.22</td>
<td>2.11</td>
<td>3.74</td>
<td>2.16</td>
</tr>
<tr>
<td>Physical Ability</td>
<td>3.61</td>
<td>2.11</td>
<td>4.61</td>
<td>1.95</td>
</tr>
<tr>
<td>Same Sex</td>
<td>5.88</td>
<td>1.39</td>
<td>6.04</td>
<td>2.32</td>
</tr>
<tr>
<td>General</td>
<td>5.88</td>
<td>1.67</td>
<td>5.48</td>
<td>1.56</td>
</tr>
<tr>
<td>Problem Solving</td>
<td>4.04</td>
<td>1.40</td>
<td>4.44</td>
<td>1.67</td>
</tr>
<tr>
<td>Maths</td>
<td>1.26</td>
<td>0.68</td>
<td>3.00</td>
<td>2.70</td>
</tr>
<tr>
<td>Parents</td>
<td>6.04</td>
<td>1.92</td>
<td>5.58</td>
<td>1.78</td>
</tr>
<tr>
<td>Religion</td>
<td>6.00</td>
<td>1.88</td>
<td>5.65</td>
<td>1.97</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>5.24</td>
<td>1.51</td>
<td>6.08</td>
<td>2.06</td>
</tr>
</tbody>
</table>

*Note. Movers = Group who moved to the Community, Stayers = Group who were Institutionalised
Effect F = Group, Time and Interaction effects of the repeated measures analysis of variance
*=p<.05, **p<.01, *** p<.001
to older people. Also, younger people have had less time to lose their academic skills. The difference between the Physical Ability subscales could relate to the fact that the participants in Stayers were younger and were all in employment.

**Results of the MANOVA on the SDQ-III**

The results of the repeated measures analysis of variance are shown in Table 7.3. For the Academic subscale there was a main effect of institution (F = 7.23, \( p < .01 \)) whereby the movers displayed statistically significant higher academic self-concept scores in comparison to the Stayers. There was a significant interaction effect (see Figure 7.2) whereby the Movers self-concept scores increased over time more than in comparison to the Stayers (F = 4.33, \( p < .05 \)). The post hoc analysis (see Table 7.3) revealed that the significant interaction was caused by a significant Time1/Time2 (F = 12.53, \( p < .01 \)) difference for the Movers and no significant Time1/Time2 difference for the Stayers.

![Figure 7.2. Graph of the Group by Time Interaction Effect for the Academic Subscale of the SDQ-III](image)

For the Physical Appearance subscale, there were no main effects for institution or time but there was a significant interaction (F = 4.97, \( p < .01 \)) with the Movers showing a large increase in Physical Appearance scores over time, whilst the Stayers’ Physical Appearance...
scores decreased slightly but were stable (see Figure 7.3). The post hoc analysis revealed that the significant interaction was caused by a significant Time1/Time2 difference (F = 4.67, p < .05) for the Movers, while for the Stayers there was no significant Time1/Time2 difference.

Figure 7.3. Graph of the Group by Time Interaction Effect for Physical Appearance of the SDQ-III

For the Emotion subscale, there was no main effect of institution; there was a main effect of time (F = 11.73, p < .001) with both groups’ Emotion scores increasing slightly over time (see Figure 7.4). There was a significant interaction (F = 4.14, p < .05) caused by a greater increase in Emotion scores for the Movers across time compared to the Stayers. The post hoc analysis showed that the significant interaction was caused by a significant Time1/Time2 difference for the Movers (F = 4.67, p < .05) and there was no significant difference for the Stayers.
For the Physical Ability subscale there was a large main effect of time ($F = 10.75, p < .01$) (both groups improved), but no main effect of institution or interaction effect (see Figure 7.5). However, as this is one of the major indicators of successful deinstitutionalisation, post hoc analysis was undertaken. This revealed that there was a significant Time1/Time2 difference for the Movers ($F = 3.92, p < .05$) and no significant difference for the Stayers. However, because the interaction effect was not significant, the larger, more positive change for the Movers was not significantly different from the smaller, less positive change for the Stayers.

**Figure 7.4. Graph of the Group by Time Interaction Effect for Emotion Subscale of the SDQ-III**
For the Maths subscale there was a main effect of institution with the Stayers displaying higher scores than the Movers ($F = 8.75, p < .01$). There was a main effect of time ($F = 16.81, p < .001$) with both groups displaying increased Maths self-concept scores. There were no interaction effects. As academic traits have been shown to improve after deinstitutionalisation, a post hoc analysis was undertaken. This found that there was a significant Time1/Time2 difference for the Movers ($F = 11.38, p < .01$) but there was no significant Time1/Time2 difference for the Stayers (see Figure 7.6).
Figure 7.6. Graph of the Group by Time Interaction Effect for Maths Subscale of the SDQ-III

There were group and time effects for the Honesty subscale but no interaction effects. There were no main effects for time or institution or any interaction effects on the Total, Parents, Problem-solving, Religion, Global, Opposite Sex, Same Sex, and Verbal subscales.

**Summary Research Question 1.1: Impact of Deinstitutionalisation on Self-Concept**

Research Question 1.1 posed whether multidimensional facets of self-concept as measured by the SDQ-III for adults with mild intellectual disabilities change after being housed in the community for 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutional setting during this time? The results demonstrate that there were significant interaction differences for the scores of the Movers in comparison to the Stayers for Academic and Physical Appearance and Emotion, whereby the Movers increased after moving to the community. These results show that the Physical Appearance self-concept, Academic self-concept and Emotion self-concept showed significant increases for the Movers, over the Stayers.

A majority of the subscales showed no significant changes and there were no results on
the SDQ-III suggesting that the Stayers increased in multidimensional self-concept facets more than the Movers. This tends to lend support to the conclusion that integration into the community did not lead to a decrease in self-concept, but there was an increase in multidimensional self-concept in some areas conceptually related to deinstitutionalisation.

**Results Research Question 1.2: Impact of Deinstitutionalisation on Self-Esteem**

This section describes the self-esteem descriptive and Time1 differences between the groups. The repeated measures analysis of variance along with the simple main effects is also presented. No hypotheses were made about the differences on these measures between the Movers and the Stayers, but because of the competing theoretical paradigms in this field, a research question was posed instead. Research Question 1.2 posed: Does self-esteem change for adults with mild intellectual disability who have moved to the community for 30 months, in comparison to adults with mild intellectual disability who have stayed in an institutionalised setting during this period?

**Descriptive Results of the Coopersmith Self-Esteem Inventory Adult Version (Short Form)**

The means, standard deviations and F-Ratios of the general/global self esteem for Movers and Stayers at Time1 and Time2 are presented in Table 7.4.

**Table 7.4**

<table>
<thead>
<tr>
<th></th>
<th>Movers</th>
<th>Stayers</th>
<th>Effect F</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Time1</td>
<td>Time2</td>
<td>Time1</td>
</tr>
<tr>
<td>Cooper smith Self-esteem</td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Coopersmith Self-esteem Inventory</td>
<td>52.4</td>
<td>14.4</td>
<td>55.3</td>
</tr>
</tbody>
</table>

The descriptive results of Coopersmith Self-Esteem Inventory Adult Version (Short Form) showed that participants with mild intellectual disability had low to average self-esteem compared to the normative groups on this measure. As discussed in Chapter 6, it was decided to
use the original norming data whereby the higher the score, the higher the self-esteem. Coopersmith cited a score of 75 as being high self-esteem. Only five out of 52 participants in this study scored in the high self-esteem criterion as defined by Coopersmith.

The means as reported for both groups of participants in this study were low but comparable to the participants in the Griffin et al. (1996) study who were not living independently. Also the results in Table 7.2 show that there were no differences between the Movers and Stayers at Time1 on the Coopersmith measure.

**Results of the MANOVA on the Coopersmith Self-Esteem Inventory**

Although the mean scores of the moving group increased slightly from Time1 ($M = 52.48$, $SD = 14.48$) to Time2 ($M = 55.3$, $SD = 14.51$), the results of the repeated measures analysis of variance on the Coopersmith Self-esteem Inventory (Table 7.4) showed that there were no statistically significant main effects for group ($F = 1.03$). Also, there was no main effect for time ($F = 0.72$) and no interaction effect observed ($F = 0.83$; see Table 7.4; Figure 7.7). The results on this self-esteem scale and those on the SDQ-III Global Scale are very consistent, with both demonstrating that no significant main or interaction effects for self-esteem were present.

![Figure 7.7. Graph of the Group by Time Interaction Effect for the Coopersmith Self-Esteem Inventory](image-url)
Summary Research Question 1.1: Impact of Deinstitutionalisation on Self Esteem

The results above indicate that no change was observed in global self-esteem for adults with mild intellectual disability who have been deinstitutionalised over 30 months in comparison to adults with intellectual disability who have not been deinstitutionalised. However, moving to the community again was also not related to any decrease in global self-esteem for the Movers.

Results Hypothesis 1.1: Impact of Deinstitutionalisation on Locus of Control

This section describes the locus of control and Time1 differences between the groups. The repeated measures analysis of variance along with the simple main effects is also presented. Hypothesis 1.1 predicted that adults with a mild intellectual disability who have moved to the community will have greater internal locus of control scores as measured by the Nowicki-Strickland Adult Internal-External Scale after being housed in the community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time.

Descriptive Results of the Adult Nowicki-Strickland Internal-External Scale (ANS-IE)

For Locus of Control the descriptive results (Table 7.5) show that at Time1, Movers ($M = 19.21$, $SD = 3.56$) and Stayers ($M = 19.1$, $SD = 4.51$) had a high external locus of control, compared to the normative sample (Nowicki & Strickland, 1973). The higher the score the more external the person is and scores over 13 are considered to be highly external (Wehmeyer & Palmer, 1997). Reported mean scores on the ANS-IE for college age students are 9.06 and a standard deviation of 5.61. For non-disabled adults in the community a mean of 10.96 and a standard deviation of 5.61 have been reported (Nowicki & Strickland, 1974).
Table 7.5
Means, Standard Deviations and F-ratios for the Adult Nowicki-Strickland Internal-External Control Scale for Movers and Stayers at Time1 and Time2

<table>
<thead>
<tr>
<th>Adult Nowicki-Strickland Internal-External Control Scale</th>
<th>Movers Time1</th>
<th>Movers Time2</th>
<th>Stayers Time1</th>
<th>Stayers Time2</th>
<th>Group</th>
<th>Time</th>
<th>Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time1</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>F</td>
</tr>
<tr>
<td>Movers</td>
<td>19.21</td>
<td>3.56</td>
<td>17.00</td>
<td>4.32</td>
<td>19.15</td>
<td>4.51</td>
<td>0.22</td>
</tr>
</tbody>
</table>
| Stayers        | 19.04      | 4.44        | **=p<.01, ***p<.001**

Both of the groups in this study scored in the external direction on both testing occasions (see Table 7.5). These findings are consistent with previous research that has found people with intellectual impairments hold externally oriented perceptions of control (Wehmeyer, 1994a).

Results of the MANOVA on the ANS-IE

The results of the repeated measures analysis of variance (Table 7.5) revealed no significant main effect for group or time and no interaction effect. There was a slight shift towards internality at Time2 for the moving group (see Figure 7.8). This shift was in the hypothesised direction; however, it was not significant.

![Figure 7.8. Graph of the Non-Significant Group by Time Interaction for the Nowicki-Strickland Adult Internal-External Locus of Control Scale](image)
Summary Hypothesis 1.1: Impact of Deinstitutionalisation on Locus of Control

The results presented above indicate that the Movers and the Stayers remained highly external in their locus of control throughout the period of this study; these results are similar to the results found for the population of people with intellectual disabilities across the lifespan. Therefore, Hypothesis 1.1, that Movers who were being deinstitutionalised would become more internal than Stayers who were not deinstitutionalised over 30 months, was not supported.

Results Hypothesis 1.2: Impact of Deinstitutionalisation on Quality of Life

This section describes the quality of life Time1 differences between the groups. The repeated measures analysis of variance along with the simple main effects is also presented. Hypothesis 1.2 predicted that adults with mild intellectual disability who have moved to the community will have a better quality of life, specifically in the Objective Community and Material domains as measured by the ComQol-I5 after being housed in the community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time. To test this hypothesis a series of repeated measures analyses were performed separately for each of the seven objective subscales and each of the seven subjective subscales of the ComQol-I5 instrument (see chapter 3). Total Objective Quality of Life scores and Total Subjective Quality of Life scores were not reported because exploratory factor analyses based on the data in this study revealed that there were no higher order factors on this measure. Also, latest theoretical developments in the quality of life literature (Schalock, 2001) no longer support the use of total scores.

Descriptive Results of the ComQol-I5

The means at Time1 of the Movers and Stayers were compared with norms from groups with intellectual disability provided by Cummins (1997a). Using the standardised comparison statistic % SM as suggested by Cummins (1997a), Table 7.6 shows that the combined Movers and Stayers at Time 1 had significantly lower scores in comparison to the norm group of people.
with intellectual disability presented by Cummins (1997a). For every subscale of the ComQol-I5 instrument with the exception of one, Objective Community, Movers and Stayers also displayed significantly lower scores in comparison to the norm group for Subjective Material, Health, Safety and Intimacy scales. Subjective Community was significantly higher for the total sample. Only in one objective scale (Objective Community) and two subjective scales (Subjective Community and Subjective Health) did the scores for participants in the present investigation exceed the normed sample.

For the Subjective scales, the productivity of the Movers was low at Time1. Subjective Intimacy, Community and Emotion were all significantly below the mean of the general population. Subjective Safety was the only subscale that approached the mean for the general population.

The results at Time1 (Table 7.2) showed that the only significant pre-existing mean difference on any of the 14 subscales of the Comprehensive Quality of Life Scale between the
two groups participating in the present investigation was in relation to the scale of Objective Productivity (F = 17.37, p < .01). This was expected given that one group (Stayers) was in employment at a workshop and the other was not. The ComQol-15 scale scores paid employment very highly as opposed to other types of involvement in the community thus accounting for the difference on this subscale.

Results of the MANOVA on the ComQol-15

The results of the repeated measures analysis of variance (Table 7.7) found that for the Objective Community subscale there was a significant main effect for group (F = 4.92, p < .05), and time (F = 3.45, p < .05). There was a statistically significant interaction effect whereby the Objective Community scores for the Movers increased slightly across time in comparison to the scores for the Stayers which decreased slightly (F = 4.01, p < .05) (see Figure 7.9). Simple means test analysis found that the Time1/Time2 difference was significant for the Movers but not for the Stayers (F = 4.15, p < .05; see Table 7.2).

Figure 7.9. Graph of the Group by Time Interaction Effect for Objective Community Scale of the ComQol-15

For the Objective Material scale there was a statistically significant main effect of group (F = 10.51, p < .01), a main effect for time (F = 32.65), and a statistically significant interaction
effect (F = 25.42, p<.01) whereby scores for the Movers increased over time more in comparison to scores for the Stayers (see Figure 7.10). Post hoc analysis confirmed that the significant interaction was caused by a significant Time1/Time2 difference for the Movers (F = 12.45, p<.01). There was no significant Time1/Time2 difference for the Stayers.

![Graph of the Group by Time Interaction Effect for Objective Material Scale of the ComQol-I5](image)

**Figure 7.10. Graph of the Group by Time Interaction Effect for Objective Material Scale of the ComQol-I5**

For the Subjective Material subscale there was no main effect for group and no main effect for time, but there was a significant interaction effect (F = 5.98, p<.05) as the Movers scores increased over time whilst the Stayers scores decreased over time (see Figure 7.11). Simple means test post hoc analysis showed that the Time1/Time2 difference was significant for the Movers (F = 4.98, p<.05) but not for the Stayers.
### Table 7.7
Means, Standard Deviations and F-ratios and Simple Main Effects for the ComQol-I5 (5th Edition) for Movers and Stayers at Time1 and 2

<table>
<thead>
<tr>
<th>ComQol-I5 (Quality of Life)</th>
<th>Movers (N = 25)</th>
<th>Stayers (N = 27)</th>
<th>Effect F</th>
<th>Simple Main Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Objective Material</td>
<td>5.12</td>
<td>1.20</td>
<td>7.04</td>
<td>1.30</td>
</tr>
<tr>
<td>Objective Health</td>
<td>9.60</td>
<td>2.42</td>
<td>9.36</td>
<td>2.41</td>
</tr>
<tr>
<td>Objective Productivity</td>
<td>7.40</td>
<td>2.48</td>
<td>7.84</td>
<td>1.91</td>
</tr>
<tr>
<td>Objective Intimacy</td>
<td>10.16</td>
<td>3.67</td>
<td>11.00</td>
<td>3.34</td>
</tr>
<tr>
<td>Objective Safety</td>
<td>11.52</td>
<td>2.08</td>
<td>11.12</td>
<td>2.32</td>
</tr>
<tr>
<td>Objective Community</td>
<td>7.12</td>
<td>1.94</td>
<td>7.85</td>
<td>1.66</td>
</tr>
<tr>
<td>Objective Emotion</td>
<td>9.68</td>
<td>2.56</td>
<td>10.20</td>
<td>2.42</td>
</tr>
<tr>
<td>Subjective Material</td>
<td>7.15</td>
<td>12.36</td>
<td>13.87</td>
<td>10.38</td>
</tr>
<tr>
<td>Subjective Health</td>
<td>4.91</td>
<td>11.27</td>
<td>3.50</td>
<td>11.59</td>
</tr>
<tr>
<td>Subjective Productivity</td>
<td>8.09</td>
<td>7.04</td>
<td>9.15</td>
<td>5.57</td>
</tr>
<tr>
<td>Subjective Intimacy</td>
<td>2.02</td>
<td>15.14</td>
<td>8.67</td>
<td>9.60</td>
</tr>
<tr>
<td>Subjective Safety</td>
<td>4.65</td>
<td>10.60</td>
<td>9.20</td>
<td>9.14</td>
</tr>
<tr>
<td>Subjective Community</td>
<td>5.78</td>
<td>11.14</td>
<td>4.70</td>
<td>9.01</td>
</tr>
<tr>
<td>Subjective Emotion</td>
<td>6.83</td>
<td>11.75</td>
<td>8.17</td>
<td>10.70</td>
</tr>
</tbody>
</table>

Note. Objective Scales = Objective Societal View of Quality of Life, Subjective Scales = Subjective Persons View of Quality of Life-Product of Importance x Satisfaction Rating, Total scores not computed

* p<.05, **p<.01, ***p<.001
For the Subjective Safety subscale there was no main effect for group and no main effect for time, but there was a significant interaction effect ($F = 4.41, p < .05$) as the Movers scores increased over time, whilst the Stayers scores decreased over time (see Figure 7.12). Post hoc analysis showed that there was a significant Time1/Time2 difference for the Movers ($F = 4.21, p < .05$) and there was no significant Time1/Time2 effect for the Stayers.

Figure 7.11. Graph of the Group by Time Interaction Effect for Subjective Material of the ComQol-I5
There were no significant main or interaction effects present for the Objective Health, Objective Productivity, Objective Intimacy, Objective Safety, Objective Emotion, Subjective Health, Subjective Productivity, Subjective Community or Subjective Emotion scales.

**Summary Results Hypothesis 1.2: Impact of Deinstitutionalisation on Quality of Life**

The results based upon the ComQol-I5 offer some support for Hypothesis 1.2, in that significant changes were found for the Objective Community and Objective Material domains, and for the Subjective Material and Subjective Safety domains in the hypothesised direction over 30 months favouring Movers over Stayers.

The move to the community for the Movers resulted in significant increases in both objective and subjective quality of life. The two objective scales that showed the significant results, Objective Community and Objective Material, were the ones hypothesised to have the closest relation to deinstitutionalisation. The Subjective subscales that showed significant increases for the Movers, Subjective Material and Subjective Safety, were also closely related.
to successful deinstitutionalisation. One of the reasons given for not placing people with intellectual disabilities in the community is that they will feel more vulnerable and less safe. Although the majority of the subscales did not show any significant results, there were no subscales where the Stayers improved over the Movers. Therefore, the move to the community did not lead to a decrease in quality of life in any area and led to increases in quality of life in conceptually interpretable areas in both objective and subjective subscales.

**Results Hypothesis 1.3 and 1.4. Impact of Deinstitutionalisation on Adaptive Behaviour**

This section describes the Adaptive Behaviour descriptive and Time1 differences between the groups. The repeated measures analysis of variance along with the simple main effects is also presented. The results of the AAMD-ABS (Nihira et al., 1974) that are reported were those of five factors that Nihira (1976) recommended for researching differences between groups. These were three factors from Part A: Personal Self-sufficiency, Community Self-sufficiency and Personal-Social Responsibility. Two factors from Part B were used: Social (Challenging) Behaviour and Personal (Challenging) Behaviour. Research Hypothesis 1.3 posed: that adults with mild intellectual disability who have moved to the community will have an increase in Personal Self-sufficiency, Community Self-sufficiency and Personal Social Responsibility after being housed in the community for a period of 30 months, in comparison with adults who have stayed in an institutionalised setting during this time. Research Hypothesis 1.4 posed: that adults with will have no increase in Social (Challenging) Behaviour and no increase in Personal (Challenging Behaviour) after being housed in the community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time.

**Descriptive Results of the AAMD-ABS**

The means, standard deviations and F-Ratios and simple main effects for Adaptive Behaviour for Movers and Stayers at Time1 and Time2 as measured by the AAMD-ABS are presented in Table 7.8.
Comparison of the Time1 scores with those reported in the literature (Fine, Tangeman & Woodard, 1990; Prasher, Chung & Haque, 1998; Young, et al., 2000) suggests that both of the groups in this study are functioning significantly above the means for the norming sample and above the means for previous research in which this scale has been used. It must be remembered however, that the AAMD-ABS is suitable for use with people who are in the moderate, severe and profound range of intellectual disability (Nihira et al., 1974). All of the participants in this study were diagnosed in the mild/moderate range of intellectual disability. The majority of the residents scored over the 90th percentile on most of the subscales, particularly in the areas of independent functioning. Table 7.2 reveals that at Time1 there was one significant difference between the groups. For the third factor, Personal Social Responsibility, the Stayers scored significantly higher in comparison to the Movers (t = 2.84, p<.01).

**Results of the MANOVA on the Five Factors of the AAMD-ABS**

The first factor of the AAMD-ABS, Personal Self-sufficiency tested the hypothesis (Hypothesis 1.3) that adults with mild intellectual disability who have moved to the community will have an increase in Adaptive Behaviour in Factor 1 (Personal Self-Sufficiency), Factor 2 (Community Self-sufficiency) and Factor 3 (Personal-Social Responsibility) after being housed in the community for a period of 30 months, in comparison to adults with a mild intellectual disability who have stayed in an institutionalised setting during this time.
Table 7.8
Means, Standard Deviations and F-ratios and Simple Main Effects for the AAMD Adaptive Behaviour Scale Factors (1974) for Movers and Stayers at Time1 and Time2

<table>
<thead>
<tr>
<th>Factor Scores</th>
<th>Movers (N = 25)</th>
<th>Stayers (N = 27)</th>
<th>Effect F</th>
<th>Simple Main Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Time1</td>
<td>Time2</td>
<td>Time1</td>
<td>Time2</td>
</tr>
<tr>
<td>Factor 1 - Personal Self-Sufficiency</td>
<td>75.4</td>
<td>7.10</td>
<td>78.6</td>
<td>6.4</td>
</tr>
<tr>
<td>Factor 2 - Community Self-Sufficiency</td>
<td>75.7</td>
<td>13.9</td>
<td>100.6</td>
<td>16.4</td>
</tr>
<tr>
<td>Factor 3 - Personal Social Responsibility</td>
<td>52.9</td>
<td>9.1</td>
<td>60.9</td>
<td>11.4</td>
</tr>
<tr>
<td>Factor 4 - Social (Challenging) Behaviour</td>
<td>36.1</td>
<td>26.6</td>
<td>28.2</td>
<td>18.1</td>
</tr>
<tr>
<td>Factor 5 - Personal (Challenging) Behaviour</td>
<td>4.3</td>
<td>4.1</td>
<td>2.7</td>
<td>3.6</td>
</tr>
</tbody>
</table>

*a Social Behaviour used to be called Social Challenging Behaviour - higher scores signify poorer social behaviour
b Personal Behaviour used to be called Personal Challenging Behaviour - higher scores signify poorer personal behaviour

**p<.05, ***p<.01, ****p<.001
**Personal self-sufficiency.** The results of the repeated measures analysis variance for Personal Self-Sufficiency (Factor 1) (Table 7.8) show that for personal self-sufficiency there was a main effect of time (increases over time) \((F = 11.13, p < .01)\) but no main effect for group or any interaction effects. Therefore, for the first factor the hypothesis was not supported.

**Community self-sufficiency.** For Community Self-Sufficiency (Factor 2), the results of the repeated measures analysis of variance (Figure 7.13) showed that there was a non-significant effect of institution, and a main effect of time \((F = 304.27, p < .001)\). There was a large interaction effect \((F = 9.95, p < .01)\) whereby scores for the Movers increased much over time in comparison to the Stayers. The post hoc analysis found that the Time1/Time2 difference for the Movers was significant \((F = 12.62, p < .01)\) but that the Time1/Time2 difference for the Stayers was not significant. Therefore, for the second factor the hypothesis (Hypothesis 1.3) was accepted.
For Personal-Social Responsibility (Factor 3), the results of the repeated measures of analysis of variance (Table 7.8)(Figure 7.14) showed that there was no main effect for institution. There was a main effect for time ($F = 19.36, p < .001$) and a significant interaction effect. There was a significant interaction caused by a greater increase in personal social responsibility scores for the Movers across time compared to the Stayers ($F = 11.28, p < .01$). Post hoc analysis showed that the Time1/Time2 difference for the Movers was significant ($F = 8.09, p < .01$) and that the Time1/Time2 difference for the Stayers was not significant. Therefore, the hypothesis (Hypothesis 1.3) was supported in relation to this factor.
Social (challenging) behaviour. The fourth factor, Social (Challenging) Behaviour was used to assess Hypothesis 1.4, that there would be no significant differences between Movers and Stayers and that the Movers would show no change in Social (Challenging) Behaviour over time (Note-an increase in scores signifies poorer behaviour). The results of the repeated measures analysis of variance (Figure 7.15) showed that there was no main effect for Group or Time. There was a significant interaction caused by a greater decrease in Social (Challenging) scores for the Movers across time compared to the Stayers (F = 4.03, p<.05). Post hoc analysis found that the Time1/Time2 difference for the Movers was significant (F = 4.06, p<.05). Therefore, the hypothesis (Hypothesis 1.4) was rejected. The Movers’ scores decreased significantly which means that their social challenging behaviour significantly decreased because of their deinstitutionalisation. There was a shift to more favourable scores for Movers as lower scores were significant for a negatively oriented construct.
Personal (challenging) behaviour. For the Personal (Challenging) Behaviour (Factor 5), the Hypothesis 1.4 that there would be no differences between groups and no main effect for time or institution and no interaction was supported (Table 7.8). The Personal Challenging behaviour of the Movers had not increased because of the deinstitutionalisation of the Movers.

Summary Results Hypothesis 1.3 and 1.4: Impact of Deinstitutionalisation on Adaptive Behaviour

Overall the above results indicated that the move to the community for the Movers was associated with positive improvement in Community Self-sufficiency and Personal Social Responsibility. The lack of significant interaction for Personal Self-sufficiency (Factor1) could reflect a ceiling effect as the participants in both groups scored at very high levels in the Subscales that loaded heavily onto this Factor. Social (Challenging) Behaviour (Factor 4) decreased significantly for the Movers over 30 months in the community but not for the Stayers, and there was no increase in Personal (Challenging) Behaviour (Factor 5) for either group. These results, then, support the contention that deinstitutionalisation will have a positive impact on adaptive behaviour. Significant improvements for the Movers were found in three of
the five factors, Community Self-sufficiency, Personal-Social Responsibility and Social (Challenging) Behaviour. Also Personal (Challenging) Behaviour, as hypothesised, did not increase after deinstitutionalisation. Again, as with all of the other measures there was no decrease in adaptive behaviour for the Movers, relative to the Stayers. Overall the finding for most of the constructs were stable for the Stayers as would be predicted for a comparison group that did not receive any type of intervention.

**Discussion**

The central finding of this study was that there was clear support for deinstitutionalisation for adults with mild intellectual disability and that there was no advantage gained by the adults remaining in the other institution. What differences there were between the Movers and the Stayers were always in favour of the Movers. At no time did the group that was not deinstitutionalised show any changes that would suggest that they benefited from remaining in the institutionalised setting and the results do not report any negative impact (changes) for the group that was deinstitutionalised. The results of this investigation support the findings of previous research that has shown the benefits to people with intellectual disabilities of the move from institutions to live independently in the community (Larson & Lakin, 1989; Kim, et al., 2001; Felce & Perry, 1996).

Each of the variables examined revealed a different aspect of the complex picture of the effects of deinstitutionalisation, and, as such, the examination of this range of affective variables strengthens the validity of the conclusions that there was a positive impact from deinstitutionalisation. This positive impact was found for facets of multidimensional self-concept, quality of life and adaptive behaviour.

**Multidimensional Self-Concept and Global Self-Esteem**

This study was the first to investigate the impact of deinstitutionalisation on multidimensional self-concept facets. The results clearly favoured the Movers over the Stayers on the dimensions of Academic, Physical Appearance and Emotional self-
concept. There were also large increases over time for the Movers in Physical Ability and Maths self-concept. The Physical Ability dimension is conceptually closely related to successful deinstitutionalisation and successful integration in the community (Kim et al., 2001) because of a person’s perceived ability to achieve tasks and to move around the community. The changes in the Maths dimension, although a little unexpected, could be accounted for by the successful use of banking facilities, shopping independently and handling money. Other studies have reported changes in academic ability as a result of deinstitutionalisation (Lynch, et al., 1997). It was, however, also encouraging to see that Physical Appearance and Emotional self-concept also improved for the Movers.

This study used the SDQ-III to identify whether multidimensional instrumentation had greater explanatory power than the unidimensional global self-esteem measures. The SDQ-III showed some significant changes over 30 months of the research period as outlined in Research Questions 1.1 and 1.2, but the Coopersmith SEI did not reveal any differences. The results of this research are encouraging although further research using the SDQ-III is needed with larger populations. The fact that not all of the subscales showed differences is similar to the findings of other studies. Often children and adults with different disabilities have been shown to score lower on self-concept scales only on those dimensions directly affected by their disability (Chapman, 1988; Grolnick & Ryan, 1990; King et al., 1993; Johnston, 2001). This might explain the change in Academic and Maths subscales, as these are the two scales most closely aligned to intellectual disabilities. The self-concept of Physical Ability subscale results were also analysed, as physical ability in previous research has had such a strong relation with successful deinstitutionalisation. Physical Ability self-concept improved over the 30 months for both groups, but much more for the Movers. The Maths subscale also improved significantly as well. The Physical Ability self-concept score changes and Maths self-concept changes must be interpreted cautiously, as the interactions were not significant; however, improvements over time for the Movers are conceptually related to positive outcomes for deinstitutionalisation. The Academic and Maths increases may seem at first tangential to successful deinstitutionalisation for people with mild
intellectual disability of this age, but there has been consistent evidence in the adaptive behaviour literature of significant increases in academic skills after deinstitutionalisation (Lynch, et al., 1997; Kim, et al., 2001). These increases in ability have been reflected in increases in self-concept for the people with mild intellectual disability who have been deinstitutionalised.

The use of a multidimensional self-concept instrument to determine the impact of deinstitutionalisation upon the self-concepts of people with mild intellectual disabilities is important. The SDQ-III measured self-concept from a multidimensional view of self which allowed comparisons within and between subjects with respect to different facets of development and competence. Newer developments in self-concept theory indicate that such specificity is needed when considering the impact of disability and deinstitutionalisation upon the development of self-concept. For example, Tracey (2002) found that only the academic self-concept of children with mild intellectual disabilities was affected by placement in different educational settings.

Previous research has demonstrated that global self-concept is not a useful construct (Marsh & Johnston, 1993). Global self-concept cannot reflect the diversity of multidimensional self-concept. Multidimensional self-concept is more useful in terms of different settings, behaviours, and interventions (Marsh & Johnston, 1993). However, Marsh and Johnston (1993) did not advocate the abandonment of measures of global self-concept, just that there needed to be more emphasis on multidimensional self-concept. The SDQ Global subscale reported, which is very similar to the Rosenberg self-esteem scale, resulted in similar results (i.e., no significant group time or interaction effects as for the Coopersmith SEI) offering further support for the need to focus on multidimensional facets of self-concept. Furthermore, the global self-esteem scale used in this study showed no significant results, confirming that the multidimensional self-concept was more informative. This extra information may allow for more specific targeting of individual needs. It also offers a stronger theoretical construct from within which to consider some of the psychological effects of deinstitutionalisation. In addition this theoretical
conceptualisation of the structure and measurement of self-concept is more closely aligned to the newer developments in the field of self-concept research and also allows the use of multivariate, between subjects research designs that have been recommended in the recent deinstitutionalisation literature.

The successful use of an instrument that measures multidimensional self-concept for people with disabilities implies that this instrument be utilised to allow comparisons with non-disabled and other populations. It may also overcome the conflicting results that have been found for people with intellectual disabilities because of the continued use of unidimensional instruments in that field. It must be recognised though, that the instrument must be administered one to one, if reliable and valid responses are to be recorded.

To summarise, the choice of a multi-dimensional self-concept instrument to assess deinstitutionalisation rather than a unidimensional instrument that dominates the research area was justified. The multidimensional instrument presented a much more complete picture of the impact of deinstitutionalisation. It could also help in predicting where intervention may be necessary and enable the specific tailoring of the transition to individuals, which could allow a smoother move to the community. SDQ-III has validity in this setting and for this population.

Another aim of this study was to attempt to see whether stigma theory or social comparison theory would have greater explanatory power in the impact of deinstitutionalisation on self-concept. The findings do not support the contention of social comparison theory, that people with intellectual disabilities who move to living in the community would experience a decrease in self-concept and self-esteem because they are being exposed to normative reference groups. The move to the community did not lead to a decrease in self-concept for the group that moved. Whilst this study is not an empirical test of social comparison theory versus stigma theory, it does add to the theory in this area (see further development of this research question in chapter 8). This is because it was impossible before to make strong hypotheses about whether self-concept would increase as a result of deinstitutionalisation as predicted by social comparison theory because participants would be making
unfavourable (contrast) upward comparisons with non-disabled people as they may have been less able to make downward comparisons with comparison groups of other people with intellectual disabilities. Alternatively, as predicted by stigma theory, self-concept would decrease because now the individual receives positive appraisals about their normality. Further theoretical development of how deinstitutionalisation impacts on self-concept is now possible.

**Locus of Control**

The hypothesis that the Movers would develop a more internal locus of control as a result of the move to the community was not confirmed. These results do not support the literature that suggests that moving to independent living leads to greater choices and more autonomy for people with intellectual disabilities, which is then reflected in a more internal locus of control (Stancliffe & Wehmeyer, 1995; Tossebro, 1995; Wehmeyer & Bolding, 1999).

The results do support the previous research that people with intellectual disabilities hold highly external perceptions of control and that these are maintained across the lifespan. The participants in this study could be conceptualised as having maladaptive perceptions of control. These may be the result of the lack of opportunities that these people have experienced as a result of their long histories of institutionalisation. Another explanation may be that they do not fully understand that effort and ability can have a significant influence on positive outcomes and they more readily believe in external choices like luck, chance and fate (Wehmeyer & Palmer, 1997). It could be that their perceptions are realistic.

These results do not support the abandonment of the locus of control construct when conducting research with people with intellectual disabilities. Internal locus of control is still considered to be closely related conceptually to quality of life and self-determination (Wehmeyer & Schwartz, 1998; Schalock, 2000). The lack of change in the locus of control construct could suggest that it is necessary to strengthen services in this area that could affect this construct. An alternative explanation could be that
the measure used in this study, although the one that has been used exclusively for this population, was not appropriate. Other measures that have been used, such as the Arc Self-Determination Scale (Wehmeyer & Schwartz, 1998) or Consumer Choice Scale (Stancliffe & Abery, 1997), may lead to more definitive results. Since the conceptualisation of this thesis, locus of control has been subsumed under the broader field of self-determination and choice-making. This broadening would be an interesting extension for further research into deinstitutionalisation.

**Quality of Life**

The findings from this study support previous research in relation to the impact of deinstitutionalisation on quality of life. The study confirmed the previous findings of studies conducted within Australia (Young et al., 1998), Britain (Emerson & Hatton, 1996) and the USA (Kim et al., 2001), in that living in the community leads to positive changes associated with quality of life. Specifically, this study found that, as hypothesised, the quality of life of the Movers increased in the domains of Objective Community and Objective Material, and Subjective Material and Subjective Safety. These results support the results of others that the domains of quality of life most likely to be affected by deinstitutionalisation were material well-being and community integration (Apgar, Cook & Lerman 1998). It is also encouraging that the Movers thought that their Safety was increased, as one of the reasons for keeping people in institutions was their perceived vulnerability in the community.

This study was the first to use Cummins Qol-I5 (Cummins, 1997a) to assess deinstitutionalisation in the Australian setting. The results support the use of a multidimensional instrument that measures both objective and subjective domains of quality of life. It reflects recent theoretical developments (Schalock, 2000) that quality of life is a multidimensional construct and that measurement of both objective and subjective domains is necessary as they are independent. The results also reinforce that the multidimensional domain scores are the appropriate unit of comparison, and not the total quality of life scores.
Adaptive Behaviour

There were statistically significant improvements in both adaptive behaviour and challenging behaviour for the Movers because of the change to community living. This increase in adaptive behaviour scores is common and is well-documented in the literature (Lowe, de Paiva & Felce, 1993; Young et al., 1998; Kim et al., 2001).

There were a number of specific findings for this study. These were that there were significant differences on the Community Self-sufficiency, Personal-Social Responsibility, and Social (Challenging) Behaviour Factors that favoured the Movers. There were no significant changes on the Personal Self-sufficiency and the Personal (Challenging) Behaviour factors. Perhaps for Personal Self-Sufficiency, the lack of positive changes could be explained by ceiling effects. Ceiling effects have been predicted by Moss and Hogg (1997) and Cummins, Polzin and Theobald (1990b) for high functioning people with mild intellectual disabilities.

The statistically significant increases in Community Self-sufficiency and Personal-Social Responsibility were in the hypothesised direction. This was encouraging and suggests that people with intellectual disabilities who are not young and have been institutionalised for long periods of time are capable of learning throughout the life span. The improvement in two factors of adaptive behaviour show that even Movers, who were older, were capable of learning new skills.

Another important finding of this study was the statistically significant improvement in Social Challenging Behaviour and the lack of change (no increase) in Personal Challenging Behaviour. This finding has not been shown in Australian studies before, as the most recent Australian studies reported increases in challenging behaviours as well (Young et. al., 2001). These results mirror the recent studies in USA (see earlier discussion in chapter 4) which have shown that the challenging behaviour problem that was evident in the 1980s has not been found in the last 10 years because of improved support in the community. Most recent studies have shown
no significant change or significant improvements (Kim et al., 2001). Rubin and Heal (1996) feel that challenging behaviour is the best indicator of poor adjustment to the community. For this study the results on the Adaptive Behaviour factors and Challenging Behaviour factors indicate that the Movers had made a successful adjustment to community living. This positive outcome for challenging behaviour in studies overseas and this research are unlike that found previously in Australia (Young et al., 1998). Perhaps the shift towards person-centred services and person-centred planning that was instituted for the Movers had reduced the need for the expression of challenging behaviour. In summary, the results on the AAMD-ABS are an internally consistent validation of the impact of relocation on real-life social behaviours.

Conclusions

The results in this study present a coherent picture of the impact of deinstitutionalisation. The question must be asked regarding these affective variables irrespective of the policy of normalisation: how statistically significant should each of these be to justify the move into the community from an institutionalised setting? This study clearly demonstrated that although accepting the limitations of the results of some of the factors within even the multidimensional instruments, there were no advantages for people who stayed behind in the institutions. It is imperative to have person-centred care and changes in program prior to placement with a follow-up service available after deinstitutionalisation. Provision of living arrangements that engender optimal quality of life for people with mild intellectual disabilities are more crucial than having statistically significant variables. The relevance of determining the affective characteristics of people undergoing transition to the community, however, cannot be ignored, both on a theoretical and practical basis. For example, the participants in this study were moving into community-based services with a commitment to normalisation and support, but no sophisticated therapeutic services (this is a usual reality in Australia). Real commitment to normalisation needs extra training to be provided in the community for the individuals who are moving.
Services, in consultation with clients, should establish skills acquisition as a specific aim rather than relying on relocation to promote these.

Cullen et al. (1995) argue that researchers should stop asking the question “Does deinstitutionalisation work or not work?”. Instead the discussion should centre on what outcomes or variables are of relevance to service users, planners and providers. A major issue raised by the results presented in this chapter is the need to promote social integration (see chapters 2 and 9). The specific areas highlighted in this examination of the affective characteristics of adults with mild intellectual disabilities include multidimensional self-concept and indicate the need to think of self-enhancement programs, combined with social skills programs to bring about change. These are the real challenges for service providers, as clients need a range of skills to participate meaningfully in their communities.

The demonstration of the presence of such cognitive processes as low self-esteem, poor social comparison and quality of life suggest that cognitive therapy techniques like the one developed for this study in Chapter 9 may be very useful. Elements of the process, such as dimensions upon which people choose to compare themselves and people against which they compare themselves may be examined within therapy. Therapy may also target the values given to other roles and activities within a person’s life (Taylor, 2000), which may act as a buffer against negative social comparisons (Dagnan & Sandhu, 1999). Future research should investigate whether such interventions can be used in the processes of social comparison for people with intellectual disability. This study supports the contention that people with intellectual disabilities need to have programs that encourage them to live and socially interact in the community.

The results support the measures used to identify the effects of deinstitutionalisation. The results (i.e., no change or very little change in the Stayers and either no change or changes in the hypothesised direction for the Movers) validate the measures. Psychological well-being of clients has been has been neglected because of problems with instrumentation (Zetlin, et al., 1985, Zetlin & Turner,
1988). With the advent of theoretically sound and more robust instrumentation, this can no longer be justified.

**Summary**

This chapter reported the results of Study 1 which was a longitudinal and comparative analysis of the impact of deinstitutionalisation on the affective characteristics of adults with mild intellectual disability. First, descriptive results were presented, followed by the results for two groups of participants, Movers and Stayers, for multidimensional self-concept, self-esteem, locus of control, objective and subjective quality of life, and five factors of adaptive behavior. Finally, the implications of the results were discussed. The pattern of results favours the Movers over Stayers. Overall the results support the positive impact of deinstitutionalisation.
CHAPTER 8

Results Study 2: The Impact of Deinstitutionalisation on the Self-Esteem of Adults with Mild Intellectual Disability—A Qualitative Analysis

Introduction

This study explored the experience of socialisation of adults with mild intellectual disabilities who wished to move to the community based upon five case studies of women undertaken over a period of 30 months. These women were being prepared for and are now living in the community. Goffman’s (1963) theory of stigma and deviance, as well as social comparison theory (Festinger, 1954), provided the theoretical framework for the study. The typology developed by Zetlin and Turner (1984) and used by Angrosino (1992) was used for the analysis of the data (see chapter 2). The typology derives its main emphasis from stigma theory but integrates social comparison dimensions as well (see chapter 2). Study 2, therefore, aimed to (a) identify the external factors that impact upon the perceived social competence of adults with intellectual disabilities who have recently moved to the community, (b) elucidate which of the two competing paradigms (stigma or social comparison theory) had greater saliency in relation to the impact of deinstitutionalisation upon the self-concepts and identity of adults with mild intellectual disabilities, and (c) test the validity of Zetlin and Turner’s (1984) typology for long-term institutionalised people with mild intellectual disabilities.

The methodology was ethnographic and the data consisted of life history interviews with participants both before and after the move to the community. Interviews also were conducted with significant others in their lives, and observations of the participants in different environments were made by the researcher. Extensive case files were also examined. This chapter first overviews ethnographic methodology, data collection procedures and the research setting. Secondly, the results of five in-depth case-studies are presented. Finally, the research questions presented in Chapter 5 are addressed.
Overview and Rationale for the Chosen Methodology

Characteristics of Ethnographic Research Methodology

The most common paradigm used by qualitative researchers to study the impact of deinstitutionalisation has been participant-observation or ethnography (Edgerton, 1984; see chapter 2). Ethnography is based on the symbolic interaction perspective (Cusick, 1997, p. 94), the same tradition that developed the concept of social identity. The critical emphasis is on the experience of the individuals being studied. The ethnographic researcher has to obtain an insider’s view of a society, and to understand the other people’s own worldview, instead of taking the outsider’s perspective. As such, ethnographic research produces situated knowledge rather than universals, and aims to capture the detail of social life through thick description (Vidich & Lyman, 1998) and slice of life accounts rather than abstracting from this detail to produce reductive models (Taylor, 2000).

The approach has certain characteristics: “The essence of the method lies in the prolonged and unobtrusive presence of a sensitive and trained observer among the person’s being studied” (Edgerton, 1984, p.339). Another important aspect of this methodology is to maintain prolonged contact with people and try to become a natural part of their lives to establish the emic (insider’s perspective) rather than the etic (outsider’s perspective) discussed above. This is reflected in the concern to represent what the participants themselves believe and say about their lives and to achieve this the person’s words and observations need to be used.

Ethnography (Fetterman, 1989) also delineates practical strategies for gathering data. Methods can include in-depth interviews, life histories, fieldwork observation, field notes, journals, key events, and document and literature reviews (Spradley, 1979). The data collected are usually presented as descriptive accounts followed by some interpretation. Triangulation is another concept basic to ethnographic research (Fetterman, 1989) and allows the testing of one source against another to strip away alternative explanations and prove a hypothesis. Another strategy that is employed to strengthen ethnographic reliability is looking for consistency in patterns of thought and behaviour. Reciprocity is also another feature
of ethnographic enquiry (Fetterman, 1989). It is often possible for the ethnographer to reciprocate the participants in their studies for their time and willingness to share their life stories by offering services and expertise that the participants value.

**Rationale for the Ethnographic Approach Used in the Present Investigation**

Because of time constraints, it was initially planned just to complete autobiographical interviews with chronological life histories (Fetterman, 1989). However, difficulties were encountered early in the project. Similar to the findings of Edgerton, Bollinger and Herr (1984), the first attempts at interview produced trivial and socially desirable responses. The transcripts of even the most able and linguistically capable of the residents were not yielding the thick description that qualitative research requires. Most of the answers were short and succinct and conveyed a summary of what could be found in personal files and other documents. Alternatively, some narratives were very rambling and disjointed. The techniques that have been used in other qualitative interviews to elucidate deeper meanings such as probing and asking “Can you tell me more about that?” usually led to confusion or inappropriate responses such as “Didn't I answer the last one correctly?”. Open-ended questions led to shorter replies rather than the expected longer answers.

Taylor, Douglas and Knoll (1987) suggest that qualitative methods depend heavily on good communication between the researcher and the participant. Whether or not qualitative techniques can be used appropriately with people with intellectual impairment whose use of language may be limited has been questioned. Taylor et al. addressed this issue by using traditional participant observation techniques. They modified their interview technique by getting to know the informant, observing participants for longer time periods, and interviewing and observing interactions with significant others. These suggestions raise the ethical dilemma that people with intellectual disabilities have long been stigmatised and effectively denied a voice. For this reason the use of significant others exclusively to express opinions on behalf of people with disabilities is no longer acceptable in this field.

Methodological issues in interviewing and testing people with disabilities have long been recognised. Heal and Seligman (1995) highlight many of these. One of the
most common is that of acquiescence, (e.g., the tendency to answer “yes” to “yes/no” questions, particularly if the interviewer is perceived to be of higher status).

“Contradictory nay saying” is also observed if the topic is threatening or taboo, whereby people with disabilities will deny feelings and events that are too stressful to recall. Heal and Seligman (1995) also discuss the threat that open-ended questions have for people with disabilities. The solution offered by them is to move to an either/or response or to offer multiple-choice formats. However, neither of these formats would yield the richness of information or the thick description that is desirable in qualitative research.

The literature on using qualitative interview techniques with people with intellectual disabilities is sparse. Angrosino (1992) when faced with similar difficulties used techniques developed by Edgerton (1967) in his ethnographic study of deinstitutionalised adults with intellectual disabilities. Edgerton (1967) made extensive use of interview materials demonstrating that people with intellectual disabilities could respond meaningfully if the researcher had enough patience. Both Edgerton and Angrosino have successfully used life-history methods. Angrosino (1992) suggested that the reason people with intellectual disabilities are often unresponsive and lack focus in interview situations is the result, in the past, of always being interviewed in the clinical setting by professionals who have power over them but whom they rarely know and do not share anything with. Angrosino spent two years with his participants before beginning to interview them. Similar to the problems encountered in this project, he found the invitation to “tell me about your life” was meaningless for people with intellectual disability. They did not seem to have a sense of their lives, but they could give quite detailed chronologies of life events, whereby they could quite clearly remember what had taken place and could express some feelings about them. However, they rarely made the imaginative leap to any abstract pattern in those events. Angrosino (1992) used his knowledge as a participant to “concretise” their life for them, for example, “You helped me play basketball last week. Who taught you that?”

Edgerton and Angrosino analysed the narratives differently: Angrosino concentrated on the formal stylistic properties of narrative as main conveyors of meaning, whereas Edgerton analysed the narratives at content level. They,
nevertheless, found the life-history method to be the most productive with people with intellectual disability. Following the initial difficulties outlined above, the research methodology for the current investigation was devised to capitalise on the ethnographic participant-observer approach suggested by Edgerton (1984) and followed by Angrosino (1992).

Methodology

Ethnographic methods employed in the present investigation included literature review, in-depth life histories, interviews before and after deinstitutionalisation, interviews with significant others (personal care workers and administrators), perusal of case files, and participant observation in different settings. In applying the participant-observer perspective, the researcher lived with the participants on site, accompanied them in everyday activities, attended and played the piano in chapel and church services and joined them on special occasions, such as Christmas parties. The researcher made no attempt to make lasting friendships; she was not resident in the same state and would not have been able to maintain these meaningful relationships once she left the research site. Nevertheless the contact lasted for a period over 30 months. The researcher visited the site five times throughout the 30 months of the research project. On one occasion she lived in the institution for seven weeks. On three occasions she lived in the institution for three weeks, another time she stayed there for two weeks. In all, the researcher lived on the same site as the participants for seven days of the week for 18 weeks. She also returned to visit the participants in their new homes after moving to the community to conduct follow-up interviews.

Although extensive long-term continuous fieldwork is the norm for ethnography, this was not possible. The approach the researcher used allowed her to conduct intensive fieldwork, pull back and make sense of what she had observed and recorded, and then return to the field to further test hypotheses. This allowed the researcher to see patterns of behaviour over time. It also allowed her to feed back observations to the participants and the staff so that meanings and understandings could be checked for validity and corrected throughout the research period. Participant observation can lead people to conceal feelings and alter behaviour
(Edgerton, 1984). This was overcome by spending large amounts of time establishing rapport. Reciprocity was established as the researcher offered participants sincere interest in their lives, concern, and at times fun (e.g., when they just went for walks or played in the pool together).

**Data Collection Methods and Instruments**

*Development of Interview*

Life history interviews were undertaken. A schedule was developed following the preliminary review of literature. At first the researcher developed an interview schedule to provide a structure that would effectively meet the goals of the project. This involved a three-step process. First, a content analysis of the relevant literature on the impact of deinstitutionalisation upon socialisation and social competencies was undertaken. This was used to guide the development of a list of possible questions. Secondly, personal care workers, administrators and residents were also asked to comment on the issues that should be covered. In addition, other people who have worked in the field also provided feedback on comprehensiveness, clarity, relevance and coverage of salient issues. Finally, a draft of the schedule (see appendix A) was shown to the administrator and the director of the program and approval was given to proceed.

The guides for elements of the ethnographic interview were used to structure the interviews as recommended by Spradley (1979). The interview contained greetings, explanations of the project questions, data recording, asking questions, expressing interest, repeating, restating the information, asking friendly questions and taking leave. Interviews were held at a location convenient to the participant and each interview was taped. The taped interviews were then transcribed. All identifying information was then removed to ensure anonymity. Tapes were securely stored with access only by the investigator. Transcriptions were coded and pseudonyms were recorded to minimise the risk of identification. In the reporting the results of this study some data examples were slightly edited to ensure anonymity. This was considered essential as most of the participants in this study were well known to one another and to their administrators and workers. Also, some of the information was
extremely sensitive (for example, admission to psychiatric ward and accusations of being at moral risk). Participants were read a copy of the transcript by the researcher to check accuracy. None of the participants asked for any changes.

The information gained from the interviews was compared with information from significant others, allowing for triangulation of the information. Participant observation field notes and memos were also written at this time. The observations and parts of the report were shown to the participants and staff to check for accuracy of the description before the researcher left the research site on each visit. Hence procedures were put in place to check the validity of the findings as each data phase was collected.

**Documents**

The major documents examined were the extensive files maintained by the institution on each resident. These contained entries for nearly 20 years of resident history at admission, program characteristics, standardised evaluations, and non-standardised evaluations carried out by personal care staff. There were also yearly reviews undertaken by the Occupational Therapist, the director of the program. Data from these documents served as a source to enable triangulation of experiences and life history and these data also helped build a profile of each person.

Hence, the data collection procedures used in this study followed the principles outlined by Edgerton (1984), that is, there should be multiple points of view, a longitudinal perspective and an ecological perspective. Multiple points of view were achieved through the interviews, the observations and the document study. A longitudinal perspective was gained because of the length of time involved and the close contact with the participants. The five periods of intensive study allowed pertinent information to be added through subsequent time periods. Ecological context was achieved through studying the same person in different settings. This was accomplished by systematically observing the person’s behaviour in all settings to which the researcher had access. All of the participants were observed in the routine aspects of their life such as housekeeping, personal grooming, using public transport, working, preparing meals and social interaction in recreational settings. Also, where
possible, the researcher accompanied people to new settings to see if they were generalising from one situation to another.

**Method of Analysis**

Data from different methods of collection were synthesised using Zetlin and Turner’s typology (1984) (see Table 8.1, also see chapter 2) Zetlin and Turner identified four distinct attitudes based on their participants’ willingness or reluctance to discuss their disability, the tension or anxiety they related in acknowledging that they had problems, the importance of their disability in their day-to-day lives and the strategies they used to cope with the impact of stigma on their self-esteem and identity. The four attitudes identified were (a) acceptance (e.g., I have a disability but there are a lot of things I can do on my own), (b) qualification (e.g., I’m slow in learning but not retarded, some of the others are much worse than me and can’t even talk), (c) vacillation (e.g., I may have trouble reading and writing but I don’t consider myself to be disabled), and (d) denial (e.g., I don’t have any problems, my need to be here is because of other reasons such as family abuse).

Once the participant’s most consistent way of responding to their disability had been classified then the typology outlines the relation with other measures of socioemotional adjustment which include strategic goals, peer relations, involvement with service systems, employment record, socialisation history and well-being.

**Ethical Considerations**

Conducting research with people with intellectual disabilities presents some ethical dilemmas. Participants will often deny that they have had experiences of the kind being talked about, particularly if the questions are controversial, seek personal information, are too difficult, or the interviewer is perceived as being threatening (Heal & Seligman, 1995). As the methodology required people to relate life histories, it was not possible to avoid personal questions. However, at no time were any participants pressured to reveal information, and if they appeared stressed or confused the interview was terminated.
Informed consent forms were signed by every participant and witnessed by the manager before any interview was conducted. These were read out aloud and pauses were included to ascertain if participants had any questions. The latter was employed because some of the participant’s literacy levels were too low to read this form independently. They were reassured that they could withdraw from the research at any time without any impact on their proposed move to the community. They all signed an informed consent form that guaranteed them confidentiality. They also agreed to have their personal records examined and photocopied by the researcher. The research study was approved by the Human Ethics Committee of the University of Western Sydney, Bankstown before implementation.

**Context**

*Research Context*

This research was undertaken in an institution which was a residential service run for men and women with mild intellectual disability. The institution was managed by a major religious charitable organisation and was run on the Christian ethos that all people are worthwhile human beings. Residents were treated largely with dignity, sympathy and understanding. No residents were ever chastised harshly, no physical punishment was administered, and exclusion or supervised time-out was not employed. At the beginning of the project, however, it was still a fairly paternalistic institution where staff and group routines dominated over individual preferences.

*Role of the Researcher*

The researcher was a close personal friend of the managers and was invited to live in their on-site residence. As the participant-observer, the researcher lived on the site a number of times over a three year period. She made a conscious effort to become part of the institution, joining in many structured and unstructured activities. She attended staff morning tea, chapel services, travelled to church, went on outings, made shopping trips and took part in more informal ways such as joining people for afternoon tea in their cottages, swimming in the pool and spending time with participants in the afternoons in the gardens.
At first the residents and staff were a little confused by her role. The first time the researcher arrived at the institution there was a team of consultants working there as well. The consultants were from a professional firm that had been engaged to provide future plans, strategies and financial planning advice to the institution. This produced some inevitable confusion amongst the staff and residents who thought that the researcher was part of the process of evaluation for their move to the community. It was necessary for her to emphasise that she was not part of this process and to build trust. She did this by joining in the life of the institution and being physically visible at times when the consultants were not there (e.g., on weekends).

Initially there was some resistance to her research project from the staff, presumably because of her relationship with the managers. Staff needed reassurance that the researcher was not evaluating them and reporting her findings to the administration. The managers had given her unlimited access to people and records. However, she had to work with two assistant managers who had much more control of the day to day running of the institution. At first, one of these people (the program director) was wary and a little unsure of the researcher’s role. The other assistant manager was also at first wary and felt that the researcher had been foisted onto her. However, after a short time of establishing rapport both facilitated the researcher’s access to the institution and the residents. This research was only made possible through the sponsorship of key individuals or gatekeepers, most notably that offered by the managers and the two assistant managers. The researcher’s fieldwork also effectively involved a series of complex trade-offs. The residents provided her with access to their life stories and she provided them with her attention, advice, genuine interest in their lives and help with transport to shopping.

**History of the Institution**

The institution was originally located on another site and originated from a previous welfare residential service that opened in 1920 with 44 girls. In 1923 the service became an industrial home for girls. During 1930 most of the girls were transferred to another site and 10 girls with intellectual disability were admitted to this home. In the 1950s this home became an all women's home. In 1980, the women and
staff moved to the current site and in 1981 men with intellectual disability moved into one of the living areas. Female residents have always outnumbered male residents.

**The Site**

The existing site was large, covering 4 hectares (10 acres). People lived in separate brick buildings, separated from the surrounding community and congregated on-site. The institution was on a very steep slope and older people and people with mobility impairments experienced difficulty negotiating the site. The institution had never been a locked facility. There were gates that could be locked, but the intention was always to protect the residents from strangers rather than to keep them locked in. At the time of this research project the gates were never locked for any reason. Throughout the three years of the study no residents left the institution unexpectedly. Occasionally, residents became lost when using public transport, but the staff were very familiar with their movements and were usually able to readily locate them. Most of the residents actually lacked the independence to leave the site individually and had to be encouraged to undertake independent trips away from the institution.

The grounds of the institution were very pleasant and the gardens were well kept. The facilities also included a large pool, a gymnasium, a chapel and a full-sized football oval. The researcher never observed residents playing organised sports, but quite often groups of residents walked around the oval or rode their bikes in the afternoon. The large dining room was no longer used except for staff morning tea and the Christmas party. No meals were prepared in the large kitchen. This area has been converted into staff offices since the end of this project. The manager told the researcher that they did not need any facilities where people would have to eat the one meal altogether at the same time.

The pool was kept locked because of concerns about the safety of residents as they could experience difficulties in the water. However, an extra safeguard was that the pool was the one depth for its whole length and the water could never be over the residents’ heads. It was mostly used on the weekends or in the afternoons if staff had time to supervise.
The site was situated in a prestigious upper middle-class residential area. However, the standard of accommodation, in particular the furnishings of the shared rooms, was not up to middle-class standard. At the beginning of the project, the residents were housed in separate buildings which accommodated groups of five or six. Bathrooms, kitchens and lounge rooms were shared. Most residents had their own bedrooms which were very large as these rooms had previously housed up to four adolescent boys during an earlier phase of the institution. The bedrooms were quite comfortably furnished and contained some personal items such as cassette players and personal mementoes such as photographs. The lounge rooms had only basic furnishings and included fairly old and faded lounge chairs, a TV and a china cabinet and bookcase. Each resident was assigned a separate lounge chair which was designated as theirs by common agreement. This procedure was introduced to reduce disputes between residents. Groups of residents often congregated outside in the very pleasant gardens to talk in small groups of an afternoon. Residents from other buildings were allowed to visit neighbouring buildings in the afternoon.

**The Staff**

At the beginning of the project many of the staff lived on the site. These included the Manager, the Assistant Manager, and three other workers. At the end of each residential unit there were three-bedroom flats that were provided for sleep-over staff as originally there was 24 hour custodial care. During the day, there was one staff member who was responsible for all of the residents in one building. These staff arrived at 7.30 am and left at 3.30 pm, similar to a nursing shift. They were responsible for implementing the individual life skills program, however, there was a reduction in staff numbers and no individual programming could take place after 3.30 pm. Staff were generally caring and concerned for the residents. However, residents were very dependent on the regular staff members and quite often seemed insecure if they were absent for the day. The staff also exhibited inappropriate feelings of ownership of some of the residents and buildings. Every staff member had an office in the buildings and they wrote notes on residents at the end of every shift. These notes served multiple purposes. They were a combination of medical records, assessment of residents’ improvement in living skills, and were used to give information to the afternoon staff about happenings on day shift. They were very reminiscent of the
notes kept on patients in hospitals. The day staff kept residents’ personal files and medications locked in these rooms. It was quite common also for the staff to take shortcuts through cottages. This gave the impression that the residents’ cottages were not theirs and that the staff were more important and busy, as they did not have the time to walk around from building to building. Some staff would enter bedrooms without knocking on doors, although the administration strongly discouraged this.

**The Residents**

All of the residents had mild intellectual disabilities. Most of them had long histories of institutionalisation, some with extensive stays in state psychiatric hospitals. Many of the residents displayed deficits in social skills and there were outbursts of unacceptable behaviour from some. Residents seemed overly dependent on staff to solve any conflict. They frequently expressed dissatisfaction with being forced to live in close proximity with one another. A small number of friendships had been established, but there were some residents who were quite hostile to one another. The great majority did their best to tolerate one another.

The residents were desirous of moving to the community. Some of the residents had very unrealistic goals and attitudes about what they could achieve by this move. However, all of them wanted to move. Even though outsiders saw this institution as a haven, not one of the residents wanted to stay; they all wanted the opportunity to live in the community. The researcher was present at the interviews which were conducted by the Department of Housing at which all of the residents expressed the desire to move to the community.

**The Philosophy of the Institution**

The administration and the senior executive staff of the institution wanted to improve the situation for the residents based on principles of equity and rights which are inherent in social justice. There was also the Christian belief that the residents should be welcomed into their local community and valued as equal citizens within the wider community. Additionally, there was the notion of positive compensation
from the executive (i.e., that extra effort should be made to assist people who were already devalued, marginalised, or in danger of being so).

The executive consisted of the Manager who was a clergyman with a wide background in social work, the Assistant Manager, who was also a member of the clergy, but was less experienced in this type of work, and the Program Director, who was an occupational therapist. This woman had responsibility for the planning of the program for the residents. She was also the supervisor of the personal care workers who implemented the program with the residents. The change of direction for this service was driven by her acceptance of the philosophy of normalisation and deinstitutionalisation. It was her vision to ensure that all of the residents would be residing in the community and the institution would be closed. The manager and the assistant manager were in agreement and as such there was no conflict over this proposed change of direction.

At the start of the project, the residents’ families and many of the staff were very resistant to the planned deinstitutionalisation. Staff were fearful that the residents would be exploited and some families seemed to fear that they would now have to be responsible for the day-to-day supervision of their relatives.

Over the previous three years the management and staff had made concerted efforts to improve the competencies of people in daily living skills, to prepare them for entry to the community. This program had taken over from a previous one where the residents spent up to six hours a day congregated in one general area doing craft. As a result, many of the residents had developed skills such as knitting, tapestry and other craft activities. However, the residents had not developed independent skills of daily living and they had not maintained literacy and numeracy skills, which many of them possessed before they came to reside at the institution.

At the start of this study, the institution was a service already in transition. It was moving from a paternalistic service which provided full custodial care to a service where the residents were being prepared for reintegration into the community. The residential service was extremely well run and had made a commitment to value the residents’ dignity and them as human beings. Each resident had an individualised program, which consisted of agreed upon goals that each resident wanted to achieve.
to facilitate their independence. Goals included self-help skills, such as shopping, washing, ironing, cleaning, cooking, literacy and travel training. These were skills which many of the residents did not have or had experienced a diminishment over the period of their institutionalisation. The large dining room had been abandoned. In its place each group now had its own kitchen, laundry and bathrooms; they prepared meals and washed their own clothes with assistance. However, they were still housed in what would be thought of as congregate care (i.e., an institution) and were exhibiting institutionalised behaviours, such as overdependence on paid staff and passivity.

Participants

The participants for this study were five women aged from 39 to 58 years who were seen as being socially competent by the staff. These residents comprised a subset of Group 1 (Movers) in Study 1 (see chapter 7). This was the first group of people who were to move to the community. To prepare for the move three of the participants, Alison, Ruby and Lorraine (aliases) had been moved into transitional housing, in a house adjacent to the congregate care facility. It was within easy walking distance and they visited the site at least once every day and were still seen a residents of the residential service. The first case studies are of these three women (Lorraine, Alison and Ruby) who were transferred first to transitional housing (i.e., they were all living together in a suburban house close to the institution). After these first interviews were completed, they moved to living individually in the community. The other two participants (Agnes and Violet: also aliases) still lived in the institution. They too moved to the community by the end of the study.

Setting for Transitional Living

The house, although in a prestigious upper-middle class area, was of below average quality for this area. The front door was approached by a high, narrow set of stairs. The house was in need of a coat of paint and had the rundown look of a rental property. The garden was minimal. The house consisted of four bedrooms and a combined living/dining/kitchen area which was quite large. This home was gradually being furnished to non-disabled residential standard by the residents and the service.
However, it would still be thought of as sparsely furnished and showed few signs of people actually caring for the surroundings. Alison, Ruby and Lorraine were living in this house. Although the furnishings in the lounge room were sparse, Alison and Ruby’s bedrooms were nicely and individually furnished. They had new beds, bedside tables and sets of drawers. The linen complemented other furnishings such as the lamps. Alison and Ruby’s bedrooms were clean and tidy without being overly orderly. Personal care workers told me that Alison would clean up Ruby’s bedroom if it became untidy or she would make Ruby do it through sheer force of character.
Lorraine’s bedroom was, in contrast, untidy and cluttered. She had no new furniture and her possessions were spread over the top of the furniture in disarray. Also, her furniture was covered in dust and she did not seem overly caring about the cleanliness and order of her surroundings. Her personal care worker and the other residents were constantly asking her to clean her room and make her surroundings pleasant. Lorraine had some personal possessions such as a cassette player, tapes and a radio. She also had some family photographs of significant events such as weddings and christenings and a formal portrait of herself as a baby.

Alison and Ruby were significantly older than Lorraine and they tended to dominate her. Ruby frequently criticised her, often using a tense angry voice. Neighbours had complained about raised voices and noise at inappropriate times.

Results

Case Study One—Alison

Physical description. Alison was a large but pleasant, outgoing, occasionally overpowering, and active 57 year old woman. She always had a smile on her face. Given that she had very little schooling, she was probably only in the borderline range of mild intellectual disability and suffered more from environmental deprivation than an underlying cognitive disability. She felt lucky that she could read and write. She could carry a reasonable discourse, appreciated jokes and was very sociable and quite confident. Her appearance, dress, and personal grooming were all appropriate for her age and income level, and she would “pass” for non-disabled in public places and the residential community.
**Background history.** Alison was born “illegitimate” (Alison, personal communication) and was given up by her mother for adoption. She was not adopted and she spent her childhood and adolescence in many foster homes.

I had so many foster homes I don’t know anyone except my foster brother who lives out here somewhere. The only person I can remember is his mother.

Alison was the most capable of all of the residents in the institution. She was one of the few residents with functional literacy and numeracy skills. She was the most accomplished in terms of daily living skills and was the acknowledged “Queen Bee” of the institution before she moved to transitional housing.

In one of the foster homes Alison was treated so badly that she suffered a “nervous breakdown” (Alison, personal communication) at 18 and was admitted to psychiatric hospital for 11 years. She was moved to another psychiatric hospital for five years until 1972. Alison, then on the pension, lived in a series of boarding houses, but had some difficulty with living skills, particularly budgeting. She used to put things on credit and was not be able to pay off her debts. The next major occurrence in her life was forming a friendship with “Jeanette”. Jeanette was a member of the clergy and she was a non-disabled member of the community. The friendship she had with Alison was reciprocal and was one of the major emotional supports of Alison’s life. Jeanette no longer lived near Alison, but she stayed in regular contact with her and they spent holidays together. Alison had also re-established contact with her natural mother, and she now feels that she has some family identity.

Then I got the Salvation Army to help me find her and then I felt really good. I often wondered if I had relations.

In 1980, Alison came to live at the institution because of her difficulties with money and her need for emotional support. She quickly established herself there as the “Queen Bee” and was quite capable of overwhelming the other residents because of her abilities and strong, cheerful, personality.
Alison had been living in the community for 20 months at the end of the research period. She lived and cared for herself completely independently. She had formed a strong alliance with Ruby and they spent most days together. Alison had made friends through community contacts and she was taken off all mood control medication. She and Ruby had joined a different church and were enjoying being part of the fellowship. They both had developed a new interest by becoming very enthusiastic supporters of a football club.

Alison was the only one of the people described in these case studies who had a positive self-esteem as determined by workers and standardised tests. She accepted her disability and had integrated it into her personality. Alison had a very strong positive self-image and coped using strategies that minimised her disability. She had integrated her diagnosis of intellectual disability and emotional difficulties into her self-image and had no need to deny it. In fact, she used it for strategic defensive purposes when necessary, for example, she would often secure discounts and free admission to social events on the basis of her disability. Alison was now living the life of a “non-disabled” senior citizen in the community. Her literacy abilities, her high self-esteem and her good social skills had all combined to make her independent and successful in the community.

**Analysis using Zetlin and Turners’ typology.** Under Zetlin and Turners’ (1984) typology Alison was an acceptor; she accepted the diagnosis of intellectual impairment in her self-definition, even though it was evident that being labelled intellectually impaired had a major impact on Alison’s life. For example, she had spent nearly all of her life in institutions or foster homes. Her formal schooling was very haphazard. She did not appear to feel that her disability was all that important in her day-to-day life. She was aware that being labelled was stigmatising, but it was not a salient feature of her self-esteem. Instead she emphasised her accomplishments and took pride in the life-style she had achieved as the following comment illustrates.

> I feel lucky that I can read.

She also felt independent, which was demonstrated by her ability to manage her own home and to budget. She also felt proud of her personal achievements, such as getting around the city by public transport, and her capacity to remember
appointments. She did not resort to defensive or blatantly self-aggrandising coping strategies. She saw herself in terms of her normative accomplishments. Although Alison saw her non-disabled lifestyle as her greatest accomplishment, she was quite willing to seek help from all of her former confederates and previous staff. Similarly, she had no difficulty in accepting services for people with disabilities. Although she could manage most daily occurrences very adequately, she would turn to personnel to sort out problems. Therefore, her reliance on others was limited and only used for specific situations. She was quite comfortable with this coping strategy.

Alison also displayed an arrogant or nurturant dominance over her two flat mates in the transitional housing. She was arrogant towards Lorraine and nurturant towards Ruby. After moving to the community she was not interested in maintaining contact with any people with intellectual disability apart from Ruby. She was however, very interested in maintaining contact with Jeanette her “non-disabled” friend. She had assumed the role of leader and helper of disabled people, thus elevating her status, something she also had undertaken within the institution.

She was content with her life and whilst accepting of her limitations, her social comparison group was the other people in the community and her friend Jeanette. She was able to contrast herself with her previous social group because of her superior abilities. Thus she used both downward comparison, to contrast her abilities with other people with intellectual disabilities but also used upward comparison with the non-disabled population. She was able to assimilate with the non-disabled group because she emphasised her similarities with this group and discounted any differences. Both of these social comparison processes enhanced her self-esteem (see chapter 2).

**Case Study Two—Ruby**

*Physical description.* Ruby was a short, obese woman of 58 years. Her face was large and round. She talked in a loud harsh voice, but she could talk quite coherently. She could understand questions that were directed to her and she had no difficulty formulating long replies. These replies were very factual and they consisted
of a lot of chronologically accurate dates and descriptions of family events and illnesses.

**Background history.** Ruby was born at in a country town in New South Wales and was an only child. Her father died in a prisoner of war camp in Japan and her mother died from a heart attack when Ruby was 20. She then lived with her uncle and aunt, cared for her grandmother and worked as a cleaner at a hotel. Ruby's family had kept in touch with her and occasionally she visited them for holidays. Ruby was literate, but she did not choose to read as a leisure activity. She found school hard and did not enjoy it because the lessons were too difficult. She did not remember school with any fondness and was intimidated by the other children.

Ruby was also a very verbal and capable person, but she had been institutionalised since early adulthood. In 1962, Ruby gave birth to a son who was adopted. Ruby told she howled and howled. She thought she could have looked after the baby. She wanted to keep him but “aunt” and “uncle” would not let her. After this Ruby came into institutionalised care.

Ruby was not considered to be a nice person by the other residents or the staff. Her personal care worker felt that she did not get along with any of the residents. She did not mix well with the other residents. Ruby did not handle frustration well and was easily upset. She had, in the past, lost her temper easily, and also she had been considered lazy, selfish and unmotivated to improve herself. She was not considered to be caring enough about her personal appearance by her personal care worker. Apart from these concerns, Ruby’s institutional life had been unremarkable. Before moving to the community, Ruby was seen as having problems controlling her money and her appetite. She would spend her money as soon as she received it on food that the staff disapproved of. Ruby spent her money on lollies, ice-creams and soft drinks and found it impossible to budget. She often had to borrow money from Alison because she ran out before next pension day.

The other major organising feature of Ruby’s life was her hypochondriacal behaviour, whereby she constantly complained of not being well. Her relatives and her own medical conditions and appointments were her prime areas of interest and
conversation. In her interview, Ruby constantly referred to illnesses and funerals. She recounted at different times illnesses as her most significant experiences. She finished the interview with a long discussion of her gall bladder operation and wanted to show the researcher the scars. She also recounted how she felt about her mother’s death.

I had terrible trouble with Mum. She dropped dead of a heart attack when I was 20. I missed out on her watch. I was working at the time as a cleaner at ------hospital.

Whilst Ruby was in the institution she would call her personal care worker after hours complaining of asthma and colds. On one occasion while the researcher was at the institution, Ruby was admitted to hospital for bronchitis. She asked the Nursing Unit Manager to leave “Vicks Vapour Rub” on her bedside table. When she was unsupervised, she proceeded to eat it and burnt her oesophagus, thereby extending her need to stay in hospital (and confirming to herself that she was very ill).

After the move to transitional housing Ruby developed a close though sometimes fiery relationship with Alison (the “Queen Bee”) and between them they managed household tasks with some supervision. Ruby also started to assume control of her eating, her coughing had decreased and she had started to save as well. Her technique for this was to ask Alison to save for her. She had to let Alison care for her money on a week-to-week basis because she was incapable of keeping any money in her purse for a long time. She also had a lot of difficulty keeping control of her personal bankbook without withdrawing money to spend on food.

Her son, who was now over 30 years old, had made contact with management during the research period, but he refused to meet Ruby when he discovered that she was institutionalised and intellectually impaired. She was distressed by his decision and expressed feelings of rejection and shame.

At the end of the research period, Ruby had been living in her own unit in the community for 20 months. The major organising feature of Ruby’s life now was her friendship with Alison. She saw Alison as her best friend and her teacher. In the community, she had replaced one type of tactical dependency for another. She now saw her aim in life as:
supporting Alison [and feels that] the best part of my life has been move to live with Alison.

She also did not give up the role of hypochondriac easily. For example, she had to be warned by the ambulance service for making unnecessary nuisance calls.

She and Alison had established a lifestyle that was not bounded to an identity as a person with an intellectual disability. They were extremely social; they were constantly busy; they had made real friends and they were looking after others around them. They were not dependent on their personal care worker for anything and they were now only on a monitoring case-list (i.e., they were only visited if they requested assistance, or if any difficulties arose). More importantly, she and Alison had a good quality of life. They were no longer dependent on the charitable organisation for protection or social support and they had not needed any major interventions.

**Analysis using Zetlin and Turner’s typology.** Under Zetlin and Turner’s typology Ruby displayed characteristics of both a qualifier and a vacillator whilst she was institutionalised, but she had moved to being a qualifier since the move to transitional housing and the subsequent move to the community. Whilst she was a resident of the institution she had developed a coping technique that Zetlin and Turner (1984) would describe as tactical dependency. These people are open about handicap and seek out benefactors in staff. They are spectators and generally have a poor self-image as they do not try to convince others of their competence in case the support they need is withdrawn. In her interview Ruby said

I don’t really care about anything at all

This negative attitude towards the self was confirmed by staff reports.

She enjoyed individual attention from the staff and in the past had sought out benefactors from them. She was keen to discuss her personal situation. She accepted staff feedback readily, but it did not seem to motivate her to change her behaviour. The staff felt that she had limited insight particularly into the controlling effect food
had on her behaviour. However, they seemed unaware that this was part of her coping strategy and her need to gain their attention.

In the past, Ruby would often lose her temper with the other residents and start arguments herself, again ensuring that the staff had to pay her more attention. Ruby’s emphasis on her illnesses may have been a way of covering her disability. Like vacillators, she was extremely sensitive to negative attitudes others displayed towards people with disabilities and she reported having experienced this discrimination at school when she said the other children used to tease and pick on her and when her son was adopted against her wishes. During the research period, as discussed above, her son had rejected her as his mother, refusing even to meet her, because of her stigmatised identity.

Vacillators are usually frustrated by their lack of achievements. They usually accept a lot of parental/benefactor involvement in their lives and rely extensively on service agencies (e.g., Ruby’s reliance on the health system and her personal care workers was seen as excessive). However, vacillators often feel stigmatised by dependency. Ruby wanted to project a “non-retarded” public image but she could not afford to give up the help of more competent others.

Vacillators also rely greatly on family (e.g., Ruby gave up her baby because of the influence of her guardians, even though it caused her acute emotional distress). Ruby had always relied on others to make major life decisions and did not really try to exhibit control over many aspects of her life. She was given little choice in her future after the baby’s adoption and had been in care ever since. She said:

I was made pregnant.
[They] said I didn’t have to stay [at the institution] but where could I go?

After her move to the community, Ruby was still employing the coping strategies that she had been using in the institution. She was still using tactical dependency; only she had transferred this to Alison. However, there had been a shift. She was developing more of the characteristics of a qualifier under the typology. She was becoming much more self-sufficient and she was much happier with her life in
general. She had a goal, which was to support Alison, and she was starting to offer assistance to elderly residents who lived near her.

Ruby’s self-esteem had definitely improved since her move to the community. This observation was confirmed by her, her personal care worker and standardised testing. She was still totally dependent on Alison's emotional and practical support for her to maintain herself in the community, but Ruby no longer had a need to be dependent on staff for attention. Thus even though Ruby was using the same coping strategies she has used in the institution (i.e., tactical dependency), the move to the community definitely increased her self-esteem. The stigma of institutionalisation was over for Ruby. She had become more giving and had been able to offer assistance to older people living in her community.

Other characteristics that would place her as a qualifier since her move to the community were that she preferred the company of someone who was mildly intellectually impaired (i.e., Alison). She had accepted Alison’s help because Alison had superior status. They shared a warm relationship, but Ruby rejected strongly anyone whom she felt was more severely “disabled”. This could explain her difficult behaviours with the other residents in the institution. She was also totally dismissive of Lorraine when they were living in the transitional house and had maintained no contact with her as she was perceived to be below her level of skill and competence.

In terms of social comparison processes, Ruby was using downward comparison with all the members of her social group who were more severely disabled than she was. She was maximising the contrast effect so that she could boost her self-esteem. This was her major comparison strategy. However, when she made upward comparisons, she did not choose members of the non-disabled population. She had chosen as her selective reference a person of superior status in her own social grouping. She could assimilate and therefore experienced reflected glory from her close association with Alison.

Case Study Three—Lorraine
**Physical description.** Lorraine was a woman of 44 years. On first impressions she had quite a pleasant appearance with large open blue eyes and a high child-like speaking voice. Her speech was clear and precise, and she smiled appropriately and initiated eye contact. She seemed to enjoy social contact with people who were not disabled. She was tall and quite obese. In fact, she was the heaviest resident of the service. She was aware of the medical implications of her size and was always trying to go on diets. However, after she moved to transitional housing, where there was much less control of her diet by staff, her weight had increased, much to the despair of her personal care worker. Her weight was well outside the healthy weight range and was concentrated in her hips, thighs and legs. Lorraine had difficulty negotiating the institution site. She moved slowly, but not totally sluggishly, yet she could complete the tasks of daily living without any difficulties. She was attempting a course in hospitality at TAFE, however, she often complained of the difficulty she had in completing the work because of the pressure her weight placed on her legs. Lorraine said she would like to lose weight, however, when the researcher visited her in her bedroom she showed her pictures of her family and there was obviously a family history of obesity. Lorraine’s mother was quite a large woman before she died.

Lorraine was described as having a cheerful, compliant personality. Although her room was untidy, within the bounds of her income she was personally clean and neat and wore appropriate clothing for social occasions. Her hair was short but it was regularly permed. Her appearance, except for her weight would not attract attention in the community.

**Background history.** Lorraine was the youngest daughter in a family which lived in rural areas in South-East Queensland. Lorraine’s family still lived in this area and she thought of it as home. Lorraine had an older brother who was also intellectually impaired and he lived independently in the community and worked as a “supervisor” in a sheltered workshop. When Lorraine was 6, her mother died of cancer. She and her brother attended the local country school until she was 12. Her older sister, her father and her older brother raised her.

Although there was no corroborating evidence, Lorraine said that she was caned so severely by a school teacher at the age of 12 that she had to be hospitalised.
After this incident, her father sent her to an institution and a special school in a small city. Her father also remarried at about this time and Lorraine had three stepsisters from this second marriage. Lorraine was assessed before she was admitted to the special school as having a mild intellectual disability. Her own account was that she was a lot brighter than the other children and that she often helped the teachers take care of the children who were in wheelchairs. At this time, Lorraine was living in an institution that was known for the strictness of its regime. Lorraine was reportedly happy in this institution because she had friends her own age. She maintained contact with her family as an older married sister visited her every weekend. She also told me that her father and step-mother provided financial support and visited regularly. Lorraine felt that she had not benefited from her schooling and was only taught to write her name. When Lorraine left school at 14, she was not given any employment but she was kept on at the institution as an unpaid worker. She used to iron school uniforms and stack the wood for the kitchen.

At 18, Lorraine was transferred to a residential service in a much larger city where there were a lot of older residents. The reason for the move was that she was now too old for what would be considered a children’s home. She was unhappy in this setting and complained about the lack of friends, privacy and autonomy. She worked in a sheltered workshop for several years. Since moving to the present institution in 1980 she had not worked, but had participated in the craft program. She had constant contact with her family throughout this time. This consisted of yearly holidays and special occasions, such as weddings, christenings and funerals.

The other residents of her home and her personal care worker perceived Lorraine as being overly passive and lazy. Her favourite activity was literally sitting, and she had few leisure activities beyond knitting and listening to tapes. She was a little unreliable in completing tasks in her home. For example, she did not always contribute equally in the areas of laundry and cooking. She preferred to let Alison do this and relied on her to teach her things. Her apparent laziness, and her passive-aggressive stance led to conflict in the house with the other two residents forming an alliance against her. Her specific wish was to live in the community on her own so that she could establish her independence, even though in her present living situation her habitual dependency and passivity were causing conflict. She also expressed the
desire to work, but the staff of the institution felt that her motivation was solely based upon financial reward. They also felt that her ability to complete five days work would be hampered by her lack of motivation and her inability to physically cope because of the strain on her legs.

Lorraine was a member of a group which is largely devalued by our society. She had been segregated and housed in congregate care since her mother’s death and her ill-treatment at school. She had little experience in the community and few normalised experiences. Since the age of 12 she spent her formative years in an institution, separated from her family, although they have stayed in regular, if not frequent contact. Lorraine was functionally illiterate (as assessed by standardised testing) and this further emphasised her isolation and dependence. Experiences like these can cause people grief, loneliness, no one to learn from, atypical life experiences, confusion and feelings of abandonment. Significantly, Lorraine told the researcher she would like to have died when her mother did.

Lorraine was being deinstitutionalised in the transitional setting. She had some autonomy in small every day matters such as what to eat and what to wear. But as yet she had little real autonomy in larger life-defining matters such as who she wanted to live with, where she wanted to go, and what sort of work she wanted to do. Lorraine had a small social network which was restricted to other residents and staff of the institution and included some immediate family members. Many of these contacts were not real friendships in the sense that the staff were paid carers and the person she identified as her best friend was actually a “legal friend” provided by the Association for People with Intellectual Disabilities. This was someone who volunteers to be a friend to institutionalised and isolated people. Also the amount of contact with family and friends had reduced since she came to live at the institution. This process started for Lorraine when she was moved at age 18 to her previous residential service. Since then her family contact consisted of letters, occasional phone calls and yearly holidays and invitations to significant family events.

Despite efforts by her personal care worker, she was still confined to a narrow range of stereotyped roles: a low status person with a disability, welfare recipient with a small number of positive community roles (e.g., shopper, public transport user, student at TAFE) and had few normalised accomplishments. Lorraine had few
experiences where she had choice and autonomy, but she definitely aspired to the independent role of worker and wanted to live independently in the community. She also wanted to increase her literacy so that she could decrease her dependency.

Well to be by myself and I would like to have, would you say, not adventures, trying to teach myself things that I haven’t been taught, you know be independent.

These goals might be realistic given her level of intellectual functioning and age. However, Lorraine's motivation to achieve her aspirations seemed to evaporate if she met any difficulties. She still exhibited the institutionalised behaviours of compliance, dependence and passivity and expected other adults to take the initiative to achieve her goals. She seemed to have internalised the role often ascribed to people with intellectual disabilities: the perpetual child who must be protected by other powerful caring adults.
Since her move to the community Lorraine had maintained her identity as a person with an intellectual disability. She now identified with this group. At first she tried to pass for being non-disabled, tried to function in the competitive workforce and to make friends through community contacts. However, she was in fact very isolated and really lived on the fringes of society. After 20 months in the community, she still lived alone and cared for herself completely but she assumed the identity of a member of a stigmatised group by living within a social group of people with mild intellectual disabilities. She attended TAFE with members of this group, she socialised with this group of people and she worked full-time in a workshop situation. She also re-established frequent contact with her sisters and travelled to visit them. Even though Lorraine had not achieved some of the normalised goals that were envisaged for her, she felt that she made a very successful transition to the community. She was very happy and had no wish to change her life. As Lorraine had a history of institutionalisation and segregation during her adolescence, she developed an identity as a person with an intellectual disability. Moving to the community had prompted her to try to pass as non-disabled, but she had reverted to previous patterns by mixing with people who had the same level of disability as herself. Lorraine still made an adequate adjustment to the community that was congruent with her previous self-esteem.

**Analysis using Zetlin and Turner’s typology.** In terms of Zetlin and Turner’s typology Lorraine was a vacillator. She was reluctant to acknowledge her disability and tried to distinguish herself from more severely disabled individuals. She said:

I was a lot brighter than the other children at the school.

This is in spite of the fact that she could really only write her name and was functionally illiterate. Most of these individuals were extremely sensitive to negative attitudes and all report having described some discrimination either at school or in society.

I was beaten until I couldn’t stand up by a teacher.
She had pursued associations with people who were at least comparable to her in ability, such as her TAFE group and she actively avoided contact with lower functioning people. She valued her non-reciprocal relationships with non-disabled people as her most important relationship (e.g., Kim, her volunteer friend). Her relationships were best described as shallow and unstable.

Her life was in many respects similar to a qualifier; she was heavily involved in support systems, relying on facilities provided for people with intellectual disabilities for her residence, her work, her education and social support. She spent a lot of time with her family and apart from them she associated primarily people with mild intellectual impairments.

Lorraine used social comparison strategies in a very similar way to Ruby. She used downward comparison and contrast effects with people who are more severely disabled than herself. She avoided upward comparison with non-disabled groups and engaged in lateral comparison to people she could assimilate with (those with a similar level of disability as herself). Her self-esteem was still not that buoyant, but she was not miserable as identified by the typology. She appeared content.

Case Study Four—Agnes

Physical description. Agnes was a woman of 50 years. She had a pleasant appearance, with a pretty face and stunning green eyes. Her skin was smooth and she did not look as old as she was. She was quite tall and slim and presented a completely non-disabled appearance from a distance. The only thing that would alert an observer to an intellectual disability was that she had slower speech and movements than most people. She also had a slightly fixed expression on her face and appeared a little rigid. Her facial expressions were limited and ranged from a fairly fixed stare to a full smile. There seemed to be few nuances in between these expressions. Her behaviour was quite acceptable. She was not overly talkative and her social skills were quite good. The volume of her voice was within the non-disabled range. Agnes was quite verbal and she could recount a good story. Agnes would speak to anyone, but she did not always initiate contact. Her personal care worker said she could be quite gossipy and manipulative with other residents. However, many of the residents were described this way by staff.
Background history. Agnes was an only child in a family that moved around rural Queensland frequently. Her story was a little confused and at times she talked about a half sister and her natural mother. There were no records of her adoption. She lived with her parents as they moved around rural Queensland with her father losing jobs because of sexual indiscretions. There was no corroboration for this contention. She attended quite a few schools and then had to enrol in the Correspondence School. She was given some cleaning work on one of the properties where her family was living, but she was not successful at keeping this employment. After the death of her mother, she remained living with her father until a crisis occurred which led to her institutionalisation. Agnes was admitted to psychiatric hospital in the 1970s. Agnes recounted a very muddled story of why she was admitted to hospital. She told of an extremely violent argument with her father where she described being attacked over the head with a chain and her father trying to shoot her.

I remember saying to him, “you missed me mad guy.”

He then reported her to the police for violent and uncontrollable behaviour and she was admitted to a psychiatric hospital. Agnes recounted with glee how her father was admitted to a psychiatric hospital himself because he was going mad and that he died there. In the hospital, she was given electric shock treatment, and she was diagnosed as schizophrenic. Since her release to the institution, there was no further history of violence or schizoid episodes, although she occasionally had illogical thoughts. For example:

My mother died in the toilet because she was no longer a Christian.

At the end of the research period, Agnes had been living in the community for several months. She had acquired a lot of independence and decreased her dependence on the charitable organisation. She had changed the church she attended and was making friends through the women’s groups at the new church. These changes started happening when Agnes was moved into transitional housing and she was given an individual program that acknowledged her as a person who had a right to make decisions and take risks. For example, Agnes did not like attending the
church where the majority of the residents attended every Sunday. She preferred to attend a smaller church in a different suburb. Because of staffing problems, there was no one available to transport her there. However, after her program was changed, it was impressed on the staff that she must be allowed the risk of public transport to achieve her goals. Agnes became quite capable of using public transport to attend the church of her choice. She had at times engaged in behaviours that the staff were concerned about, such as talking to strange men at the station, but these issues were being addressed through education programs in the community setting.

**Analysis using Zetlin and Turner’s typology.** In terms of Zetlin and Turner’s (1984) typology Agnes was a “blame attributor” and a denier. She saw others as the cause of her problems. One of the first things she said to the researcher was to establish this.

You have heard that I had brain damage, head injuries as a child

She attributes her intellectual disability, her psychiatric condition and the need for institutionalisation to this condition which was caused by others.

As you know a person who is suffering from head injuries can’t fend for himself much.

Agnes chose to deny her “retardation” and blamed it on the accident she suffered at the hands of a school teacher.

Dad wouldn’t let me [go to school]. He was afraid that I would have the same problem that I had at the other place.

[What problem was that?]

In learning or so he saw it to be. Only mum knew, suspected, mum suspected I had head injuries.

The head injuries occurred in the first year of school and of course accounted for the subsequent difficulties she had in learning.
That happened the first year I went to school. That was at the state school. And when anyone does that the see-saw jars and the person goes upward and lands on top of their head—well that’s what happened to me.

The doctor wasn’t a very good doctor. He didn't have the full knowledge of a doctor in his head. He understood it to be concussion when it wasn’t. I didn't know what was wrong with me until I got to [psychiatric hospital] in nineteen seventy-something they x-rayed my head over there and discovered my brain had been injured.

After being transferred to a Catholic school Agnes was at first happy. Again the lessons became too hard and she blamed the teacher for not helping her learn.

Sister Thomas would not help me learn.

Sister Thomas was described as being responsible for the disability because she also “caused” the brain injury.

It wasn’t until I grew up that I discovered that the person who caused the injury to me right here had been killed in an accident a year or two later.

I discovered Sister Thomas had been killed in a car accident.

She was the one that injured me by pushing me from behind.

Agnes was a classic denier, she preferred to see herself as brain damaged and a psychiatric patient rather than as intellectually impaired. She obviously preferred her mother’s interpretation of her as brain damaged, to her father’s interpretation that she had problems with learning. As she was not really open about her feelings of stigma this was hard to assess. This characteristic is typical of a vacillator who has to deny the deviance. Agnes refused to admit any personal incompetence or any definition of being intellectually impaired. She chose instead to redefine her disability in the less stigmatising medical conditions of acquired brain injury and psychiatric patient.

Her life had obviously been significantly altered by the presence of her disability. She was a patient at psychiatric hospital, and seems to have had a difficult relationship with her father who characterised her as intellectually impaired. Since moving to the community Agnes, had also increased her self-esteem. She still blamed
the unsubstantiated accidents for her disabilities; she no longer blamed others for the things that were happening in her life. She had made friends in the community through her church affiliation with people who were not intellectual impaired. These relationships appeared at the time of the project to be non-reciprocal and shallow.

As she was able to deny her status as a person with an intellectual disability because she had “acquired brain injury”, she compared herself to non-disabled groups. She did not use downward comparison to other people with intellectual disabilities because she did not identify with that social grouping at all. She used lateral or upward comparison with the non-disabled population and could explain any contrast effects she had on the basis of the accident that resulted in her brain injury.

Case Study Five—Violet

Physical description. Violet was a tall, well-built woman who was aged 39 at the beginning of the research period. She was one of the youngest of the residents in the institution. She wore simple clean clothes that were not always colour coordinated. She was neat and tidy, but she had little idea of using grooming (e.g., hairstyles, etc.) to make herself look more attractive. She was quiet and unobtrusive in public places and in groups, even when she was very familiar with them. Her habitual response to questions or greetings was to laugh rather loudly and repeat

I don’t know about that.

Background history. Violet’s educational background seemed to have involved long periods in residential special schools but exact details of her education were very sparse. She had attended an opportunity school in Queensland for children with developmental disability and a residential school in Adelaide. At 18, Violet was removed from her mother and grandmother’s care because of abuse. She then came into care at the institution where she had remained ever since. Her mother and grandmother ceased all contact with her at 18. Recently, she had re-established contact with her younger brother and sister. Violet had a substantial hearing impairment and her speech was a little indistinct. She was not considered literate but she could read “a bit”. She did not string sentences together to describe an event or
situation. Violet was not encouraged by her mother and grandmother to make contact with people outside of the home. She was not encouraged to socialise with peers or neighbours.

Violet was never aggressive or hostile to staff, but she had in the past hit her head or bitten herself when frustrated. The social worker who intervened when she was 18 thought that Violet had suffered from considerable environmental deprivation. She was locked in her room at night and at times during the day. She was not allowed to go out to attend a sheltered workshop or an activity centre and she was unable to make use of her limited community skills. She was suffering from abuse, physical punishment, confinement and being offered an inadequate diet. Water was the only drink Violet was allowed to have at home by her mother and grandmother. Also, Violet was made to go to bed at 6:30 p.m. and was locked in her bedroom for the night because they could not cope with her. Violet ran away and reported her family’s ill-treatment to the police who came and chastised her mother for her poor treatment of her. Her mother refuted the allegations and there was some suggestion from her of Violet exhibiting uncontrollable sexual behaviour.

If she goes out she will make a pest of herself particularly if there is a man about.

Her mother and grandmother used this as their excuse for locking her up when they went shopping, but they were totally unable to substantiate this. In fact, Violet had never been sexually promiscuous. Violet was removed from her family at their request as their treatment of her was deteriorating. The social worker who assessed her felt that she was in danger of serious physical and emotional abuse at the hands of her mother and grandmother. Violet’s account corroborated this.

They asked me to do something and I didn't do it properly so they belted me till I was black and blue and locked me in my bedroom. They got my pension one day. They asked me to write my name on the back of it, they kept it. I didn’t get nothing to spend or anything. Kept all my money....

Violet was living in the institution at the beginning of the research project. She then moved to transitional housing with another resident before moving to
independent living in the community. She was considered to be suitable for open employment, although she failed at the first job she was given because of the need for excessive supervision. Violet had no highly visible concept of self. Her self-image was very low as reported by her personal care worker and results of standardised tests, because of the abuse and rejection she suffered within her family situation. Denial of her intellectual disability was possible because, in light of her background, the intellectual impairment was not that important. Other factors might have led to her depressed self-image.

She coped socially within the institution by means of a tactical dependency on staff and other higher status residents. In other more public settings, she coped by passing as a quiet well-mannered woman without a disability. This is the classic pattern suggested by Edgerton (1967) in the “Cloak of Competence”. In the community, Violet coped by means of passing, as being non-disabled. She only placed herself in situations where she would not be noticed. She re-established contact with her family and was finding pleasure in earning money and working in the competitive workforce. She made few friends outside of her family but she re-established good contact with the younger brother, whom she said loved her. She furnished her home beautifully and was extremely proud of her accomplishments. She continued to avoid contact with non-disabled people in the community and she successfully passed as a non-disabled, quiet person with a hearing impairment. In a sense this was a coping strategy that ideally suited her. Because of her level of deprivation and the undiagnosed hearing impairment, she probably only had a borderline intellectual impairment. She was unwilling to try new activities or make contacts that might endanger her sense of esteem, which had been carefully developing over the past few years.

*Analysis using Zetlin and Turner’s typology.* In terms of Zetlin and Turner’s typology, Violet was a denier. Violet was able to deny the importance of her intellectual disability.

I don’t know why I went to that school.
Her family’s attitude towards her disability was typical of this category. They avoided becoming involved in any way with her disability and justified their overprotection and overregulation of her through accusations of her promiscuity. She had few or no peers in her social grouping in the community and preferred to be surrounded by the family members she had re-established contact with.

The social comparison processes she used were similar to Agnes. Her selective reference group was the non-disabled population. She could assimilate with them as she could ascribe any contrast effects to her abuse and abandonment at the hands of her family and her hearing impairment. However, to maintain the denial of her disabilities, she had to socially isolate herself, and really only mix with her family. She did not use downward comparisons to bolster her self-esteem because she did not identify with people who have intellectual disabilities. In a sense she was protecting her self-esteem by reducing the number of comparisons she was making.

Discussion

The discussion of the findings will be presented in the context of the research questions posed in Chapter 5.

Research Question 2.1: External Factors Impacting Upon Skills and Attitudes

Research Question 2.1 posed: What are the external factors (socialisation, life experiences with significant others and carers) that have impacted on the skills and attitudes of adult with mild intellectual disabilities?

The life histories presented above suggest that all of the participants had experienced the rejection of society usually precipitated by a crisis that had branded them as needing institutionalisation. These crises had ranged from an unplanned pregnancy and the accusation of sexual vulnerability, to families’ inability to cope and, in two cases, psychiatric breakdowns. Once institutionalised these women were not moved back into the community for very long periods of time, because of the social policies that were in place at the time.

All of these women had experienced very different family backgrounds and had different histories of institutionalisation. However, they had all been separated
from society, suffered from segregation and felt isolation from non-disabled contexts. Their lives had been lived mainly in structured and ordered contexts. They had been isolated from unstructured contexts where they would have to discover and negotiate the rules of social behaviour. These women had a limited idea of conventional desirable lives. The vast majority of the participants had lived their lives at home and then at the institution. Some of them had moved from one institution to another including state psychiatric hospitals. Even those who lived at home until they were adults had been treated by parents or foster parents as children. One participant suffered environmental deprivation and another emotional, environmental and physical abuse. As such the core of their social experience had been limited to their families, their special schools and their institutionalisation following on from the crises in their lives. They had experienced rather restricted environments made of prohibitions promoting an attitude of dependence on others. Learning opportunities had been severely limited because of over protection. They had had very limited access to the general rules and norms of behaviour. They had minimal real autonomy. They had never really been exposed to situations in which they could learn the non-disabled social rules or at least learn how to deal with a wider variety of social behaviours and norms.

The participants were involved in networks such as daily contact with paid carers that are not normally encountered by most people in the community. Also the content of their social interactions was impoverished. Most of their interactions had been with people with intellectual disability or with paid carers and family members. They had all been socially deprived because of the control of their life’s experiences by others. There were few significant relationships outside of institutions and they all had small and socially isolated social networks. Hence, secondary socialisation outside of these contexts had been denied to them. Given this, it is easy to understand their lack of social competencies, skills and depressed self-image, at the beginning of the project.

In summary, the findings suggest that limited socialisation experiences, impoverished social engagement, and treatment as a dependent child by family members and carers, had all been significant external factors that had limited the
development of social competencies and skills and had shaped the participants’ attitudes about themselves.

**Research Question 2.2: Self-Concept After Deinstitutionalisation**

Research Question 2.2 posed: What is the nature of the self-concept of adults with mild intellectual disability who have recently moved to the community and have been assessed as showing competence in social settings?

Only one of the participants (Alison) had a positive self-image before the move to living in the community. However, after the move Ruby, Lorraine, Violet and Agnes expressed more positive feelings about themselves. The data revealed that the differing patterns of socialisation were the primary reason for the self-perspectives that were developed by the participants in regard to their disability and to their lives. The analysis of the data, guided by Zetlin and Turner’s typology, indicated that different socialisation experiences had a profound effect on the participants’ attitudes to their disability and attitudes to themselves as adults. The acceptor (Alison) and the qualifier (Ruby) believed that they were capable of normalised goals (e.g., Alison and Ruby were living as non-disabled senior citizens in the community, and previously, Ruby had sincerely believed that she could have cared for her baby). These participants wanted to achieve normalised goals, such as self-sufficiency. Alison and Ruby’s successful achievement of this normalised lifestyle reassured them that they were successful adults and therefore enhanced their self-esteem. In comparison to this, the vacillators and deniers (Lorraine, Violet and Agnes) had greater difficulty establishing an identity and a coherent sense of self. They had tended to be more overprotected or overregulated than Alison and Ruby, and had been offered very restricted experiences in their developmental period. This resulted in individuals who had not always achieved their potential, and as adults had not always tried to achieve normalised accomplishments, (e.g., Lorraine had a history of not achieving her goals, and Violet failed in her first attempt at competitive employment). These participants still exhibited a more vulnerable self-esteem at the end of the research project.

In the Zetlin and Turner typology both the acceptors and deniers refer to non-disabled adults for social comparison and are seen as establishing a positive reference group. The qualifier in this study was close to achieving her goal (i.e., increased self-reliance). Both qualifiers and vacillators are conceptualised as being uneasy about
their status as people with a disability and one of their goals was to project a positive social image. They did this by contrasting themselves to members of the population of people with intellectual impairment who had more severe disabilities than they did. Acceptors and deniers compared themselves laterally to non-disabled people and can use affiliative effects to make coherent images of themselves. Qualifiers and vacillators emphasize their differences. In Zetlin and Turner’s typology, the use of a negative reference group does not allow for a healthy sense of self. However, this finding was not replicated by this study in that the acceptor in the present investigation was the person with the most buoyant sense of self and the person with the poorest self-concept was a denier.

The results also showed that the self-esteem of adults with intellectual disabilities was quite depressed, but that a significant change of context can lead to an increase in self-esteem even for those people who have a long history of institutionalisation (e.g. Ruby changed from a vacillator to a qualifier throughout the research period).

Research Question 2.3: Awareness of Stigmatised Identity

Research Question 2.3 posed: Are people with an intellectual disability who have moved to the community aware of a stigmatised identity?

The findings demonstrated that all of the participants were aware of the stigma associated with being labelled intellectually impaired. Their reluctance at first to discuss their life histories with the researcher may have been an acknowledgement of their stigmatised identity. In terms of stigma theory, their silence was a sign of their awareness of their stigma and their fear of rejection by a non-disabled world (Goffman, 1963). In Goffman’s analysis, silence provides a way to manage information about identities, to keep a discrediting fact secret and to maintain desirable public selves. However, as Goffman predicted, as people established ties and rapport the participants were aware that the researcher was understanding. Therefore, there was less need to call upon self-protective actions to deny the spoiled identity (Goffman, 1963). As the field experience progressed and the researcher was seen as non-threatening, participants became more open about referring to their limitations and sensitive events in their life.
Given the emphasis on intelligence, academic skills and competence in our society it is hard to imagine that people with an intellectual disability can be unaware of stigma. Several of the participants mentioned that they had been subjected to teasing and abuse because of their disability. Also, all of these participants had to bear the additional stigma of being institutionalised for most of their adult lifetime. They were able to give very detailed accounts of the crisis that led to their institutionalisation (e.g., nervous breakdown, unplanned pregnancy, physical and emotional abuse). Other research has shown that people with good social support and access to normalised roles and accomplishments can be immune to stigma (Taylor, 2000). The participants in this study had few social supports and the number of normalised roles (e.g., wife, mother, worker) that they had access to was severely limited. Although the residential service where they were living was run on compassionate and humane regimes, not one of the participants wanted to stay there. They all aspired to the normalised role of an adult living independently in the community. After living in the community they were unaware of stigma due to the select groups they chose to interact with and their judgements of the new relationships they were able to develop were considered as positive, despite some of these relationships being shallow.

It has been found that as people successfully adjust to the demands of community living, they come to see their disability as insignificant (Edgerton & Bercovici, 1978). The acceptor and qualifier (Alison and Ruby) were already satisfied with their life that confirmed for them their success as adults. They did not focus on any incompetence they may have experienced. The vacillator (Lorraine) seemed to be very content in a world that was still related to a stigmatised identity. Hence, these results suggest that institutionalised adults with intellectual disability are aware of a stigmatised identity, but on moving to the community they establish relationships that they perceive as positive. In regard to the latter, their association with non-disabled adults seems to have a reflected glory effect whereby they emphasised the similarities they had to the non-disabled population on selective dimensions and chose not to make comparisons where they may be vulnerable, such as skills and intelligence. Other participants chose to associate with adults with a mild intellectual disability of the same competence or slightly higher competence level as themselves and thus avoided making upward comparisons with a more advantaged group. They also still
used downward comparisons to maximise contrast effects with people who had more severe disabilities than they had.

**Research Question 2.4: Coping Strategies**

Research Question 2.4 posed: What is the nature of the coping strategies that people with an intellectual disability who have moved to the community have used in the past and have these changed now that they have moved to the community?

The coping strategies that the participants had employed to deal with their attribution of disability were quite diverse and, in Agnes’s case, quite creative. These coping strategies had allowed the women to establish some image of their own identity. As predicted by Zetlin and Turner (1984), they were then able to convert these coping strategies into reasonable adaptations in the community. For example, Ruby was still a tactical dependent, but this dependency was now based on a genuine friendship. Agnes will always claim that her disabilities were caused by head injuries from accidents at school but she no longer needs to attribute blame to those around her. Lorraine had maintained her identity as a person with an intellectual disability, but she was mixing with people who are, at least physically, integrated into the community. Most of these friendships and contacts were real relationships based on common background and interests and not paid carers. Thus, they could all be seen as having made successful adaptations, but they all made adaptations that were different and coherent with their previously internalised self-image.

The above results suggest that there is a relation between the social coping strategies of deinstitutionalised adults with mild intellectual disabilities, as suggested by Zetlin and Turner (1984), and the development of consistent self-images. People with strong self-images such as Alison chose to cope by means of strategies that have allowed her to minimise the effects of the disability. She had integrated her disability more or less comfortably into her self-image and therefore had no need to deny it. Conversely, Violet’s self-image was very negative but her feelings were not the result of stigma from her disability. For her, denial was possible because her intellectual disability is probably the least of her burdens. Ruby had coped by acknowledging her disability and enlisting the support of powerful others to achieve her goals. She was still using tactical dependency but it was employed now in more positive ways. Lorraine had enhanced her self-image by assuming the identity of the member of a
minority group. These adaptive strategies were more than just momentary responses. They reflect the person’s pre-existing internalised self-image and since the move to the community they have enhanced that self-image by engaging in social interactions and gaining independence.

The nature of these women’s self-concept was initially negative because of a history of control, deprivation and enforced dependency. Each one of these people had developed an internalised self-image that was coherent with their understandings about their life histories. They were using different coping strategies to protect these self-images in different ways. After the move to the community, all of the women employed the same coping strategies in the new context, but they had adapted these strategies to be more positive coping strategies.

**Research Question 2.5: Social Comparisons**

Research Question 2.5 posed: What are the overall patterns of the social comparisons that people with an intellectual disability who have moved to the community make, and do people with an intellectual disability categorise themselves through these social comparisons?

The patterns of social comparison that these women used were complex. Upward comparison with the non-disabled was used by both the acceptor and a denier (Alison and Violet). These patterns reflect the findings of the Finlay and Lyon’s (2002) study. The upward comparison and assimilation effects were used on dimensions that emphasised the non-disability of achievements, on dimensions such as independence, socially valued goals and normalised accomplishments. Upward comparison was also used by the deniers but they had to resort to denial of their intellectual disability to be able to protect their self-esteem. Downward comparisons were used much more by the vacillators and the qualifiers to enhance their self-esteem. They used contrast effects. They did not use upward comparison and assimilative effects with the non-disabled populations. The qualifier used upward comparison to a higher status member of her social grouping. The vacillator used lateral comparison and assimilative effects to a similar group to herself. The results of this study show that people with intellectual disability will try to present themselves as positively as is possible by emphasising similarities and by not making intergroup
comparisons with the non-disabled population on the dimensions of skill and intelligence, but making comparisons with subgroups who are less able.

Social comparison theory has emphasised that the dimensions for comparisons are flexible (Finlay & Lyons, 2000). It can be seen from these results that the participants are displaying selective industry of the mind (James, 1890). It is an important finding that the participants are not using the category, intellectual impairment, as their social category because their assignment to this category has been a major determinant of many different aspects of their lives. The participants were also able to construct social comparisons more positively, through selecting normative accomplishments which they shared with non-disabled people, through focussing on dimensions selectively and through making comparisons with people with more severe intellectual impairments than themselves.

Research Question 2.6: Theoretical Explanative Power

Research Question 2.6 posed: Does social comparison or stigma theory have the greater explanatory power in the examination of the impact of deinstitutionalisation on the self-esteem of people with mild intellectual disabilities?

This study found support for both of the theoretical paradigms. It could be concluded from the fact that the participants’ self-esteem improved after moving to the community that stigma theory was supported more than social comparison theory. However, the participants did not always respond in the way that stigma theory would predict. They used a range of comparisons which were more useful in their lives and which allowed a positive representation of themselves. The participants were able to use selective industry of mind to give selective attention to dimensions, contexts and stimuli that are not always predicted by stigma theory. This finding has important implications for theorising and research with low-status groups, such as people with intellectual disabilities, where the researcher assumes certain dimensions, context and stimuli are salient, but they are not represented this way by the low status groups.

The study also found that the impact of stigma on self-esteem is not simple. One participant was able to maintain a positive sense of self, even though she was aware of the negative stereotypes and had been rejected by others because of the label applied to her. This participant had maintained a relatively buoyant self-esteem.
without having to resort to denial of her disability, distancing herself from the group entirely or an exaggerated use of downward comparisons. There is obviously a need for stigma theory to acknowledge that the impact on self-esteem is complex. The relations between stigma perceptions and self-esteem could be affected by the way that people accept that the label and the associated negative stereotypes defines their self.

**Research Question 2.7: Validity of Typology**

Research Question 2.7 posed: Is the typology of reactions to the stigma of being labelled intellectually impaired proposed by Zetlin and Turner (1984) valid for long term institutionalised women who have moved to the community?

The criterion for selection as a participant in this study was being assessed by their personal care workers as having reasonable personal and social adjustment. Therefore, it was surprising that the five participants revealed very similar profiles to those outlined by Zetlin and Turner (1984). However, differences were found between this study and the typology. The first difference was that Lorraine, the vacillator, was not miserable but appeared content. Also the qualifier, Ruby, although responding in many ways as described by the typology, had made a successful adaptation to the community and had established a more robust self-esteem than predicted by the typology. The third difference was that the deniers did not have a more positive sense of self, through identifying positively with a non-disabled comparison group. The other sections of the typology, the variations in self-perception as people with a disability, the strategic self-presentation that they use to cope with their social reality and the relationships they maintain with family members, peers, friends and carers and delivery systems were largely found to be valid. Hence the typology was deemed valid.

**Implications of the Findings of this Study**

The first major finding of this study was that the restriction of socialisation experiences led to a lack of skills and social competencies. Hence it may be useful for further research to examine how socialisation potential can be developed to maximise the personal and social adjustment of people with intellectual disabilities. This study also indicated that a better understanding of how to guide parents, teachers, carers and
administrators might be beneficial. For example there seems to be a need for parents, teachers, carers and delivery systems to be aware of the importance of normalised accomplishments, so that people with intellectual disabilities can develop positive social identities and positive self-esteem. Such an awareness could serve to inform interventions. There is also a need for compensatory intervention programs such as social skills training programs that may be able to ameliorate the lack of the secondary socialisation that participants in the current investigation have experienced.

The data also demonstrated the link between the past environment and circumstances, and self-esteem. Self-esteem was depressed for most of the participants at the beginning of the study, but it was shown that it was capable of improving when the context changed. This finding suggests, that along with socialisation experiences that encourage normalised accomplishments, self-esteem enhancement programs could be beneficial to people who are moving to the community.

The study provided further evidence for the importance of self-comparisons in the experience of stigma. At first, it would seem that, as the participants’ self-esteem improved after deinstitutionalisation, then stigma theory was supported more than social comparison theory. However, the participants did not always use self-categorisation processes and make comparisons that would be suggested by stigma theory. Some of the participants in this study were able to present themselves positively by comparison with people who were non-disabled. They used dimensions, such as normative accomplishments and avoided making comparisons on dimensions such as intelligence and skills, where their group is known to be vulnerable. Other participants with poorer self-esteem used downward comparison with other people with more severe intellectual disabilities and avoided making comparisons with groups that were more advantaged than they were. The groups also displayed contrast and affiliation effects to enhance their self-esteem. Hence a variety of social comparison processes consistent with social comparison theory were utilised to protect and enhance self-esteem.

All participants used a range and complexity of strategies which were useful in their lives and which allowed them to make as positive presentation of themselves as
possible. They had developed coping strategies that enabled them to present themselves more positively. These coping strategies were consistent with their previously developed internal concept of their self-esteem and followed the typology suggested by Zetlin and Turner. These coping strategies had not changed in the community; however, they seemed to be used more positively.

Also, although stigma theory was more salient in predicting the direction of the change in self-esteem after the move to the community, social comparison theory gave greater insight into the mechanisms by which the participants had maintained their self-esteem in spite of membership of a stigmatised group. Qualifiers and vacillators, as suggested by Zetlin and Turner, used downward comparison with other people who are more severely impaired than themselves, thus maximising contrast effects, and used lateral comparisons only to members of their own group. Acceptors and deniers used upward and lateral comparisons to non-disabled people as their reference group, but did so on selected dimensions and thus maximised assimilation effects and experienced reflected glory. As such, Zetlin and Turner feel that deniers and acceptors are able to establish a more positive sense of self. This contention was not replicated by this study. The person with the highest self-esteem (based on test scores and inferences from the interviews) was the acceptor but the person with the lowest self-esteem (based on test scores and inferences from the interviews) was the denier (Violet). However, the qualifier and the vacillator were the participants who used downward comparison to enhance their self-esteem. Overall, the study suggested that the major use of social comparisons, whether upward, lateral or downward, was to protect the self-esteem. These differences also provided evidence that people with mild intellectual disabilities showed selective industry of the mind when making social comparisons. This suggests that self-esteem enhancement programs should be designed to account for the complexity of comparison processes that people with intellectual disabilities can use to protect their self-esteem. As such interventions could be developed to teach people to protect their self-images from comparisons that are overly negative. For example, if their self-esteem is threatened, they could be encouraged to make upward or lateral comparisons to the non-disabled population (inter-group comparisons) based on selected dimensions on which they are not vulnerable and experience reflected glory. Alternatively, they could be encouraged to make downward comparisons to more severely impaired members of their groups.
(intragroup comparisons) and then be able to use contrast effects to protect their self-esteem.

Summary

This chapter has presented the findings of Study 2. The aims, rationale, the choice of methodology for the study were delineated. The use of ethnography was explained and justified. The results showed that a lack of socialisation experiences was the primary reason for the lack of social competencies and skills exhibited by the participants and that this lack of socialisation also had an impact on their self-esteem. The participants’ self-esteem had improved on moving to the community, lending support to Goffman’s theory of stigma rather than to social comparison theory in predicting the direction of the change.

Analyses using Zetlin and Turner’s typology indicated that the women were using the same coping strategies they had used in the institution and these strategies seem to be utilised to protect self-esteem. The social comparison processes employed suggested that they were using very selective upward, lateral and downward comparisons and assimilative and contrast effects to maintain their self-esteem. Hence, these results offer support for stigma theory in relation to the increase in self-esteem that occurred after the move to the community. In addition, they also offer support for social comparison theory in that comparison groups seem to be deliberately selected in a complex manner in order to protect self-esteem and attempt to develop a positive identity. An understanding of the latter processes may be central to ensure that social comparisons that could be damaging to the individual’s self-esteem are precluded.
CHAPTER 9
Interpersonal Cognitive Social Skills Intervention for Five Adults with Intellectual Disabilities

Introduction

The acknowledged gap that has been found in the implementation of deinstitutionalisation and the normalisation principle has been the social integration of people with mild intellectual disabilities into the community (see earlier discussion in chapter 2). The reasons for this may be complex, but one of the reasons could be the lack of social competence and social skills that are often demonstrated by people with mild intellectual disabilities. If social integration is a goal, then it is necessary to investigate how to enhance social integration.

One of the most widely recognised obstacles to social integration is that people with intellectual disabilities are excessively dependent upon external agents for maintaining behaviour (Ferreti, Cavalier, Murphy & Murphy, 1993). These authors suggest that the goal of deinstitutionalisation should be the goal of autonomy. They feel that implicit in the concept of normalisation is that people will become less dependent on structured learning programs, employed personnel, and should become increasingly self-regulating.

However, self-regulation can be difficult for people with intellectual disabilities because they often display ineffective decision-making skills and problem-solving strategies. Educational researchers and practitioners have emphasised the necessity of teaching problem-solving skills to achieve positive vocational (Chadsey-Rusch, 1992), academic (Buser & Reimer, 1988) and social (Foxx & Bittle, 1989) outcomes for people with intellectual disabilities. Problem-solving and decision-making seem be extremely important skills for achieving self-regulation and autonomy in the community (Mithaug, Martin & Agran 1987; Wehmeyer, 1992a; 1992b; see earlier discussion in chapter 4).

Therefore, if people who are moving to the community are going to be socially integrated, then they need to be introduced to social skills interventions. An intervention program could improve their social competence and develop their autonomous, self-
regulatory strategies, particularly those that encourage problem-solving and independent decision-making (see earlier discussion in chapter 4).

This chapter reports the outcomes of an interpersonal cognitive social problem-solving intervention for five people with mild intellectual disabilities who were moving to the community. The results of both the acquisition of the problem solving process and the implementation in generalisation settings are presented.

The intent of this research was to extend the current literature in two important aspects by:

1. Examining in detail the acquisition of the process of a fairly complex problem-solving process.
2. Assessing the maintenance of the intervention over time and generalisation of the intervention to the community and living situation using different sources of data collection including subjective evaluations, observations and standardised tests.

The study evaluated the strength of the intervention in a number of ways. First, generalisation probes were conducted in near and far settings before and after the intervention. Secondly, follow-up assessments were conducted for six months following the removal of training. Finally, the generalisation was extended to an analysis of real-life behaviour (self-direction and socialisation) using the AAMD-ABS and to interpersonal characteristics such as problem-solving self-concept, and global self-esteem. These last measures were taken in an attempt to assess whether the intervention was strong enough to lead to increases in social competence in contexts not directly treated by the intervention.

In summary, the primary purpose of this study was to determine if an interpersonal cognitive social skills intervention was an effective method for teaching community-related social skills and generalising these cognitive techniques across untrained exemplars and settings. Secondary questions addressed were the time needed to learn the self-management skills, and the efficiency of the instructional techniques.

Method

Participants
Five participants took part in this study. All participants had been diagnosed as having mild intellectual disability and were being prepared to move to the community. The participants were assessed by their personal care workers and administrators as having social skill difficulties and ineffective problem-solving skills which could delay their move to community housing. The participants provided written consents.

**Participant Diana.** Diana was a woman of 39 years, who had a mild intellectual disability and a hearing impairment. Diana was a very competent lady who cared for herself independently. Diana’s overall functioning on the AAMD-ABS Part A was at the 81st percentile for people with an intellectual disability. Her ranking on the socialisation subscale was at the 72nd percentile, and her ranking on the self-direction subscale was at the 78th percentile. Her language ranking was at the 86th percentile. Diana’s speech at times showed characteristics of deaf speech; her speech could be soft and monotonous. Also, she would often repeat the same phrase in answer to questions. Diana’s personal care worker was concerned that Diana, although willing to go out and participate passively in group activities, would never initiate a conversation or social interaction. Diana had no family support as her family showed very little commitment to one another and Diana was initially removed from her family’s care because of abuse. Diana was an ideal candidate for living in the community but it was feared that she might remain quite lonely and become isolated. She found it almost impossible to initiate conversations and social interactions away from the residence.

**Participant Joanna.** Joanna was a woman of 32 years. Joanna had Down Syndrome, a mild intellectual impairment, and severe asthma. She scored at the 76th percentile on the AAMD-ABS Part A overall score. Her socialisation subscale score was at the 62nd percentile, and her self-direction subscale score was at the 56th percentile. Her expressive and receptive language were good. She scored on the 89th percentile for language and she could read and write. She had previously lived at home with her parents and attended a workshop. She was desirous of living independently in the community and was offered a permanent placement at the residence to enable her to do this. She was extremely competent, but had not developed the necessary living skills, such as cooking and laundry, because her mother had always done these for her. She had adapted very well, but there was interpersonal conflict in her residence.
Participant Simone. Simone was a 50 year old woman with a mild intellectual disability. Simone also has a moderate to severe hearing impairment and wore bilateral hearing aids. Simone was functioning at 66th percentile on the AAMD-ABS Part A overall score. She scored at 18th percentile for socialisation subscale and 30th percentile for self-direction subscale and at the 68th percentile for language. Simone’s speech was soft but not overly characterised by hearing impaired characteristics. Simone was independent in her personal care but required support from staff for her interpersonal difficulties. Simone enjoyed being on her own. She needed help to be more assertive initially and to try new things. Simone needed a lot of encouragement to do things independently even though she was quite an able person. Her personal care worker felt that her most important goal was to think through what she wanted to do with her life in a realistic way and to make plans to achieve this. However, Simone did not have the skills or the motivation to do this.

Participant Fleur. Fleur was 49 years old and had a mild intellectual impairment. She was functioning at the 67th percentile on the AAMD-ABS Part A overall. She scored on the 34th percentile for the socialisation subscale and her score on the self-direction subscale was on the 68th percentile. She scored at the 64th percentile for language. There have been indications that her receptive language was not as strong as expressive language. Fleur was thought to respond to keywords in receptive language, rather than to comprehend whole phrases. Fleur was a competent person who could handle the activities of daily living quite independently; for example, she could use public transport and could do so to complete her weekly shopping. However, Fleur was reliant on personal care workers to maintain her interpersonal relationships in her residence. She did not handle frustration or criticism at all well and would cry very easily with staff, or resort to arguments and anger with her flatmates. When she lost her temper, she was very hard to reason with.

Participant Chloe. Chloe was a very capable and helpful person who was 50 years old. She had a mild intellectual disability. She managed well in familiar situations, but quickly panicked with new or slightly different situations. Chloe preferred to work with personal care workers and became easily intimidated when other residents told her what to do. When Chloe was anxious she began to feel physically sick and occasionally vomited and
had suffered from stress incontinence. Chloe felt anxious about the move to the community, about using public transport and about her family. She scored at the 80th percentile on the AAMD-ABS Part A overall, with a score on the 80th percentile for Socialisation subscale, and a score at the 38th percentile on the Self-Direction subscale. Her language score was at the 85th percentile.

**Target Behaviour Selection**

Target behaviours selected for the intervention were based on subjective daily routine evaluations completed by personal care workers, observations by the researcher, and in consultation with personal care workers and administrators. These resulted in identification of specific social skills which were in need of remediation before the person could move to the community. Observations were conducted in the natural environments to obtain specific information on these social skills. Procedures that resulted in pinpointing target behaviours are explained separately for each participant. These are summarised in Table 9.1.

**Table 9.1**
Participants’ Characteristics and Target Behaviours

<table>
<thead>
<tr>
<th>Participant</th>
<th>Disability(ies)</th>
<th>Targeted Behaviour(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diana</td>
<td>MID and hearing impairment</td>
<td>Initiate social interaction, and start a conversation at shopping centre and at women’s group</td>
</tr>
<tr>
<td>Joanna</td>
<td>MID and Downs Syndrome</td>
<td>Turning off TV at night and sitting too close to people</td>
</tr>
<tr>
<td>Simone</td>
<td>MID and hearing impairment</td>
<td>Initiate new activity with personal care worker and verbalise two problem solving strategies</td>
</tr>
<tr>
<td>Fleur</td>
<td>MID</td>
<td>Responding to criticism without anger or frustration</td>
</tr>
<tr>
<td>Chloe</td>
<td>MID and psychiatric disturbance</td>
<td>Not panicking in new situations</td>
</tr>
</tbody>
</table>

*Note. MID = Mild Intellectual Impairment.*

**Participant Diana.** Diana’s target behaviour was to verbalise “hello” and maintain an interaction with a sales assistant/retailer for at her local shopping centre She was also initiate a social interaction by saying “hello” and maintaining a conversation at the women’s group she had been attending for some years. The lack of social interaction, verbalisation in public and conversation was observed by the researcher at the women’s monthly meeting and also
when Diana was out shopping on two occasions. Diana could converse with people she knew quite adequately so a detailed analysis of interacting with a retailer and holding a conversation was not attempted.

**Criteria for participant Diana.** The criteria were that she was to say “hello” and interact with a retailer for two minutes in her shopping centre and that she would say “hello” and maintain a conversation for two minutes with two people at the women’s group.

**Participant Joanna.** Two behaviours were chosen for Joanna. Joanna’s behaviour was to stop turning off the TV at night in the common lounge room, when she wanted to go to bed but other people were watching it. She was to ask her flatmates if they still wanted to watch the TV. Joanna would also sit too close to other people and would invade their personal space by standing too close when she was talking to them. Observations of this behaviour were made by the researcher and by and administrator in the natural setting (i.e., her residence).

**Criteria for participant Joanna.** The criteria that were set for Joanna were to check with her flatmates before turning off the TV with her flatmates for three nights in a row and to not sit or stand closer than 0.75 metres to her flatmates, her personal care worker and the administrator during her daily review on three days.

**Participant Simone.** Target behaviours chosen for Simone were to show initiative in choosing a recreational activity from a list negotiated between Simone and her personal care worker and to demonstrate independent problem-solving when faced with minor occurrences in her residence. Simone showed a very passive attitude to initiating any realistic new recreational activities. She was totally dependent on staff to solve any problems that arose in her residence. Her only problem-solving strategy was to refer everything to her personal care worker. If her personal care worker was not available she would retreat into her room and stay there for long periods every day. These behaviours were observed by the researcher and her personal care worker and were also mentioned in her case notes recorded regularly every three months.

**Criteria for participant Simone.** The criteria that were chosen for Simone were that she would choose a recreational activity from the negotiated list and that she would ask her personal care worker and her administrator to facilitate her involvement in this activity. When
a problem arose in her residence she would be able to vocalise to her flat mate and display two problem-solving strategies independently apart from withdrawing into her room or referring to her personal care worker. She would be able to do this on three occasions.

**Participant Fleur.** The target behaviour chosen for Fleur to react to criticism or frustration by counting to three telling herself to calm down and responding in a normal voice. She responded very negatively to criticism from staff and other residents and would cry or yell when this happened. Observations of this behaviour were seen in her residence with her flatmates when the employed staff were absent, and in the community, when the employed staff had to speak with her about interpersonal difficulties in a shopping centre.

**Criterion for participant Fleur.** The criterion that was set for Fleur was that Fleur would respond to criticism from her personal care worker, her administrator and her flatmates by counting to three, telling herself to calm down and responding in a normal voice. This response would not be accompanied by crying, anger or a loud argumentative voice. She would display this behaviour in her residence and in the shopping centre on at least three occasions.

**Participant Chloe.** The target behaviour that was chosen for Chloe was for her to calm down and not panic in new situations. Chloe would panic if she was placed in a situation in which she had to make decisions or problem-solve, and she would refuse to do anything at all when she was in this state. This behaviour was exhibited when Chloe refused to go to the toilet independently when she was out shopping because she was afraid that she would get lost. At another time, Chloe was being encouraged to travel into the city independently and she was literally feeling sick. At another time, Chloe needed to go to hospital and became so agitated that she hit her personal care worker and hurt her, out of sheer anxiety. These observations were made in her shopping centre and in her residence.

**Criterion for participant Chloe.** The target behaviour that was chosen for Chloe was that she would demonstrate the behaviour of stopping, counting to three and telling herself to calm down when she was in a new situation, such as catching public transport independently or using the toilet facilities in her shopping centre. At the same time she would not feel ill or hit her personal care worker. She would display the behaviours of stopping, counting to three and telling herself to calm down on at least three occasions.
Setting

The intervention was conducted in various staff rooms, common living areas, and outdoor areas of a residence for people with intellectual disability who were being prepared to live independently in the community.

The intervention was conducted in several venues as this has been reported to enhance generalisation. Two instructors (the researcher and a personal care worker) conducted the problem-solving training sessions which lasted for 30 minutes, three times per week, for up to six weeks for some participants. The researcher trained the personal care worker to reliably implement the interpersonal problem-solving intervention and observers to record the target skills respectively. Two graduate students with Masters in Education Psychology were trained to measure the acquisition of the process from tapes used in the training sessions.

Near and far generalisation observations were undertaken in the residences, the grounds and the local shopping centre, as well as at the women’s meeting that Diana attended.

Pre-intervention observations were taken in a different setting to post-intervention settings, if this was possible, but as the criterion for target behaviours was to be expressed in the same settings, this was not always practical.

It is obvious from examination of the observations that problem-solving was a common theme, but a variety of problems were idiosyncratic to the individual. Other studies have concentrated on one behaviour being the focus of training at a time. This intervention, by comparison, aimed to target individual behaviours and give the participants a generic problem-solving training strategy.

Dependent Variables and Data Collection Procedures

The focus of this study was the generalisation of a cognitive interpersonal problem-solving package to untrained scenarios and to behaviours in the home setting and to the
community. Data were collected before and after the intervention in the home and the community. Observations of individual problem solving abilities and social skill deficiencies were made before and after the intervention. A total of 18 instructional sessions were planned; every second session was assessed for acquisition of the training process (training data in graphs) and probes to untrained generalisation scenarios were made after every third session. The personal care worker and the researcher conducted the sessions and the personal care worker; the researcher and an administrator made the observations. Standardised tests were used as well. Data were also collected on the acquisition of the interpersonal cognitive problem-solving processes. Every session was tape-recorded. The two graduates with a Masters in Educational Psychology evaluated the tapes of these sessions. In reality, some participants reached criterion before 18 sessions were completed and the intervention for two participants had to be suspended for a time because of behavioural difficulties.

The seven steps of the problem-solving process taught are outlined in Figure 9.1. Target responses were:

1. Remembering the seven steps of the problem-solving process as outlined in Figure 9.1.
2. The ability to apply the steps of the problem solving process. Each step of the problem solving process and its application was defined. The rate of acquisition and application was recorded (see Table 9.2).

The pretest/post test data and probe data were reported as a percentage of appropriate responses to training scenarios and to untrained scenarios. Criteria were defined and the two previously mentioned graduate observers were trained to rate the recorded records. Observations of participants’ performances on target behaviours were made in both the living and community generalisation settings. The researcher and the personal care workers made these observations. Some quantifiable observations were possible in these environments, but mostly they were qualitative in nature and anecdotal as it was impossible to have total control over this aspect of the observations. However, observations were made three times on standardised observation sheets, using the criteria that were agreed upon for the target behaviours. The personal care workers kept records on a daily basis of the rate of occurrence of the behaviours.
Training Data

The problem-solving training sessions were conducted three times a week for six weeks. However, some participants reached 100% criterion before 18 sessions were completed. Data were collected from over 50% of the sessions on the acquisition and application of the Seven-Step Problem-Solving process outlined in Figure 9.1. These behaviours were measured in the training sessions, which lasted for 20-30 minutes. Data were collected in the following manner; tape recordings were made of the sessions and rating scales were taken if the participant had shown (a) acquisition or (b) application of the seven steps throughout the training session.
Acquisition of the step was defined as the participant being able to verbalise the step in the appropriate context and application was defined as being able to apply verbally steps to the scenario under discussion in the training session.

**Post-Training Session Data**

The following measures were taken immediately after the training sessions were completed. Data were collected on (a) the ability to verbalise the steps and (b) the ability to apply steps to the scenario trained in session that had just been completed. Data were reported as the percentage of correct possible responses per testing time. Measures were taken every second training session up to when intervention ceased unless the participant had reached criterion.

**Generalisation to Untrained Scenarios (Probes)**

Data were collected using the same techniques as the post-session data except that they were conducted every three sessions (i.e. there were at most six data collection times) and participants were asked to apply the techniques to untrained scenarios. These scenarios were individualised according to the specific needs of the participants as perceived by their personal care worker, the administrator or by themselves.

**Self-Instructional Data**

To allow for comparisons with other studies (Agran et al., 1987; Hughes & Rusch, 1989; Park & Gaylord-Ross, 1989), it was planned to make observations of the self-instructional aspects of this procedure as well. However, it was not possible to assess this, for except for two occasions in the home instructional setting, no self-instructional verbalisations were emitted.

**Living Environment Data**

Three measures were taken in the home setting. These were:

1. Subjective and anecdotal observations of target behaviours in the normal living environment. The rate of behaviour was also recorded.
2. AAMD-ABS Part A, Coopersmith Self-esteem Inventory (Short Form) and Problem-solving Subscale of the SDQ-III (see chapter 6 for a detailed description of the properties of these standardised tests).

3. Subjective anecdotal measures of problem-solving skills by the researcher and the personal care worker.

**Pre Intervention Data**

Three measures were used to assess living behaviour. First, the personal care worker completed the AAMD-ABS Form (1974) pre- and post-test the problem solving sessions (Table 9.2). Secondly, naturalistic observations were made of the participants by the researcher and the personal care worker in three separate occasions in their living environment. Thirdly, naturalistic observations were undertaken for some participants in the community on three separate occasions pre- and post- the intervention. The researcher undertook these observations. The measures that were taken have been summarised in Table 9.2.

**Reliability Procedure**

Reliability checks were collected across all phases of the intervention. Reliability was calculated using the numbers of agreements dividing by the by the numbers of agreements plus the numbers of disagreements and multiplying by 100% for the components of the training procedure. The subjective observations were submitted to a third observer (a senior administrator) for 50% of the time to determine if the researcher and the personal care worker were in agreement about the criterion for the target behaviours.
### Table 9.2
Summary of the Pretraining, During Training and Post-Training Assessments of the Intervention

<table>
<thead>
<tr>
<th>Phase of Assessment</th>
<th>Assessment Measures</th>
<th>Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pretraining</strong></td>
<td>AAMD-ABS Part A Overall Score, Language Self-direction and Socialisation Subscale scores, SDQ III-Problem-solving Subscale, Coopersmith Self Esteem Inventory, Adult Nowicki-Strickland Internal-External Locus of Control</td>
<td>Problem solving abilities</td>
</tr>
<tr>
<td></td>
<td>Measures of social skills in living situation</td>
<td>3 times minimum</td>
</tr>
<tr>
<td></td>
<td>Community observations of participants</td>
<td>3 times minimum</td>
</tr>
<tr>
<td></td>
<td>Daily anecdotal reports</td>
<td>Daily</td>
</tr>
<tr>
<td></td>
<td>Baseline measures of specific program components and ability to apply them</td>
<td>3 times minimum</td>
</tr>
<tr>
<td><strong>During Training</strong></td>
<td>Post session measures</td>
<td>9 times for some participants, taped</td>
</tr>
<tr>
<td></td>
<td>Probes to untrained scenarios</td>
<td>6 times taped</td>
</tr>
<tr>
<td></td>
<td>Observations of acquisition and application of components of problem-solving process in training sessions</td>
<td>Ongoing, written, taped records</td>
</tr>
<tr>
<td></td>
<td>Observations of social skills in near (living) and far (community) settings</td>
<td></td>
</tr>
<tr>
<td><strong>Post Training</strong></td>
<td>AAMD-ABS Self-direction subscales, and Socialisation Subscale and SDQ III Problem-solving Subscale Coopersmith Self-esteem Inventory</td>
<td>Immediately after intervention; 6 months after intervention</td>
</tr>
<tr>
<td></td>
<td>Observations of target behaviours in near generalisation setting - living environment</td>
<td>3 and 6 months</td>
</tr>
<tr>
<td></td>
<td>Observations of generalisation social skills in far generalisation setting – community</td>
<td>3 months; 6 months</td>
</tr>
<tr>
<td></td>
<td>Maintenance of acquisition and application of problem-solving process-training setting</td>
<td>3 and 6 months</td>
</tr>
</tbody>
</table>

Instructional Content

The problem-solving program incorporated the components of a number of metacognitive programs and was a synthesis of the approaches of Meichenbaum (1995), Gow, Ward and Balla (1986), Kam, Greenberg and Walls (2003) and McFall (1982). A manual outlining detailed lesson plans is in appendix B. Each training session utilised teaching techniques that have been found to enhance generalisation. These are shown in Figure 9.2.

<table>
<thead>
<tr>
<th>Verbal self-instruction training (VSIT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed strategy training</td>
</tr>
<tr>
<td>Conditional knowledge</td>
</tr>
<tr>
<td>Dialogues</td>
</tr>
<tr>
<td>Scaffolding</td>
</tr>
<tr>
<td>Reciprocal teaching</td>
</tr>
</tbody>
</table>

Figure 9.2. Intervention Was Based on these Teaching Techniques

At the beginning, social skills training procedures followed this general outline:

1. Presentation of training summary and rationale (principles of informed strategy training and conditional knowledge).
2. Presentation of first training picture/scenario and verbal description of social situation.
3. Model of problem solving rules as it applies to situation (principles of VSIT training).
4. Role-playing of problem-solving steps as applied to same social situation (prompts given for incorrect responding; principles of VSIT and scaffolding).
5. Encouraging the participants to perform the problem-solving steps while verbally self-instructing themselves (scaffolding and reciprocal teaching and transferring control to the learner).
Initial training concentrated on teaching a seven-step process for problem solving (see Figure 9.1). Scenarios were written that applied directly to the problems the participants had encountered in their everyday environment or the community. These were identified by supervisors, by observations or by the participants themselves. The process was introduced as a whole but with particular emphasis being given to particular steps at any one lesson.

**Experimental Design and Conditions**

**Experimental Design**

In a review, Huang and Covo (1997) found that of all the multiple baseline designs, the most common was the multiple baseline-across-participants design. This design has been used to demonstrate effectiveness of training across many different types of social skills (Chadsey-Rusch, Karlan, Riva & Rusch, 1984; Agran et al., 1987; Collett-Klingenberg & Chadsey-Rusch, 1991; O’Reilly & Chadsey-Rusch, 1992). The multiple baseline design can overcome many problems in this area. It does not require researchers to withdraw a successful treatment, which is impossible with social skills training and the design still controls threats to internal validity and allows an analysis of the functional relationship between the procedure and the target behaviour. The multiple baseline design has been found to be both experimentally powerful and ethically and conceptually more acceptable (see chapter 6 for an outline of this methodology). Therefore, a multiple baseline design across two participants and behaviours was chosen. Experimental conditions included (a) baseline, (b) problem-solving training, and (c) maintenance.

**Baseline.** Behavioural baseline measures were collected in the training, living and community settings. Training baseline was five to 10 minute individual sessions where participants’ responses to scenarios were assessed. This occurred three times for the first two participants (Diana and Joanna), six times for the second two participants (Simone and Fleur) and nine times for the last participant (Chloe) before the intervention commenced. The problem-solving scenario was read out to the participants and the responses were scored. During baseline no training feedback was provided, however each participant was personally thanked for taking part in the research.
Baseline measures were also collected in the living environment and in the community. In the living environment observations were taken of specific social skills that had been determined by personal care workers and administrators. Qualitative observations were made of participants’ interaction style and problem-solving abilities in this setting. However, specific criteria were set for each target behaviour; also daily records were kept of the occurrences of target behaviours throughout the baseline and intervention phases.

In the community, observations were made before and after the intervention. The participants’ responses to the AAMD-ABS (Nihira et al., 1974), Coppersmith Self-esteem Inventory (Coopersmith, 1967) and the Problem-solving Subscale of the SDQ III (Marsh, 1989b) were also recorded by the researcher and the personal care worker.

**Problem-solving training.** Training occurred three times per week in an individual setting for each participant. Each session lasted approximately 30 minutes. Training sessions were conducted by the researcher and a personal care worker. Training goals, general methods and vocabulary to be used in problem solving sessions were agreed to before training commenced, but as the goal of problem-solving methods was to avoid welding and to encourage generalisation, it was not considered necessary to teach in any prescribed format. It was one of the principles of the intervention to train loosely.

**Observers**

The researcher gathered pre and post-test data. The two graduates assessed the tapes of the problem solving sessions. It was not possible for them to be unaware of the purpose of the study. Before beginning collection of data, they were trained on the forms and procedures to be used. The two observers reached 80% agreement on the forms and procedures three times before observation began. Each assessor of the tapes coded data independently of the other for 50% of the sessions. They also rated the pretest, post-tests and probes from the training sessions. The personal care worker and the researcher rated the target behaviours, using observational schedules developed after the selection of the target behaviours and the criterion. The researcher and the personal care worker completed the living environment and community observations and conducted the problem solving sessions.
Agreement across all of these measures was calculated by taking the number of agreements on responses made by the participants and dividing by the number of agreements plus the number of disagreements multiplied by 100. Average inter-rater reliability was 82.6% with a range of 70% to 93%, after the observers had been trained. Reliability of 50% of the observations was assessed by a senior administrator. Where disagreements occurred a consensus was reached through a discussion of the differences.

Results

Pretraining

Preliminary observations of the participants undertaken prior to the implementation of the problem-solving sessions confirmed the learning styles of many people with special needs. These included:

1. The tendency to be passive learners (participants Simone, Chloe and Fleur). This characteristic was frequently exhibited by Simone and Fleur for significant amounts of time.
2. A lack of independence and self management skills (Simone, Chloe, and Fleur).
3. Attentional deficits (Joanne, Chloe and Fleur).
4. A lack of problem-solving skills where the participants demonstrated inflexibility and repetition of past strategies (all participants).

At the beginning of this study, all participants had some difficulties with problem-solving. They used ineffectual strategies that centre around passivity, avoidance and perseverance. When placed in a problem-solving situation, they became quite passive and relied on the instructor to make suggestions first. Alternatively, they denied any ability to solve problems. Simone particularly said, “I don't know a lot” and did not employ any other strategies. Participants avoided a task or assignment if they considered it was too difficult. Finally, if the participants did try to complete tasks, they showed little flexibility in changing strategies. They persevered in the belief that, if they kept trying, they would eventually
succeed. They did not use evaluative strategies such as, “This is not working, what else could I try?”. In fact, none of the participants was able to generate alternatives.

In addition, participants typically had poor impulse control. Fleur and Chloe could be observed to be exhibiting this characteristic, which has been noted in people with intellectual disability (Embregts, 2002).

It was obvious from the outset of the observations, the living situation, and the community evaluations that problem solving ability and inability to adapt to changes were common themes running through these three sources of data, but community related social skill problems were idiosyncratic to the individual participants (see previous section on Target Behaviours). Other studies have used one common behaviour as the dependent variable, but in this study, this was not ecologically valid as each participant presented with a diversity of problems. Therefore, generalisation to individual problems was assessed for each participant in the residence and the community.

**Training Data**

The results reported here are of the interpersonal cognitive problem-solving training sessions that were undertaken over nearly six weeks. Measures taken include acquisition and application of the problem-solving process within the training sessions, measures taken immediately after each second session of acquisition, and application of the scenario trained in the immediately preceding session (post-tests), and probes to untrained scenarios which were measured every third session. All five participants’ baselines revealed a trend allowing comparison with the intervention data.

**Acquisition of the problem-solving process.** (Figures 9.3a-e) show the training data for Diana, Joanna, Simone, Fleur and Chloe for each of the components of the problem solving process. Although all of the participants acquired all of the components, the rate of acquisition was different for each participant.

Diana acquired the first three steps of the problem-solving process quickly. It took much longer for her to reach the same level on Step 4 (generating alternatives). However, she
could rank effectively by Session 3, and she acquired Step 6 in training by Session 4. A similar pattern was seen for Step 7 (evaluation). After 14 sessions, Diana had reached 100% criterion on all steps and therefore, it was decided to cease the intervention.

Joanna took longer to show any acquisition or application of the problem-solving process. It took until Session 6 to see any changes from baseline. Then Joanna seemed to acquire the process as a whole. Joanna maintained 100% criterion for all sessions, the exception was Step 6 for Session 8 and 9. Consequently her intervention was ceased after 14 sessions.

Simone, like Diana, acquired the first three steps of the problem-solving process by the third session, however she took longer to acquire the other components. Step 4 (generating alternatives) took until session 9 to be acquired. She also took longer to reach the criterion of implementing which was Session 14, and evaluating, which was Session 10. Her intervention was continued until session 15 because she did not reach 100% criterion on all steps until session 12. The last step she acquired was implementing, which mirrors her problems of initiating independent activity.

Fleur took longer to acquire all of the steps of the problem-solving process. She acquired Step 2 by Session 4, she acquired Step 1 by Session 5, she acquired Step 3 by Session 10. Interestingly, she had started to acquire some of the more advanced steps before this. She acquired Step 4 (generating alternatives, which can be very difficult for people with intellectual disabilities) by Session 7. She reached criterion on Step 5 and 6 by Session 6. She reached 100% criterion on Step 7 by Session 8. She reverted to baseline for Session 16 and 17 because of behavioural difficulties (a change in her personal care worker) in the residence. However, she reached 100% criteria on all steps again at Session 18.
Figure 9.3a. Multiple Baseline-Across-Pairs-of-Participants Percent Correct on Process Component Steps (Stop, What, Who, List, Rank, Implement, Evaluate), Training Probes and Generalisation to Untrained Exemplars for Participant Diana
Figure 9.3b. Multiple Baseline-Across-Pairs-of-Participants Percent Correct on Process Component Steps (Stop, What, Who, List, Rank, Implement, Evaluate), Training Probes and Generalisation to Untrained Exemplars for Participant Joanna
Figure 9.3c. Multiple Baseline-Across-Pairs-of-Participants Percent Correct on Process Component Steps (Stop, What, Who, List, Rank, Implement, Evaluate), Training Probes and Generalisation to Untrained Exemplars for Participant Simone
Figure 9.3d. Multiple Baseline-Across-Pairs-of-Participants Percent Correct on Process Component Steps (Stop, What, Who, List, Rank, Implement, Evaluate), Training Probes and Generalisation to Untrained Exemplars for Participant Fleur
Figure 9.3e. Multiple Baseline-Across-Pairs-of-Participants Percent Correct on Process Component Steps (Stop, What, Who, List, Rank, Implement, Evaluate), Training Probes and Generalisation to Untrained Exemplars for Participant Chloe
Chloe, like Fleur, took longer to show any acquisition of the program. However, like Joanna, she acquired all steps by Session 6. Because of behavioural difficulties caused by a change in personal care worker, Chloe reverted to baseline in Sessions 7 and 8, and her intervention ceased for Sessions 9 and 10 because she was too emotionally disturbed to take part in them. However, Chloe reached 100% criterion when the intervention was reintroduced at Session 11. She maintained 100% criterion for the remainder of the intervention, which was continued until Session 18.

**Post-test session data.** Figures 9.3a-e show post-session data for the five participants. Diana reached criterion on the post-test for steps 1, 2 and 5 (ranking) quickly; there were also changes from baseline for Step 7 by Session 4. She reached criterion on 71% of the process by Session 6 and reached 100% criterion by Session 8.

Joanna reached criterion on 80% of the process by Session 8 and reached 100% criterion at Session 10. She maintained this until her intervention ceased at Session 13.

Simone was much slower to reach criterion on the post-test. By Session 6 she could apply 55% of the process, by Session 8 she had acquired 88% and reached 100% criterion on Session 10.

Fleur also showed little difference from baseline until Session 6. At this session she showed 28% of the application of the process to the post-test. By Session 8 she had 58% of the process and she reached 100% criterion by Session 12. She maintained this until Session 16 when she was behaviourally disturbed and returned to baseline for 2 sessions. She then returned to 100% criterion for her final session.

Chloe showed no difference to baseline until Session 6. She then acquired 66% of the process at post-test; there was a sharp decrease to baseline during a period of behavioural and emotional disturbance. After this there was a complete return to 100% criterion, and at Session 12 this was maintained until the end of the intervention.

**Generalisation to untrained exemplars.** (Examples of probes are contained in Appendix B under section Research Notes) Figures 9.3a-e show that all participants exhibited...
nearly zero levels of applying the problem solving process to untrained exemplars during baseline. Once the intervention commenced, performance showed a rapid change. For Diana, performance showed rapid change for Step 4; she achieved 100% by Session 6. Her performance stabilised at 100% at Session 9 and remained there for the remainder of her sessions.

Joanna reached 100% accuracy on Session 6 for Step 5. She reached criterion 100% at Session 10 and stayed there for the remainder of her sessions.

Simone was slower to show generalisation to probes. She showed generalisation of the first three steps at Session 6 and she achieved 80% of the generalisation at Session 9. She attained the 100% criterion by Session 12 and maintained that for the rest of her intervention.

Fleur exhibited generalisation of the process to untrained exemplars much later than the first three participants. She took to Session 5 to show any change from baseline. At Session 9 she achieved generalisation of 57% of the procedure. She attained the criterion of 100% of the procedure after Session 12, except for listing the alternatives (the hardest step), and maintained this at the two subsequent probe evaluations.

Chloe, like Fleur, only exhibited generalisation of the process to untrained exemplars after six sessions. At that time she was capable of generalising 61% of the process. She reached 100% criterion at Session 12 and maintained that until the end of her intervention.

All participants showed improvement in their abilities once the intervention was implemented. However, the rate of acquisition was different for each participant: Some participants acquired the process sequentially (Diana), while others (Joanna and Chloe) acquired it as a whole process after five to six sessions. Fleur and Simone acquired the process more slowly than the other participants, but did reach criterion before the 18 sessions. All participants had reached criterion on the training data, the post-test data and the probe data by Session 12 (Simone reached 66% on training probe). Only one participant needed to complete all of the 18 sessions of the intervention phase. It was decided to continue Chloe’s intervention phase because of behavioural irregularities that occurred in the middle of their intervention.
Post Training Data

Data collected in the target behaviours designated for near and far generalisation showed instances of generalisation (see Figure 9.4).

Living environment data (near generalisation). Diana was observed in the shopping centre where she said “Hello” to two shop keepers, on three occasions. Joanna’s negative behaviours showed a decrease in both near and far generalisation settings, and by Week 4 of the intervention she had reached criterion on turning off the TV; she reached criterion on standing too close in the community in Week 5, and standing too close in the residence at Week 6. Her personal care worker and the administrator both reported that there had been positive changes in her behaviour after Week 6.

Simone achieved criterion on one task only, which was to initiate an activity of her own choosing and ask her personal care worker to initiate this and follow it up realistically. She achieved this at the end of intervention after Session 15. This was to buy a sewing machine and to look for, enrol and attend sewing lessons. Fleur achieved criterion in responding to criticism at Week 8 of the intervention in both near and far generalisation settings. This was the only one of the two instances where self-verbalisations were emitted. She was observed telling herself to calm down and think. Chloe reached criterion on not panicking by Week 5 of the intervention in the near generalisation setting of her residence, even though she had a complete return to baseline for Weeks 6 and 7. She was extremely nervous during this time, but used the problem solving process to calm herself down and to think of different strategies to achieve her desired outcome.

Observations of generalisations of process to community (far generalisation). Data collected in the community showed promising trends in generalisation for at least three of the participants. Diana was observed at the next three, monthly women’s meetings she attended. She was able to speak to two women. She displayed this change at Week 4 and Week 6 in the near generalisation setting (the shopping centre) and Week 5 and Week 9 in the far generalisation setting (the women’s group). Simone was not shown to make any changes in the community, but at the six month follow-up she was a different person. She was now
employed as a French polisher and she was engaging in social interactions with her co-workers. At the three and six month follow up, Fleur had returned to baseline in her behaviour in the residence. Chloe had also returned to baseline.

**Maintenance and generalisation measures.** Maintenance of the problem-solving abilities and generalisation measures were assessed at three months and six months by the researcher. Diana had retained the process and could generalise it on both occasions. At three months follow-up, she was able to initiate conversations at the women’s meeting and at the shopping centre. At six months, she was working full-time at Pizza Hut. She was socially interacting with co-workers and was able to maintain competitive employment. She was able to display appropriate work-related social skills. She has since moved to the community where she lives completely independently.

Joanna, at the three and six months follow-up, had maintained 100% criterion on the process and the application to untrained exemplars. There had been no return to baseline for any of her target behaviours. Joanna’s target behaviours did not relate to the community, but her personal care worker reported that she had no social problems at all. At the six months follow-up, she was working as a cleaner/clerk at a hospital. She had taken the initiative to ask for a job. This was a competitive employment job in which she was considered to be a valuable employee. She interacted appropriately with co-workers and did not invade their personal space. She has since moved to the community where she lives completely independently.

Simone at the three and six month follow up evaluations, had retained the process and could apply it to untrained exemplars at the 100% criterion. She was assessed as taking more initiative for her life and making more decisions for herself. At the six month follow-up she was working as a French polisher four days a week in a furniture factory. She was assessed as being a valuable employee, with a strong work ethic. She did not show the passive attitude previously exhibited in her residence. She lives completely independently now in the community.

Fleur and Chloe showed different outcomes. Both of these participants had returned to baseline in terms of the problem-solving process and the generalisation to untrained
exemplars at the three month and six month follow-up. Fleur’s target behaviour also returned
to baseline level in the residence, but not in the community where she was employed four
days a week as a cleaner at the Red Cross. Her work-related social skills were excellent and
she was a valued, enthusiastic and energetic employee. She has since moved to the
community where she lives completely independently.

Chloe’s target behaviour of calming down and not panicking had not remained at the
criterion reached at the end of the intervention, but her incidence of panicking had decreased.
She has moved to an independent living situation, but she is still monitored by a personal care
worker to make sure that she remains on her medication and that she is coping well.
Figure 9.4. Multiple Baseline Across Pairs of Participants to Assess Effect of Intervention on Targeted Social Skills Percent Correct in Near and Far Generalisation Settings
Generalisation of Social Competence to standardised measures. Table 9.3 shows that there were some encouraging results on the Problem-Solving Subscale of the SDQ-III. This demonstrated that there were changes for three out of the five participants on the Problem-solving subscale of the SDQ-III immediately post intervention and that this was maintained at the six month follow-up.

Table 9.3
Scores on the SDQIII Problem-Solving Subscale Score at Pre and Post the Intervention and Six Months Follow-Up

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pre intervention</th>
<th>Post Intervention</th>
<th>6 Months Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diana</td>
<td>26</td>
<td>28</td>
<td>28</td>
</tr>
<tr>
<td>Joanna</td>
<td>25</td>
<td>32</td>
<td>33</td>
</tr>
<tr>
<td>Simone</td>
<td>16</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Fleur</td>
<td>15</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Chloe</td>
<td>14</td>
<td>29</td>
<td>29</td>
</tr>
</tbody>
</table>

For the Coopersmith Self-Esteem Inventory, there were trends shown in that three out of five participants showed increases in self-esteem scores, one participant no change and one participant’s score was lower as measured by the Coopersmith Self-esteem Inventory (Table 9.4). The increases in scores are similar to those observed by King, Lancaster, Wynne, Nettleton and Davis (1999).

Table 9.4
Scores on the Coopersmith Self-esteem Inventory (Adult Short Form) Pre and Post the Intervention

<table>
<thead>
<tr>
<th>Participant</th>
<th>CSEI-Pre-intervention</th>
<th>CSEI-Post Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diana</td>
<td>36</td>
<td>56</td>
</tr>
<tr>
<td>Joanna</td>
<td>68</td>
<td>68</td>
</tr>
<tr>
<td>Simone</td>
<td>28</td>
<td>36</td>
</tr>
<tr>
<td>Fleur</td>
<td>40</td>
<td>64</td>
</tr>
<tr>
<td>Chloe</td>
<td>32</td>
<td>28</td>
</tr>
</tbody>
</table>

The results on the Socialisation and Self-Direction subscales of the AAMD-ABS are presented in Table 9.5. They show that for all participants there were generalisations of the process to real-life behaviours. There were encouraging trends in both of these subscales for
Table 9.5

Scores on the AAMD-ABS, Part A Total Score, Language Subscale, and Self-Direction, Socialisation Subscales on Three Occasions, Pre-Intervention, Post-Intervention and Six Months after the Intervention.

<table>
<thead>
<tr>
<th>Participant</th>
<th>AAMD Total</th>
<th>Language</th>
<th>Pre-Self-Direction</th>
<th>Pre-Socialisation</th>
<th>Post Self-Direction</th>
<th>Post Socialisation</th>
<th>Six Month Self-Direction</th>
<th>Six Month Socialisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diana</td>
<td>81</td>
<td>81</td>
<td>78</td>
<td>72</td>
<td>99</td>
<td>72</td>
<td>99</td>
<td>82</td>
</tr>
<tr>
<td>Joanna</td>
<td>76</td>
<td>89</td>
<td>56</td>
<td>62</td>
<td>99</td>
<td>68</td>
<td>99</td>
<td>90</td>
</tr>
<tr>
<td>Simone</td>
<td>66</td>
<td>68</td>
<td>30</td>
<td>18</td>
<td>38</td>
<td>22</td>
<td>54</td>
<td>40</td>
</tr>
<tr>
<td>Fleur</td>
<td>67</td>
<td>64</td>
<td>68</td>
<td>34</td>
<td>68</td>
<td>55</td>
<td>68</td>
<td>66</td>
</tr>
<tr>
<td>Chloe</td>
<td>80</td>
<td>80</td>
<td>38</td>
<td>54</td>
<td>55</td>
<td>80</td>
<td>49</td>
<td>80</td>
</tr>
</tbody>
</table>
almost all of the participants. Only one participant, Chloe, decreased on the Self-Direction subscale at the six month follow-up.

**Discussion**

This research both confirms and extends previous findings concerning interpersonal cognitive problem-solving interventions with people with mild intellectual disability. It sought to extend this area in three important ways. The intervention endeavoured to teach a method of problem-solving that incorporated some of the insights gained from higher cognitive abilities research (i.e., Verbal Self-instructional Training, informed strategy training, scaffolding, transferring control to the learner, teaching in different contexts, using different instructors and training loosely). These features were used so that maintenance and generalisation would be enhanced. Maintenance and generalisation data were gathered from a wide variety of sources, subjective anecdotal observations of target behaviours, and standardised tests. This occurred over a reasonably long time frame which facilitated the assessment of the robustness of the intervention to untrained contexts and to untrained interpersonal behaviours.

**Training Process**

The study demonstrated that, like the Park and Gaylord-Ross (1989) and Collett-Klingenberg and Chadsey-Rusch (1991) studies, participants with mild intellectual disability are capable of learning this fairly high level complex approach. The interpersonal cognitive problem-solving process was acquired by the some participants sequentially and by participants nearly as a whole task acquisition. The method was acquired quite quickly, usually in a shorter time than had been thought necessary, so that it is fairly efficient in terms of staff time. Therefore, effectiveness and efficiency of the method of training was confirmed.

In the acquisition of the process (training data), the participants with better language skills acquired the steps of the process quicker than those with slightly poorer language. This replicates the findings of Castles and Glass (1986), Chadsey-Rusch (1991) and Ferretti et al. (1993). The study also adds to our knowledge of the
acquisition problem-solving in two important ways. The first was that the most
difficult step for all participants was the generation of alternatives. Once, the
participant was prompted on this step, she was very easily able to rank the
alternatives. The second was that it was obvious from a comparison of
the baseline and intervention data that the process did encourage generalisation of
thought processes. As a component analysis of the approach was not conducted, it
was not possible to conclude which strategy was most effective. However, the process
as a whole did encourage generalisation to untrained exemplars for all five
participants.

Generalisation of the Social Skills to Near and Far Settings

Generalisation in the natural settings occurred with all participants throughout
the intervention. However, it was the focus of this study to see if introducing elements
to enhance maintenance and generalisation would be successful for up to six months.
At the three month follow up, three of the participants had maintained the process. The
other two participants showed a different pattern of results. Neither had retained the
process and there had been a return to baseline for both of them on all aspects of the
training process. For social skills, there was sufficient trend in baseline data and
sufficient difference between baseline and intervention phases of the social skills to be
able to make some relevant comparisons. For three participants, the target behaviours
were maintained at the three month and six month follow up; for the other two
participants though, there had been a return to baseline in the near setting for one and a
partial return to baseline for another. At the six month follow-up, for Fleur, there was a
decrease in the near generalisation setting and for Chloe there was a regression
towards baseline in the near generalisation setting, but a better result for the far
generalisation setting.

The generalisation to real-life behaviours showed impact for four of the five
participants and led to increases in the AAMD-ABS scores in the subscales of Self-
Direction and Socialisation in both the near and far generalisation settings. The
participant who benefited least from the intervention was Chloe. It became apparent
during the intervention that Chloe had a dual diagnosis, that is, she was both
intellectually impaired as well as having a psychiatric disorder.
The intervention had to be suspended at one point for Fleur and Chloe because they had some behavioural disturbances. These behaviour problems related to changes that were occurring in the residence and did not relate to the intervention per se. However, the break in instruction could have had deleterious results on their acquisition of the training process. Chloe also may not have been interested in succeeding in the intervention, as she was anxious about the move to the community. Valliant, Jensen and Raven-Brook (1995) have found that this type of training can only be successful if the individual concerned also accepts the goal of the training. Meichenbaum (1977) has said that cognitive-behavioural therapy only provides the means by which to achieve improvement in behaviour, the desire to achieve these ends must be possessed by the participant. One issue that was not addressed in this research was assessing the goals and perceptions of the target individuals before the intervention began. Very few studies have ever reported whether the individuals themselves are committed to the research goals. Further, they do not assess the impact of the training on the individual or how the individual felt about the training. Usually it is the perception of significant others that leads to the involvement of individuals in these types of interventions. In this case, participants were chosen by an administrator who wanted them to be prepared to move to the community. However, particularly for people with mild intellectual disability, it could be very important to encourage some interest in the training. If this had been done in this study, then the impact may have been greater, as it was obvious that two of the participants may not have been totally committed to achieving the goals as outlined by the personal care worker and the administrator.

It must be noted that there was a new naturally occurring, but unplanned, contingency that may have been supporting the behavioural changes in the maintenance and generalisation phase. Four of these five participants were employed throughout this time in the competitive workforce. Skinner (1973) contended that self-control procedures are never completely without external influences and, therefore, the motivation these participants had to stay in the workforce may have also resulted in their being highly motivated to implement greater problem-solving, self-direction and socialisation skills.
The personal care workers were at first sceptical about the implementation of the intervention, but they were satisfied with the effectiveness of the intervention based on the outcomes achieved. Embregts (2002) found that staff being supportive of an intervention was extremely important. This factor could also have enhanced generalisation and maintenance in this study, as the personal care workers who assisted with the intervention were still working with some of the participants on a daily basis. Throughout the generalisation phase, the personal care workers were encouraged to prompt and reinforce the target behaviours.

Further research is needed to replicate the present findings and extend this methodology across different degrees of intellectual disability, settings and both pro- and anti-social behaviours. This is necessary to tease out if this intervention can be implemented successfully with people with dual health and disability problems. Future replications of this research would need to have more consultation with individuals concerned as to what goals and or social skills they wished to acquire. Also, self-monitoring techniques would have been a useful adjunct to the intervention. A feature of this study was the successful generalisation to the near and far settings, but this could have been facilitated because the personal care worker who assisted with the intervention was in daily contact with some of the participants throughout the follow-up time. Although no direct teaching was continued, her presence could have served as a reminder of the intervention. If this was an important prompt to retaining the process and the target behaviours, then perhaps self-monitoring techniques should be introduced as a viable technique for facilitating transfer to natural situations and implementing this type of intervention in the community setting where personal care workers will not be seen on a daily basis.

**Limitations of the Study**

Although the results of the present study are encouraging, there were some disappointing findings in that Fleur and Chloe returned to baseline in the residence. This result may have been because the intervention focussed on prosocial behaviour. Additional training and or experiences might be required by people who have fairly frequent anti-social behaviour, such as these two participants. Perhaps, this training
needs to occur before prosocial behaviour replaces more maladaptive behaviour in the participant’s natural environments.

A second factor that would have to be taken into account is the method of gathering generalisation data in natural environments that differ for every participant. Logically, the types of targeted behaviour occur inconsistently and in low frequency in the natural environment. At specific times nothing may occur that is of any significance. Also it is very difficult to control variables such as another resident’s response. It is entirely possible that an observer would miss important times when generalisation has taken place. Collett-Klingenberg and Chadsey-Rusch, (1991) placed micro-cassette recorders on their participants. However, they also found that very low rates of generalisation were recorded. It could be difficult to gain acceptance for this procedure from all stakeholders involved. They suggested that future research use the strategies employed in this present study, which included co-worker and supervisor reports. One area that has shown promise is self-monitoring. This could be a useful inclusion in future research.

Thirdly, in this study there was no withdrawal phase as there has been inconsistent support for withdrawal phases in the literature (Emmregts, 2002). Such a process would have ethical implications. In addition, it has been found difficult to withdraw the acquisition of a cognitive process. This was particularly true during the generalisation phase as the personal care workers were still intermittently reinforcing the appropriate behaviours. Also, there were no specific reinforcers beyond the naturally occurring reinforcers in the environment of the participants. The intention was to train loosely so that the participants would not become dependent on external reinforcements and external reinforcers. This rigid structure has been criticised and linked to lack of maintenance and generalisation in previous interventions. The intention was to develop self-control, however, self-monitoring techniques would have been a useful adjunct to the intervention.

Summary

The results of the present investigation suggest the interpersonal cognitive problem-solving programs that specifically program for maintenance and
generalisation offer a useful intervention technique for improving the social skills of people with mild intellectual disability in their natural environments. The intervention was relatively efficient also in terms of staff time.

The effectiveness of an interpersonal cognitive problem-solving social skills intervention for five adults exhibiting different social skill deficits was evaluated. This intervention had special features to enhance maintenance and generalisation. The intervention was acquired within 18 sessions by all of the participants. However, those participants with better language acquired the skills more quickly. The intervention also produced changes in targeted behaviours for all participants. There were promising signs of generalisation, both in near and far generalisation settings. Three of the five participants maintained improvements in target behaviours for up to six months following the removal of the intervention. There were two participants who returned to baseline on both the acquisition of the program and the specific target behaviours. One of these, nevertheless, maintained increases in real-life behaviours over six months. The participant who displayed the least impact of the program was a participant with a dual diagnosis and the intervention might not be robust enough with this type of participant. Additionally, increases in other adaptive social skills not directly targeted by the intervention (i.e., appropriate work-related social behaviours) were observed after the intervention was withdrawn. Participants and personal care staff indicated that they were pleased with the results of the intervention.

Future research could investigate what type of interventions might be useful for people with dual diagnoses, differing levels of disability and in different contexts. The introduction of self-monitoring processes might lead to even better generalisation and maintenance outcomes. The motivation of participants also needs to be addressed. Hence, the present investigation offers promising directions for further strengthening intervention design.
CHAPTER 10

General Discussion, Strengths, Limitations of the Study and Implications for Research and Practice

Introduction

Social integration of people with intellectual disabilities is the last great challenge of the deinstitutionalisation movement. There is no longer support for separating people with intellectual disabilities from their families and peers and placing them in congregate care. However, physical integration into the community, which has been the major mechanism by which deinstitutionalisation has brought about the changes in policy and practices, has not been followed by social integration. People with intellectual disabilities are at risk of being socially isolated with few genuine relationships and limited or non-existent social networks.

Even though the lack of social integration has been acknowledged for some time, there have been few studies which have addressed this issue. The appalling conditions, that many people were subjected to within institutions, and political and policy changes, have led to the closure of many institutions. The consequences have been that people have been rehoused without appropriate support with person-centred programming or interventions. Many projects have been evaluated overseas with the emphasis being either on assessing improvements in adaptive behaviour or more recently, on the harder to conceptualise and measure construct, quality of life. Few studies have examined the impact of deinstitutionalisation on the variables that could be conceptualised as being closely related to successful social integration. These are the affective variables of multidimensional self-concept, global self-esteem and locus of control. Affective variables are an important part of how people present themselves to others. They play a central role in any concept of social competence and have a direct bearing on the success of social integration.

The lack of research which has addressed the impact of deinstitutionalisation on affective variables and social competences is a serious gap in the empirical literature. This study represented a multifaceted approach to this potentially difficult
social phenomenon: the social integration of institutionalised people with intellectual disabilities into the community. The results have important implications for social policy and its implementation. The study also raises questions that require further research so that the transition of this group from a closed community to the general community continues to have successful outcomes as defined by the principles of normalisation. This chapter presents an overarching discussion of the key findings, summarises the strengths and limitations of the study, and outlines the implications of the study for future research and practice.

**Discussion of Key Findings**

The deinstitutionalisation of adults with mild to moderate intellectual disabilities has been demonstrated by this study to have a positive impact on multiple facets of self-concept, quality of life and social competencies. As such, the findings confirm results emanating from previous research and provides further empirical support for the current social policy of moving adults with mild intellectual disabilities into the community.

This study has extended the literature by using a multidimensional self-concept instrument to examine the impact of deinstitutionalisation on the self-concept of adults with an intellectual disability. This is the first time that the author is aware of, that a rigorously validated multidimensional self-concept instrument has been used in this context. The results of the study also support the contention that the impact of deinstitutionalisation will be better assessed using multidimensional instrumentation. These instruments allow for more complex research designs and allow more exact comparisons to be made of how multidimensional affective constructs relate for people with intellectual disabilities. The use of overly simplistic self-concept assessment tools with limited reliability and validity and the use of proxy respondents is dubious. This argument is supported by the present investigation as this study demonstrated that people with mild intellectual disabilities can reliably self-report emotional states when slightly modified testing protocols are used.

For multidimensional self-concept, the pre-existing difference in age, in that the Stayers were younger than the Movers, could have given the Stayers an
advantage. Given their additional life opportunities, the result of changing social policies, they may have been more capable of learning. Hence, the Stayers may have been more able to score in the positive direction for many of the sub-scales, such as physical appearance and physical ability. Interestingly, this did not occur.

The finding that multiple facets of self-concept are enhanced by the move to community was demonstrated by both quantitative and qualitative study components. The qualitative studies, drawing from the richness of individual experiences from the perspective of the individual, enhanced the findings and suggested that the interplay between the paradigms of stigma and social comparisons was important for evaluating the impact of deinstitutionalisation. Hence, a multimethod research design enabled the key findings to be fully elucidated with the results of the qualitative study supporting the quantitative findings. Stigma theory was more salient in predicting the direction of the change in self-concept after deinstitutionalisation, but social comparison theory was more useful in predicting the strategies by which people with intellectual disabilities maintain their self-esteem.

Using both stigma theory and social comparison theory as a platform for the theoretical thrust of this study was justified as both these approaches helped to explain the psychological health of people with intellectual disability. The stigmatised status of people with intellectual disability was confirmed, but social comparison processes offered a psychological perspective that was more useful in understanding the social lives of people with intellectual disabilities. The results showed that people with intellectual disabilities use complex social comparison processes to protect their self-esteem and protect their identities from the impact of stigma. The comparison processes they used included mechanisms such as upward and lateral comparisons to normalised groups, but only on dimensions where they did not feel vulnerable. These upward and lateral comparisons were then followed by assimilative and reflected glory effects. Downward comparisons with more severely impaired members of their group were more common for those people with lower self-esteem, and these were then followed by contrast effects. Hence, social comparison offers a more complex structure for assessing the psychological effects of integration and segregation. The results of the qualitative study suggested that the interplay between the paradigms of stigma and social comparisons was important for evaluating the impact of
The other major finding of the qualitative study was that deficient socialisation experiences were the primary reason for the lack of social competencies and skills exhibited by the participants. Deficient socialisation experiences also had an impact on their self-esteem. Given it is imperative that the total psychological impact of the move to the community is evaluated for each individual, both stigma and social comparison theory are useful theoretical approaches from which to structure these evaluative efforts.

Interestingly, both the quantitative and qualitative data presented in this thesis demonstrates that people with mild intellectual disabilities actively use cognitive processes (low self-esteem, maladaptive locus of control and social comparison processes) that are remarkably similar to the non-disabled population.

The study also supports the effectiveness of an interpersonal cognitive social skills intervention for people with intellectual disability who are moving to the community. The intervention demonstrated that people with intellectual disability can acquire this complex process in a fairly short time-frame and apply it in their naturalistic environment. However, if generalisation and maintenance are to be enhanced, special features have to be included in the way the process is taught. The intervention was highly successful at maintaining generalisation and maintenance for some of the participants over a relatively long time-frame. The participant who showed little benefit from the intervention had additional presenting mental health problems beyond her mild intellectual impairment. As the targeted behaviours were specific for all individual participants, the research had a positive benefit for them as well as providing strength to the argument that such interventions should be concurrent with any move to the community. Therefore, the findings indicate that the use of interpersonal cognitive therapy techniques could be implemented in the community to improve the social competencies of people with mild intellectual disabilities. This could increase their social integration.

Social integration is crucial for the successful implementation of deinstitutionalisation policies. Without the ‘safety net’ of such therapeutic
interventions, deinstitutionalised people with intellectual disabilities will become marginalised, forgotten or lost in the general community. Such consequences have a human toll, as well as bringing into question the appropriateness of the normalisation process.

**Strengths of the Study**

The overall strength of this study resulted from a fusion of quantitative and qualitative observations. The sound multi-method research design enabled the major findings to be fully elucidated by drawing upon extant theories to critically assess the impact of deinstitutionalisation. The key strengths of the study were (a) the longitudinal/comparison design over 30 months, (b) the use of multidimensional self-concept instrumentation, (c) concentrating on objective and subjective scores for the quality of life construct, (d) using five factors of adaptive behaviour construct as advocated by researchers, (e) an emphasis on self-reporting techniques, (f) employing a qualitative study to elucidate the impact of the two competing paradigms in the area-stigma theory and social comparison theory, and (g) implementation of a successful cognitive social skills intervention that was designed to enhance generalisation and maintenance in the community setting.

The use of a longitudinal/comparison group design over a 30-month period enabled the impact of deinstitutionalisation to be fully examined. Other research has found that the initial euphoria on the move to the community subsides after 12 to 24 months, and that gains either become stable or return to baseline after this time period (Conroy et al., 1991). In contrast, the present investigation found changes indicating a positive impact of deinstitutionalisation were still evident after 30 months, long after the initial euphoria would have subsided. Hence, the use of a longitudinal design and a comparison group addressed limitations of previous research in which a longitudinal design was not of sufficient length or where no comparison group was used.

A variety of procedures were used in this research that assessed a comprehensive range of variables. The instruments employed were based on recent advances in theory and research and included multidimensional self-concept and objective and subjective quality of life scores within a multidimensional instrument.
The use of separate domain scores as the unit of analysis for quality of life recognises and accounts for new theoretical understanding about this construct. Multidimensional instrumentation garnered wide-ranging and specific data on people with mild intellectual disabilities in the context of their move into a community setting. This represents a potentially rich source of information to be mined regarding the specific impact of deinstitutionalisation and the process of normalisation in general. In addition, the study used self-report measures for people with intellectual disabilities and did not rely on proxy-responding, demonstrating that self-reporting is justified for people with mild intellectual disabilities.

Finally, the qualitative components of this research allowed this study to interface with the real world in a practical manner. Based on the richness of observations over the extended period of the study, an important component of the investigation assessed the implementation of a social skills intervention program that used techniques designed to increase maintenance and generalisation of specific and tailored skills in the community. It assessed the impact of this intervention using a wide range of measures, with an emphasis on real-life social behaviours. The assessment of the latter has been rare in previous research.

**Limitations of the Study**

When people are the focus of research, there will always be limitations that need to be acknowledged. These can be amplified in the context of the group of individuals who are the focus of such research. For a target group such as people with intellectual disabilities, there will be limitations in regard to sample size, variability within each group and for individuals, and the ethical issues associated with the allocation of participants to a group. Ethical issues do, and must, override the best-case design. As a consequence, it is conceded that there were some ways in which this study could have been stronger.

The study was conducted with a smaller number of participants than is normally considered to be optimal in experimental designs. This again is a characteristic of all research involving people with intellectual impairment. There are obvious practical limitations when focusing on a group that is represented by only a
small number in the general population. In addition, participants were not randomly assigned to the groups and this is a common problem in research with people with disabilities where it may not be ethical to match groups or randomly assign individuals to treatment regimes. However, the results show that there were very few significant pre-test differences between the Movers and the Stayers on multiple variables that have traditionally been related to deinstitutionalisation.

Another limitation was the lack of generalisability. The Movers could not be considered to be a random sample of residents in institutions since this study only included Movers from one institution. The participants were not representative of the institutionalised population, as the study focussed on people with mild or mild/moderate disabilities. However, focussing on just one level of disability does control for the confounding effect of differing disabilities that has plagued previous research.

The methodology of participant observation described in Chapter 8 does have some limitations. First, the time that was possible to spend at the site might not have been sufficient. Observer bias can also be a problem. This was controlled by referring the tapes and record of the observations to the participants and the staff at least five times throughout the research project. Also, it has to be acknowledged that these women may not be representative of most people with disabilities. They were chosen because of their perceived social competence. However, it is precisely because they possess this quality that their experience can inform current theories of the self and socialisation of people with disabilities.

This study aimed to have an impact on the individual behaviours of the participants through a social skills intervention. As such it was a multiple baseline across participants and differing behaviours study. Therefore, a potential limitation of this study is that it is difficult to establish causal effect due to the potential number of confounds.

Implications for Future Research
The current investigation has advanced our understanding of the impact of deinstitutionalisation on affective variables particularly in the area of multidimensional self-concept. The results indicate that research design may be enhanced by recent advances in self-concept theory, research, and measurement utilising multidimensional self-concept measurement instruments in future research with this population. The use of multidimensional self-concept instruments allows for multivariate between subjects designs and also allows for meaningful comparisons with the non-disabled population. For the quantitative aspect of this study, it will be necessary to administer the instruments (particularly the SDQ-III and the Com-Qol-I5) to larger numbers of participants to fully test the psychometric properties of this instrumentation with this population sample. It also allows for a construct validity approach to the study of intervention effects as advocated by Craven, et al. (2003).

The delineation of the findings of the SDQ-III for people with mild intellectual disabilities should lead to the abandonment of the sole focus on unidimensional self-esteem measures for examining both multidimensional facets of self-concept and measuring general self-esteem. A more defensible approach would be to include both measures in all future research (Marsh, Craven, & Martin, in press). More research is needed on the successful social integration of people with intellectual disabilities in the community. Reliable and valid assessment devices such as the SDQ-III will play an important role in that endeavour.

For the social skills intervention, the results were encouraging; however, some modification of the intervention may be necessary in future research to cater for people with a long history of antisocial behaviour and dual diagnosis. It will be necessary to conduct further studies that include additional procedures to make this type of intervention robust enough for people with intellectual disabilities who demonstrate these additional difficulties. This study used three points of baseline data to establish the stability of the dependent variable, and although this is the criterion in the literature, to ensure that the intervention is causing the changes in the dependent variable a greater number of data points might be useful to incorporate in future research.
The impact of deinstitutionalisation on locus of control was not significant in this investigation. This raises a question about the validity of this construct in the context of the questions addressed in this thesis. Further research is needed to examine the relationship of this construct to other areas such as choice-making and self-determination. A new instrument is needed, based on the current multidimensional theory of locus of control given the apparent inability of the standard instrument to determine differences within a population of people with intellectual disability.

The use of self-report measures is justified for people with mild intellectual disabilities as they can reliably self-report emotional states when slightly modified testing protocols are used. This study suggested ways that instruments designed for the non-disabled population can be administered to people with mild intellectual disabilities in a manner that can provide reliable and valid information. This approach should be continued in ongoing research. Another valid direction for further research would be to address whether the information gained from the interviews was consistent with the scores on the various measures. If greater numbers were available for interview, key methodological questions could be addressed which test to what extent do the two procedures (scales & interviews) provide an ecologically valid representation of social emotional factors associated with deinstitutionalisation, and a comparison of the salience of each.

The findings of the current study have significant ramifications for the saliency of stigma theory and social comparison theory for people with mild intellectual disability. The interplay between the theories is obviously important for critically analysing the processes by which people with disabilities respond to major social changes in their lives. Further research is needed that focuses on the interaction of these theoretical constructs, and to examine closely some of the newer developments in social comparison theory such as counterbalancing assimilation and contrast effects (Marsh & Craven, 2002). It is possible that stigma theory is the external process that stimulates the internal development of social comparison processes, and this could be investigated by prospective cohort studies. The findings also have implications for stigma theory. Zetlin and Turners’ typology has shown that the relationship between stigma and the impact on the self is not simple. More
research is needed to examine more closely the internalisation of negative representations, how these representations may be changed by living circumstances and the conditions that minimise internalisation.

Implications for Practice and Policy

Public policy is in train to deinstitutionalise people with intellectual disability, moving them into the community and thus validating the principles of normalisation. This process will continue as government and non-government organisations divest themselves of the provision of residential services for all but the most vulnerable. Irrespective of whether this policy could be changed, this study has demonstrated that the move to the community by the participants did not lead to any decrease in personal affective variables. Importantly, this research has implications for the continuing process of deinstitutionalisation.

The use of multidimensional instrumentation as assessment tools should lead to the development of interventions that are more specifically tailored to improving the social competencies and affective attributes of people with mild intellectual disabilities. Such an approach could help determine where intervention for the improvement of self-concept may be necessary for people to make a successful transition to the community. This treats people as individuals who have specific needs and by doing so would reduce the potential for difficulty in and/or failure of the deinstitutionalisation process. Ultimately, this would reduce the impact of the move and may even reduce the economic cost of support for such a transition. Nevertheless, there is no justification for keeping people in institutions on the basis that they might be experiencing negative social comparisons in the community. In this study, people with intellectual disabilities were still using the same coping strategies and comparison groups when they moved to the community as they had used in the institution and throughout their lives.

The positive improvement in real-life social competencies shown by the improvement in adaptive behaviour reflects the change to person-centred services and person-centred planning, and this implies that this type of support is necessary for successful integration. It is not sufficient to rely simply on relocation to the
community to bring about these changes: support services as well as specialist therapeutic services that can implement programs such as the interpersonal cognitive problem-solving program described in this study will be essential to successful social integration. It was further implied by the findings that socialisation experiences need to be as normalised as possible, for the development of social competencies and healthy psychological development. As such there is a need to encourage parents, policy makers and service providers to emphasise normative achievements. This requires the specific development of policy, guidelines and education programs. The delivery of the required extensive support and allocation of resources for social integration must be emphasised and this should occur before, during, and following the transition. In this respect, integration should be based on humanitarian values and not be driven by a policy to reduce service delivery costs.

Social comparison was found to be a very useful theoretical construct. Parts of the theory, such as the dimensions that people choose to compare themselves on, could be examined through therapy. Therapy could target other values and roles that can provide protection against negative social comparisons that may occur for people with intellectual disabilities. The demonstration of social cognitive processes such as low self-esteem, assimilation and contrast social comparison effects, suggest that cognitive therapy techniques for social skill interventions such as the one used in this study to enhance problem-solving may be very useful for improving the social skills of people with intellectual disabilities living in the community. More importantly, they could result in people with intellectual disabilities feeling good about themselves. There is also a need to increase self-determination and choice-making in all programs as people with intellectual disabilities have maladaptive perceptions of control. All of these issues have the potential to improve the outcome from the move to the community by an individual with intellectual disability. It is socially responsible that any policy in this area is optimised to make a real difference to people’s lives.

Summary

Deinstitutionalisation does have a positive impact on the social competencies and affective variables of people with mild intellectual disabilities. The study also extends the literature in regard to stigma theory and social comparison theory, and
demonstrates that the social comparison processes used by people with intellectual disabilities are complex and need further investigation. The results of the three complementary study components of this thesis support the contention that people with mild intellectual disabilities possess cognitive abilities related to their social competencies and that these social competencies can be strengthened in the community. In conclusion, an understanding of how deinstitutionalisation has impacted on affective variables and social competencies should foster more research and better policy initiatives, so that social and not just physical integration of people with intellectual disabilities into the community becomes a reality. Australia is a better place than it once was for people with intellectual abilities but not as good as it might become. The strategies emanating from this study may provide promising new directions for enhancing life enjoyment and opportunities for vulnerable Australians. When these areas are finally addressed, the moving out of people with intellectual disabilities, will no longer be a transition, but a complete process of social integration.
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APPENDICES
APPENDIX A

Semi-structured Interview

N.B. Not all questions covered for all participants

*Suggested opening:* I am interested in finding out about your life and what you would like to do in the future.

What has life been like for you up until now?

What have been the most significant events in your life?

What are some of your experiences as a child? And living at the institution?

Who are your friends?

Do you have family or friends that you can discuss problems and feelings with?

Who do you visit?

Where do you go on outings?

Where would you like to go on outings?

Do you have regular activities?

Can you tell me about your week?

Could you tell me about a typical day for you here at the Institution?

Do you watch T.V.? What programs do you like?

Are there any limitations on your social contacts?

What is the best thing about being at the Institution?

What is the worst thing about being at the Institution?

When do you expect to move into the community?

Where would you like to live?

Who would you like to live with?

What will you be doing when you move to the community?

What kind of support will you need?
Is there anything you have to achieve before you can move?

Do you worry about the future?

How do you see your life in 5 years time?
APPENDIX B

FACILITATING INTERPERSONAL UNDERSTANDING AND PROBLEM SOLVING SKILLS

AN OUTLINE OF A PROGRAM TO ENHANCE SOCIAL SKILLS FOR ADULTS WITH AN INTELLECTUAL DISABILITY
INTRODUCTION

People with disabilities have come to expect increasingly that they should have the opportunity to participate as fully and as autonomously as possible in social and economic life. Competitive employment is seen by most individuals as a 'major and essential means of gaining income enhancing self-esteem and increasing quality of life, options and opportunities' (Riches, 1993, p.1).

Despite of the development over the last fifteen years of a variety of approaches (work experience, community service, subsidized work introduction, specialized units for work introduction and transitional-employment programs) both here and overseas, we are far from achieving the goal of obtaining and maintaining employment for many young people with disabilities.

Despite the fact that the largest proportion of people with a disability is made up of those individuals with a mild intellectual disability there is a dearth of research on the best practices needed to teach these people effectively. Riches (1993) found that those teaching or training individuals with a mild intellectual disability have swung between three differing approaches. First, individuals with mild disabilities have been treated as slow learners who only need extra time to catch up to non-disabled peers. Alternatively, they have been exposed to more traditional task analysis and instructional training programs. Thirdly, work experience programs with minimal supervision and training have also been attempted in the belief that exposure to the work environment would provide sufficient training to maintain employment.

Successful employment results when an individual performs valued labour over extended periods of time with minimal supervision (Mask and Berner, 1985). Traditional approaches to teaching people with intellectual disabilities have relied on behavioural techniques such as task analysis and complex schedules of reinforcement. The many deficiencies of these techniques have been recognized (Gow and Ward, 1985; Ward and Gow, 1982). One of the major deficiencies is the failure to generalise skills from one domain to another. Even though researchers in the field have been aware of problems with generalisation, behavioural techniques for skill acquisition still far exceeds any practical behavioral techniques for maintaining acquired skills.

For over twenty years researchers have been aware of the difficulties people with an intellectual disability have in transferring skills from one environment to another. They have also been aware that efficient and effective training is often seriously undermined by overreliance on external supervisors and trainers to maintain gains. In fact, employers both overseas and in this country have used these characteristics to deny people with an intellectual disability employment (Ward et al, 1980). They assume that they will require extra supervision than their non-disabled peers and will require excessive amounts of training time to acquire new skills etc.
WHY TEACH SOCIAL SKILLS

Along with lack of generalisation another major theme that has emerged is that failure in the workplace amongst young people and people with mild disabilities has often been attributed to problems with everyday work attitudes, behaviours and poor social skills (Greenspan and Shoultz, 1981; Calkins and Walker, 1989; Brickey, Browning and Campbell, 1985; Chadsey-Rusch, 1986). Ward et al (1980) found that normal social behaviour and good work habits are seen as crucial to most employers.

There has been an increasing awareness of the importance of teaching social skills related to employment, particularly for people with an intellectual disability (Collett-Klingenberg and Chadsey-Rusch, 1991; Foxx et al, 1986; Foss et al, 1984). Most studies have utilized a traditional social skill training approach that consists of:

- a rationale for why the behaviour is important
- examples of the behaviour
- opportunity to practice the behaviour
- feedback regarding performance

Social skills, the focus of previous research include interviewing (Kelly et al, 1980), compliance (Karlan and Rusch, 1982), asking questions in conversations, (Chadsey-Rusch et al, 1984) and accepting criticism, taking a joke, and soliciting assistance (Shafer et al, 1985). These studies have shown success in increasing social skills, but have shown also that the social skills training has not been generalised beyond the training milieu nor the gains maintained over time.

WHY TEACH SOCIAL-COGNITIVE PROGRAMS

Several researchers have advocated using a cognitive-process problem solving approach to teach social skills because it may promote generalisation (Chadsey-Rusch, 1986; Hollin and Trower, 1988; Ladd and Mize, 1983; McFall, 1982; Park and Gaylord-Ross, 1989). In two studies Park and Gaylord-Ross (1989) demonstrated that the cognitive process approach lead to generalisation of social behaviours across settings in youth with mental retardation.

With a cognitive-process approach individuals are taught a generative process rather than specific component behaviours (Hollin and Trower, 1988). There have been few applications of its use because it relies on receptive and expressive skills and may be thought of as inappropriate for individuals with developmental delay. However, Collet-Klingenberg and Chadsey-Rusch (1991) also demonstrated that two of three participants with moderate mental retardation could learn this approach.

Because appropriate social skills are crucial to the success of workers with disabilities in competitive employment settings (Chadsey-Rusch, 1986; Greenspan and Shoultz, 1981; Salzberg et al, 1987) there is a need for training approaches that are effective, convenient to use, and teach the complexities of social interactions. The strength of this approach is that it teaches a strategy that could be generic to all social situations.
PURPOSE OF THIS MANUAL

In the hospitality industry successful employment hinges upon both the ability to generalise and at least average social skills.

This particular manual outlines a problem solving approach introduced in an integrated vocational college that awarded certificates in hospitality. However, as problem solving is an executive strategy these techniques could be easily modified to many different settings.

The purpose of the unit taught in the college was to enhance employment-related problem-solving so that students could approach employment related problems in a more flexible and effective manner. By teaching young adults to take responsibility for their own actions, to think logically and to handle problems independently we can help them gain a greater sense of competence and self-control. Furthermore, this process should enhance self-esteem and healthy personality development.

Another important feature of this approach is that it was implemented in an integrated setting and was assessed as being of benefit to all of the participants and not just those with special needs. A novel feature was that these techniques were implemented in a group setting and not just on an individual basis.

The accompanying volume provides a discussion of the problem solving process. The actual lessons that follow provide an outline and examples of one approach in implementing the 7 step process. These 7 steps and the teaching techniques employed we have endeavoured to incorporate recent advances in meta-cognition literature. We believe that these steps are uniquely important and distinctly teachable parts of the problem solving process.

They are:

1. stopping and calming down
2. identifying the problem
3. who owns the problem
4. listing the solutions
5. ranking solutions
6. trying your solution
7. evaluating your solution

UNDERLYING RATIONALE

This program incorporates the effective components of a number of metacognitive programs and is a synthesis of the approaches of Michenbaum, Gow, Greenberg and McFall.

Effective components of the program include:

- Metacognitive explanation and modeling
What the strategy is. Define the strategy and describe critical features
- e.g. 7 steps and suspension of ranking until you had thought of lots of alternatives
- Why the strategy was useful
- Explained benefits and purpose of the strategy

How to use the strategy
- Explained each step very clearly
- When and where strategy is to be used
- How to evaluate strategy (being completed now)
- Second feature of the program was use of scaffolded instruction
- Emphasis on dialogue between tutor and students
- Reciprocal teaching to emphasise zone of proximal development
- Emphasise interactive communication and flow of information
- Strategies have been embedded in the training sessions but each session has highlighted or focussed on particular steps in problem solving outline
- Transfer of the technique has been encouraged by suggesting real life occurrences at workplace and in incidents that have occurred at the college.
- Cognitive coaching
- Dialogues, metacognitive explanations, modeling and encouragement
- Cooperative learning
- Students work together to complete tasks
- Extensive oral discussion
- Some disagreements seem to stimulate students to restructure
- Cooperative setting lowers anxiety level
- Eclectic program
- All teaching techniques provide explicit information to students about thinking processes
- They also explicitly encourage appropriate learning goals and feelings of self-efficacy
- Method can be used with groups of students, pairs of students and with groups of mixed ability
- It avoids the stigma of instructional grouping

Each training session will encompass procedures that have been found to enhance generalisation. These include:

1. Verbal self-instruction training
2. Informed strategy training
3. Conditional knowledge
4. Dialogues
5. Scaffolding
6. Reciprocal teaching
7. Small group instruction

Training sessions should be undertaken by at least two instructors to promote generalisation.
• Training sessions should be undertaken in different locations to promote generalisation.
• Additional college staff, administrators, structured work placement supervisor and employees should be familiarised with the aims of the curriculum.

At the beginning work related social skills training procedures would follow this general outline:

1. Presentation of training summary and rationale (Principles of informed strategy training and conditional knowledge)
2. Presentation of first training picture/scenario and verbal description of social situation
3. Model of Problem Solving rules as it applies to situation (Principles of VSIT training)
4. Role-playing of problem solving steps as applied to same social situation (Prompts given for incorrect responding) (principles of VSIT and Scaffolding)
5. Encouraging the participants to perform the problem-solving steps while instructing themselves out loud in small groups (Scaffolding and reciprocal teaching and transferring control to the learner)

The problem-solving steps also could be presented concretely in the seminar room to serve as a concrete prompt.

Intervention procedures should be modified throughout intervention to facilitate generalisation and acquisition of higher-order cognitive strategies. Rosenshine and Meister suggest diminishing overt models and prompts gradually increasing the complexity of material. Diminish student support Practice putting all steps together and provide independent practice.

TEACHING TIME

This program requires 2x30 minutes per week. It can be taught on an individual, small group or large group basis. It has been designed to be taught in an integrated setting with young people that have a mild intellectual disability. Significant adaptations will need to be made to implement the program with other degrees or types of disability.

Initial training will concentrate on teaching a 7 step process for problem solving. They are:

1. stopping and calming down
2. identifying the problem
3. who owns the problem
4. listing the solutions
5. ranking solutions
6. trying your solution
7. evaluating your solution

Each training session will encompass procedures that have been found to enhance generalisation. These include:
1. **Verbal self-instruction training**
2. **Informed strategy training**
3. **Conditional knowledge**
4. **Dialogues**
5. **Scaffolding**
6. **Reciprocal teaching**
7. **Small group instruction**

**SAMPLE LESSON**

Scenarios should be written that apply directly to the problems the participants have encountered in the college or in the workplace. These are identified by superiors or by observations or by themselves.

This is a picture of a worker like you. He is working slowly. His boss is telling him to hurry up and finish mopping because he has other chores to do. You be the worker and I'll be the boss. "John, you need to mop faster, you have other jobs to finish before lunch."

At the beginning of the intervention the instructor would model the problem solving regime out loud.

1. Problem identification
   
   *What is going on? The boss is upset with me. I am taking too long to mop the floor*

2. Who owns the problem

   *The boss, myself*

3. Listing the solutions

   *Getting angry, apologising, trying to work harder, faster.*
   *Talk to other workers*
   *Ask other workers for help*

4. Ranking the solutions

   *Apologising*
   *Work faster and complete task without speaking to the boss*

5. Select the best solution

6. Trying this selection out in the role play situation

7. Evaluating the outcome

   *What happened?*

8. Trying another solution

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TEACHING PRINCIPLES

At the end of each training the instructor will present the same picture/scenario as in the beginning of the lesson and as participants how they would decide what to do in the situation the instructor is to give no feedback to the participants response.

All feedback should endeavour to develop self-reinforcement in individuals. Tutor comments should attribute responses to internal states that are under the individual's control such as effort.

The process is introduced as a whole but with particular emphasis being given to particular steps at any one lesson. At the end of every third lesson students should be encouraged to apply steps to different examples so that generalisation is developed.

It is important to encourage brainstorming in every lesson. The experience already gained from the pilot of these procedures is that people with intellectual disabilities found this the hardest part of the process. The purpose of brainstorming (generating alternatives) is to build more reflectivity and flexibility into the student's thinking. It was necessary to set a minimum criterion of three. The purpose of this was to develop and strengthen underlying skills that can then be used in real life situations.

MODELLING THE PROCESS

It is important for the instructor to model the process and deal with a wide range of problems. Especially at the beginning of instruction this modelling and structuring in which the teacher and others overtly discusses the internal dialogue that is occurring both assists the students in problem identification and makes "visible" the internal cognitive/linguistic process of problem solving.

TECHNIQUES FOR GENERALISATION

Training sessions should be undertaken by two instructors to promote generalisation.

Training sessions should be undertaken in different locations to promote generalisation.

Real life dialoguing and the use of a problem box.

REMEMBER THINKING TAKES TIME FOR US ALL

For many people with an intellectual disability this will be a new and difficult task. Remember to slow down thinking takes time. When you ask a person with an intellectual disability a question give that person plenty of time to think. Do not go quickly to the person who you know has the correct answer.
SECTION B

LESSON OUTLINES FOR PROBLEM SOLVING

LESSON ONE

GENERAL OBJECTIVE
To provide an overview of the problem solving skills unit
To review the fact that everyone has problems
To introduce the first step in problem solving: STOP AND CALM DOWN
To introduce the problem bag

MATERIALS
Problem solving chart
Problem box
Slips of paper and pencil

RESEARCH NOTE
Pretest of problem solving procedure
e.g. May be written or discussed one to one with special needs.
May be any problem that has arisen individually for this student in work related social skills. Or write a scenario.

PROCEDURE
1. Discussion of rationale for problem solving - everyone has problems sometimes

2. Outline steps of problem solving
   a. Stop and Calm down
   b. what is the problem
   c. who owns the problem
   d. list the solutions
   e. rank the solutions
   f. try a plan
   g. evaluate your plan

3. One of leaders to give example of problem, decision of challenge they faced recently e.g. I have a problem when I was in the pouring rain and my windscreen wipers stuck. I have a problem when I've promised to take my son shopping and my boss wants me to stay late for a special meeting.

4. Ask students to think of work related or interpersonal problem. How did they solve it e.g. If response is just ask your supervisor or your parents - Then outline that you are going to help them learn strategies that will mean they don't have to depend on their supervisor at all times.
5. Elicit from students how you know you have a problem
   -feelings
   -decision
   -challenge

6. Introduce problem bag - Ask students
to write problems on apiece of paper and put them in the bag.
Tutors must do this as well. Accept all problems but try to get
students to focus on work related problems as well. e.g.

7. Choose a problem from bag and model problem solving
technique. Remember to verbalise all of the process or conduct
a full class discussion.

   e.g. Michelle has to start work at a motel 30 minutes
       from where she lives at 8 o'clock, but the first bus leaves
       at 8 o'clock.

--------------possible break point---------------------

8. Ask students how they relax if they have upset feelings of
they feel frustrated or if they can't make a decision.

   Suggest alternatives - at least 3
   e.g. Take three deep breaths
       Go for a walk
       Listen to some music
       Tell yourself to calm down
       Count to three

As a group practice techniques
Discussion on where the technique was useful
   -different circumstances in which to use technique

LESSON TWO

GENERAL OBJECTIVE

To review steps of problem solving

SPECIFIC OBJECTIVE

To identify a problem by examining
   its elements of who what where and when
To introduce the second step in problem solving: Identify the
   problem
MATERIALS

Problem solving chart
Problem bag

RESEARCH NOTE

Pretest/Posttest on session content

e.g. Written scenario- You are housekeeping in a motel.
A guest has left a gold watch behind, what do you do?
You need to ask your supervisor a question, however,
they are talking with their boss. What would you do?

PERSONNEL

Appropriate time to introduce different tutor

PROCEDURE

1. Revision of steps of problem solving. Use chart as reference.

2. Revise what to do when you need to stop and calm down.
   Ask for or give examples of when you have used technique.

3. Describe a problem -choose one from the problem box.
   Set up headings
   Who What When Where
   Restate the scenario chosen or the problem from the problem bag
   Introduce new question
   Why or what happened before?

4. Model for students using different possibilities from each category.

5. Apply this strategy to a new scenario.

------------------Possible break point-----------------------------

6. Choose a problem from the problem bag. Choose people who can prepare role play quickly. Cue others as to what to look for so that they be able to identify the problem.

7. Elicit identification responses from people in the audience.

8. Who can tell me some thing about the problem?
   Who can tell us some thing else about it?

9. Ask responses from every category and,
10. Have student state the problem all together. Use other students to model problem statements.

11. Draw another problem and repeat procedure.

LESSON THREE

GENERAL OBJECTIVE

To encourage thinking about different perspectives.

SPECIFIC OBJECTIVES

To introduce next step in problem solving: who owns the problem.

RESEARCH NOTE

If this is the third session then a probe should be made to untrained exemplars. If it is the fourth it should be done at the conclusion of the previous session.

PROCEDURE

Write a range of scenarios model for them who owns the problem

Ask students in pairs (may be regular-special needs dyads) to interpret scenarios

Encourage brainstorming

LESSON FOUR

GENERAL OBJECTIVE

To provide a review of the problem solving process

SPECIFIC OBJECTIVES

To remind participants to use self speech to talk themselves through a problem.

To widen zone of proximal development

To gradually withdraw prompts and scaffold
MATERIALS

Problem solving chart
Activity sheet

RESEARCH NOTE

Activity sheet can be used as part of pretest/posttest of this session students have requisite linguistic abilities.

PROCEDURE

1. Revise steps of problem solving as a group.

2. Give out work sheet

3. First Scenario - Provide scaffold problem solving steps, particularly emphasise with, who, what, when, where, for problem identification.

   Second scenario- withdraw scaffold

4. Review worksheet as a group

LESSON FIVE

GENERAL OBJECTIVE

To reinforce the idea of personal control in the problem-solving process

SPECIFIC OBJECTIVE

To introduce the importance of generating alternatives and solutions

PROCEDURE

1. Generalisation - Ask students if they have applied problem solving techniques to range of problems. If they haven't, tell them different range of situations where you have used it. Informed strategy training

2. Ask students to think: If they had an hour to spare what are different things they could do. Try to encourage all students to give as many ideas as they can. Criterion has been set at least

3. Reinforce all efforts to individuals e.g. give credit for generation of ideas and ascribe it to internal sources such as ability to think of alternatives.
Resist reinforcing actual ideas themselves. In group setting it is important to stop other participants from commenting on the actual ideas as well.

3. Continue to elicit and record solutions. Offer prompt as necessary perhaps offering a different category of solutions so that students don't all offer variations on a theme.

4. Encourage generalisation by asking students to write a problem for problem solving bag.

NOTE: In the piloting of this program this was found to be the most difficult exercise for people with special needs - be patient.
Offer no evaluation; if people give vague answers ask them to be more specific, do not prompt by improving on the answer.

LESSON SIX

GENERAL OBJECTIVE
To provide further practice in generating solutions

SPECIFIC OBJECTIVES
To teach students to go beyond thinking of just one solution
To teach students to think of different categories of solutions

RESEARCH NOTE
Pretest/ posttest on Scenario e.g. used in this session
By the end of this term in structured work placement a person has to service a motel room to hospitality industry standard in 25 minutes time. The individual concerned knows they are not quick enough to accomplish this. What can they do?

Probe to untrained exemplar e.g. Sean has been turning up too early to his structured work placement. Supervisor is not ready to work with him and previous shift don't know what to get him to do. Out of courtesy they are stopping work and getting him a cup of tea. This is annoying the supervisor of this shift and the staff. Industry standard is that anything more than 15-20 minutes before shift starts is a nuisance. Can you solve this problem?

Probe can be separate lesson or administered individually /or it could then become part of a group discussion.
PROCEDURE

1. Divide the class into two teams and see which can find the most ways to solve a problem (Try to ensure that teams are of equal ability level).

2. Outline an actual problem such as the one above and allow 8-10 minutes for students to solve problem

3. Remind them that only different ways of solving the problem count.

4. Point out usefulness of having more than one solution. You have greater choices if the first solution fails.

5. Posttest on Scenario may be written; amount of prompting and scaffolding should be decreasing.

LESSON SEVEN

GENERAL OBJECTIVE

To emphasise the importance of thinking of many different solutions

SPECIFIC OBJECTIVE

To demonstrate technique of enhancing problem solving ability that is under the control of the individual i.e. listening carefully to other people’s ideas.

PROCEDURE

Have students sit in a circle.

1. Explain the gains made from listening to others

2. You have more ideas to choose from.

3. Choose a problem from the problem bag and as a group go through first stages of problem solving.

4. Go around the circle and take turns thinking of lots of ways to solve this problem, but before you say your solution you must repeat what the person in front of you has said

5. If group perseverates or gets stuck on one type of problem summarise this as one way and ask for other ways.
6. If group needs more practice repeat this activity as necessary or play a modified version of telephone.

LESSON EIGHT

GENERAL OBJECTIVE

To review the problem solving process

To promote generalisation to different settings and situations

To promote individual practice in the application of problem solving

SPECIFIC OBJECTIVE

To expose students to situations that are novel and need application of problem solving techniques

RESEARCH NOTE

This situation could be observed as either a probe or a measure of far generalisation depending on the design of the study.

MATERIALS

Fax machine and a photocopier.

PROCEDURE

This session should be taught by different personnel who have experience with machinery but are aware of problem solving techniques.

1. Tutor to model problem solving technique including self speech

I have a problem I have to use photocopier and I don't know how

2. Ask for suggestions from group.

3. Make sure that students with special needs are participating in the discussion and not relying on stronger students.

4. Each student should then be given an opportunity of photocopying the required article.
5. Records taken of time trials, prompts and corrections
6. Move to fax machine, repeat procedures.

LESSON NINE

GENERAL OBJECTIVE
To discuss a personally relevant problem.

SPECIFIC OBJECTIVE
To encourage students to apply techniques across a range of situations such as interpersonal conflicts.

PROCEDURE
1. Divide class into groups of 2 or 3 and present them with scenarios
2. Have students role play scenarios
3. Debrief students after the activity.

LESSON TEN

GENERAL OBJECTIVE
To review the steps of problem solving

SPECIFIC OBJECTIVE
To introduce the next step of problem solving

Rank the alternatives

RESEARCH NOTE
Pretest/Postest on knowledge of steps and on ability to apply them to novel situations.
e.g. Situation chosen for this: exams preparation

PROCEDURE
(Other personnel should be leading this session).
1. To make this valid to students it should be emphasised that it is their decision as to choose what is the best solution for them.

2. Students have to delineate personal problems in this situation.

3. Rank the alternatives from their own perspective. E.g. in Sean's case his study timetable is not working because he can't concentrate long enough; Michelle can't study because of house work demands; Allison has not started studying because of fears of personal inadequacy.

5. Generate a number of alternatives.

6. Encourage students to identify naturally occurring rewards in the environment if they achieve goals.

7. Ask students to actually apply these techniques to workplace, to personal and to college situation.

LESSON ELEVEN

GENERAL OBJECTIVE
To review the problem solving steps learned thus far

SPECIFIC OBJECTIVES
To provide continued practice in problem solving
To provide continued practice in ranking solutions
To provide continued practice in identifying natural reinforcers
To emphasise the importance of thinking before acting

PROCEDURE
1. Show problem-solving chart for 20 seconds

2. Go through steps in pairs with special needs students directed to be the tutor.

3. Introduce a relevant scenario: e.g. you are in charge of an excursion to Cabaravale Diggers Club but just as you are about to leave the college the bus breaks down.
4. Encourage students to think before they write or talk

5. All students to complete problem solving.

6. Draw together all groups solutions

7. Ask students to place a star beside solutions they could personally accomplish, or that they prefer. e.g. one girl who had no knowledge about mechanics suggested fixing the bus herself.

8. Students are then asked to formulate a plan.

**LESSON TWELVE**

**GENERAL OBJECTIVE**

To provide continued review and practice in applying problem solving steps to reinforce the importance of thinking before acting.

**SPECIFIC OBJECTIVE**

To introduce next step of problem solving which is to make a plan.

**RESEARCH NOTE**

Pretest /Posttest of Scenario
e.g. A worker with special needs has been assigned to kitchen work in a private hospital. The worker is very capable but has some physical balance problems. Because of these the employer will not assign her tasks of any real difficulty and she has spent most of her time washing up. The college wants her to seek more challenge in the workplace by asking employer for extra and greater range of duties.

Probe to preparing Christmas function at Leisure Club.

**PROCEDURE**

1. Point to each of the 7 problem solving steps on the chart.
2. After we have picked the best solution or the one that is the best for us, then you need to try your plan.
3. There are 2 parts to planning: making a good plan and then trying your plan.
4. Continue with Scenario outlined under research section
5. As a group go over steps already mastered and then have students role-play development of scenario. Allison asked supervisor for more challenge (asked to do cooking) and he said no. Guide discussion into asking in right way for
a. appropriate tasks  
b. body language  
c. tone of voice  
d. choice of words  
e. whom to ask  
f. timing  
g. what to do while waiting

7. Re-enact role-play to see what else might have happened. (Privately prompt player to carry out solution in an inappropriate way and tell other player they don't have to respond according to predicted responses.)

8. Role-play many different responses and discuss how it worked.

Note: This session may have to stretch over two days.

LESSON THIRTEEN

GENERAL OBJECTIVE  
To provide review and continued practice in applying problem solving steps

SPECIFIC OBJECTIVE  
To encourage generalisation by applying procedures to a real life problem.  
To introduce next step of problem solving and evaluate your solution

MATERIALS  
Activity Sheet outlining all of steps  
Session should be taken by alternative personnel

PROCEDURE  
1. Ask students to think of any problem they have that needs solving in the next week ask them to write down steps of problem solving and make a detailed realistic plan. (PROMPT any students who need help with this step.)

Check for individual concerns with work place supervisor E.g. Sean had inadequate personal appearance. Michael was not being given enough challenge. Michelle had not reached criterion on making a bed. Judy was running late every morning because of conflicting demands of running a small business and attending college 4 days a week. Allison was not coping with the heavy amount of writing involved in instruction and not completing note taking.

2. Get them to write down what happens on
Activity Sheet.

3. Ask them to bring it with them next session.

LESSON FOURTEEN

**GENERAL OBJECTIVE**  To provide continued review in using the 7 steps of problem-solving

**SPECIFIC OBJECTIVE**  To promote discussion on why some good solutions fail