

# **Support of daily living for adults with an intellectual disability**

**Review of the literature prepared for the  
National Advisory Committee on Health and  
Disability to inform its project on services for  
adults with an intellectual disability**

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## **PLAIN LANGUAGE SUMMARY**

### **Introduction**

In the past, many people with an intellectual disability lived in large institutions, often a long way from family and friends. Most countries like New Zealand have now moved people out of these institutions to live in the community in ordinary houses.

Studies have shown that people learn more and are generally happier living in the community. However, for this to happen they need support for their daily living needs, not just moving from an institution to a house. They may also need help to be part of the community and to make friends.

The place where an adult with an intellectual disability lives should be their **home**, not a facility. Too often, the houses people live in have been like small institutions. The individual person has often had little choice in where they live, who lives with them, and what they can do. Other people have assumed that adults with an intellectual disability can not have **homes of their own**, like other people usually do.

### **“Supported living”**

Supported Living is a new way to support people with an intellectual disability, to live their own lives – not simply to fit them into a “residential service”. Supported living looks at each person and helps that person to be supported in the lifestyle that person prefers, in a home they choose to live in.

This report looks at this new type of support, and recent studies and ideas. Institutions are not seen as an acceptable type of service any more. It looks at some of the problems in only providing group homes, where five or six adults with an intellectual disability live together.

### **How have residential services changed over the past 30 to 40 years?**

Up until the 1970s, many adults lived in large hospitals, or institutions. Beginning in the 1980s, some of them started to move out, usually into group homes provided by agencies like IHC. These homes gave them a much better life and they learned lots of new skills. However, not many people moved on to more independent living, into homes of their own. Sometimes they did not get on with the other people they had to live with. Also, group homes often did not help people to become part of their community. They often just had to learn and do things the staff decided, and had little choice or chance to learn to be more independent.

**Supported living**, as a new approach, means that what each person needs and prefers, is looked at carefully. This then leads to planning a service for this individual person. It also means the person has more say in their own life. The new service is about helping people to live good lives, not about just “minding” them.

## **What are the best ideas about supported living and how to make it work?**

Supported living, as a way of providing services, means that what is provided is different for each person, because everyone with an intellectual disability is different.

Studies on supported living talk about the importance of:

- a home of one's own
- having choices, and providing support for these
- how services need to change from the usual "group homes"
- how staff may need to change, and how important staff training is
- smaller rather than bigger homes
- providing support for people to involve them in everything that needs to be done in their home
- staff being committed to people and seeing their work as special and "not just a job".

## **What do studies of adults' own views tell us?**

Adults with an intellectual disability say they want to:

- have more choices about where they live
- do more things for themselves
- have better relationships with their families and the staff who support them
- have more power and control in their own lives
- experience better treatment by some staff
- have good friends.

Studies show that supported living services are more likely to provide the sorts of lives that adults with an intellectual disability want in their own communities.

## **What are the difficulties in providing supported living?**

Present services need to change in these ways:

- the way the service works
- staff roles
- staff values
- how staff work with adults with an intellectual disability
- planning to be based on individuals' strengths and choices
- supports need to be relevant to the person
- to move away from creating more buildings for individual support
- adults with disabilities **must** have a voice in the planning process.

## **What does all this mean for us in New Zealand?**

Have the new ideas about supported living changed services in New Zealand? Studies suggest that lots of overseas services **have not** changed, and this is probably the same in New Zealand. Many of our services still use group homes as the only way to provide support for daily living.

## **What would need to change?**

Supported living is very different to the way we usually provide services. Therefore, lots of changes might be needed. Some of these are:

- the large size and inflexibility of some service providers
- leadership and shared understanding of this new idea and how it needs to work
- government departments and agencies working together more
- staff training
- more involvement of adults with an intellectual disability, and their families
- the way residential support is funded
- more understanding about the **differences** among adults who have an intellectual disability
- changes in public attitudes towards adults with an intellectual disability
- providing a greater range of supports in all areas of a person's life where they need help
- more studies on New Zealand services for adults with an intellectual disability, including studying what Maori and Pacific peoples prefer.



# **CHAPTER ONE**

## **SUPPORT FOR DAILY LIVING FOR ADULTS WITH AN INTELLECTUAL DISABILITY**

### **Introduction**

The past two decades have seen a considerable expansion in the provision of residential services using ordinary housing, for people with an intellectual disability. In the United Kingdom, Scandinavia, North America, Australasia and elsewhere, institution closure policies have been implemented based on a critique of the negative effects of institutional living, and on research which points to the relative advantages of living in the community (Felce 1996). Empirical literature has demonstrated the efficacy and appropriateness of community placement for people with an intellectual disability, including people with the most significant challenges – adaptive behaviour and skills increase and quality of life improves (Spreat and Conroy 2001).

At the time of writing this review, the planned closure of New Zealand's remaining large residential institutions has been announced by the Government, focussing attention once more on the identification and provision of supports for daily living, which enhance the quality of life of people with an intellectual disability when they are living in the community.

### **What is support for daily living?**

Fundamental to service provision and supports in this area is the recognition that a move from an institutional facility to a house is more than just a change of address, and involves more than simply getting the physical support to cope with daily life (Fitzpatrick 1996; O'Brien and O'Brien 1994). Supports for daily living should have as their goal “ordinary patterns of living” and “high resident involvement in the activities of everyday life” (Felce 1996: p 117), with service providers ensuring that people with an intellectual disability not only **have** the opportunities inherent in ordinary housing to lead an ordinary lifestyle, but are also **able to take those opportunities up**. Supports for daily living, then, must also include both personal and social supports needed to experience community presence and participation.

Supports for daily living will include an element of direct teaching of daily living skills which many of us take for granted (eg, household tasks; using money; moving safely about the community). Learning adaptive behaviours such as these, and reducing challenging behaviours, remain important outcomes for adults with an intellectual disability. However a much broader range of lifestyle issues are addressed in the current research on supports for daily living (Stancliffe et al 2000). To reflect this broadened focus, service providers are urged to provide supports which **enhance choice; quality of life; relationships; satisfaction; safety; participation and health**. Taylor (2001), in his review of policy developments in community inclusion in North America, for example, asks some critical questions:

*How can people with developmental disability be supported to participate in the life of the community? How can community services be offered in ways that maximise personal autonomy and choice without jeopardising health and safety? ... What are the characteristics of responsive and effective organisations supporting people with intellectual disabilities and their families? (p 15).*

Other researchers working in this area remind us that community life is multi-faceted, and information is needed on a wide variety of outcomes to inform both public policy and personal decisions about services and living arrangements (Emerson et al 2000; Stancliffe et al 2000).

### **Having a “home”**

The place where one lives, one’s *home*, is an important determinant of one’s quality of life. It can be a reflection of who we are as individuals and family members; of our preferences; personal style; and our priorities in life. A discussion about supports for daily living is best located within the context of the place that is called home, and within the context of the relationships with others which are an integral part of that place.

Residential supports and services, both in New Zealand and elsewhere, have traditionally been based on assumptions that people with an intellectual disability **cannot** have homes of their own. Since the 1980s group homes (or “facilities”) have become established as the typical form of service provision as people have moved out of more restrictive institutional settings. Residential supports have been provided in staffed houses based on the use of domestic housing with developments firmly focused on facility-based services (Felce 1996; Felce and Repp 1992; O’Brien 1994; Van Dam and Cameron-McGill 1995). Group homes have been criticised, however, for their capacity to reinvent themselves as “mini institutions”, where support is interpreted as “care and treatment” of people with an intellectual disability (Howe et al 1998). Within this context, it has been argued that people with an intellectual disability are at risk of being **in** the community, without **actually participating in or being members of** their local community (Allard 1996).

An alternative approach in services and supports in the 1990s has seen a move away from deinstitutionalisation, to community membership and the concept of supported living (Allard 1996; Felce 1996). Supported living is based on a premise that people with disabilities want not just a physical place to live, but a “home” in which there is **a sense of place, a sense of personal control, and a sense of security** (Annison 2000; O’Brien 1994). Providing supported living means supporting people to experience community presence and participation in homes of their own - it is not about services which are facility based, nor does it mean placing people in facilities as vacancies arise (Howe, Horner and Newton 1998).

Supported living requires that service providers think differently about the process of finding homes for people with an intellectual disability, and about the processes of supporting them once they are there. While there are several different ways of thinking about supported living, a common thread running through all discussions is the emphasis on people with an intellectual disability **having choices**, and the

**restructuring of formal residential agencies** to become flexible service providers focussed on meeting individuals' changing support needs. Within this context, person-centred planning involves the person with a disability and those who know him or her well in the active process of shaping a quality life in the community (Becker, Dumas, Houser and Seay 2000; Bradley, Ashbaugh and Blaney 1994; Whitney-Thomas et al 1998).

### **The focus of this literature review**

This review of the literature looks at some of the current trends and issues in support for daily living for people with an intellectual disability. Much of the research reviewed is part of a "second generation" of community living research (Stancliffe, Emerson and Lakin 2000), which seeks to explore and account for variations in quality within community services and to examine the benefits of such services against normative standards. This body of research moves away from earlier research which used institutional environments as a yardstick against which to evaluate community services. The literature concerned with daily living issues for adults with an intellectual disability is extensive, and covers a broad range of topics. It is not possible to cover the full range for the purposes of this review. The review maintains a current focus by reporting on literature from the last decade. An attempt has been made to cover empirical research published during this period, although the review also looks at some important philosophical work which forms the basis for current policy and practice in adult daily living services and supports.

The review is based on an underlying assumption that support for daily living should provide people with an intellectual disability with a high level of involvement in the activities of everyday life (Felce 1996), and make participation in and membership of their local community a reality (Allard 1996). Within this context, it critiques the traditional practice of supporting people with an intellectual disability in group homes, and considers the potential of "supported living" as an alternative approach to realising community membership

Community living and support services covers a very wide area "from the personal to the political" (Stancliffe et al 2001) and this review cannot address all of these. The reader is referred to other related literature reviews written as part of the present contract between the Donald Beasley Institute and the National Health Committee, which also address issues relevant to the topic of support for daily living. In particular, the review on "Community participation for adults with an intellectual disability" provides a detailed explanation and analysis of the concepts of community and community participation. The reviews on "Education for adults with an intellectual disability" and "Work for adults with an intellectual disability" address two aspects of adult life which contribute to a meaningful and purposeful day. The review on "Relationships for adults with an intellectual disability" looks at the relationships with family, friends, and others which are critical to a well supported and quality adult life in the community.

This review focuses primarily on supports provided to adults with an intellectual disability in the place where they live, the place they call home, and on the

relationships with other community environments which contribute to a person's experience of home life.

The review attempts to answer the following questions:

- What types of support might people with an intellectual disability need in daily living?
- What do we know about the views and preferences of adults with disabilities in relation to support for daily living?
- How can daily living supports meet the preferences and needs of a diverse group of people with an intellectual disability (including people with very high needs for support)?
- What do we know about current best practice in daily living support?
- What barriers are there to support services achieving best practice in support for daily living?
- What are the implications for disability support services and generic services in New Zealand?

## CHAPTER TWO

### SUPPORTS FOR DAILY LIVING: TRENDS AND CHANGES IN SERVICE DELIVERY MODELS

It is important to have some understanding of the historical context in which ideas about daily living support have evolved. Ideas about what constitutes “supports for daily living” will vary, in response to changing perspectives on what “community living” means for people with an intellectual disability.

The 1992 AAMR definition of mental retardation, with its increased specification of adaptive skills, the primacy of the environment, and focus on individual supports (see the related literature review on “Definitions of intellectual disability”) has significant implications and challenges for service delivery systems. Trends in the field of intellectual disability have transformed the vision of what constitutes the life possibilities for people with an intellectual disability. Services have been challenged to respond to emphases on “strengths and capabilities; the importance of normalised or typical environments; the provision of age-appropriate services; individualised needs for supports; and the possibilities for enhancing adaptive functioning, and empowerment” (Luckasson et al 1992: p 135).

#### **The normalisation principle and a change in thinking**

These trends have resulted in the evolution of a “new service paradigm” (Bradley 1994). From the early 1980s, the movement to increase the inclusion of people with disabilities in the community has been hastened by a deeper understanding of the ideal of community integration and its link to the concept of normalisation. First articulated in Scandinavia by Bank-Mikkleson and Nirje, ideas about normalisation were introduced to North America by Gunnar Dybwad and Wolf Wolfensberger (Bradley 1994). Nirje (1980) stated that all people should be able to participate in the normal rhythms and routines of the human life cycle: they should be able to participate in daily events such as cooking, going to work, shopping; in annual rhythms such as wearing different clothes in winter and summer; and in the normal life cycle by doing things appropriate to their chronological age. Normalisation is also concerned with:

*... freedom of choice: the right to make decisions about what you eat, where you live, what type of job you do, and so on. It is argued that service provision should take into account the principle that all people have the right to develop and achieve to the best of their abilities (Gething 1997: p 23).*

While community integration was seen as one of the major means for achieving acceptance and accomplishing adaptive behaviour change for people with an intellectual disability, Wolfensberger (1972), in his formulation of normalisation, distinguished between physical and social community integration. He warned that physical integration alone was not sufficient to guarantee social integration. Yet until the late 1980s, services and supports aimed at community integration have not always attended to this idea:

*...the (intellectual disability) field has focussed first on physical integration and is only now learning Wolfensberger's lesson that integration is more than just the opposite of segregation. People can be desegregated and be as isolated and as out of the mainstream as they were in their segregated settings, even though they may be living, working, or attending school in the community. Being **in** the community is not necessarily being **a part of** the community (Bradley 1994: p 12).*

The experience of segregation in the community has been borne out in the research. While the move from institutional to community living for people with an intellectual disability carried the expectation of access to more normative settings and experiences:

*...there is evidence that inadequate support from staff and low activity, at least among people with severe retardation, are enduring problems, even in decent home-like environments with high staffing levels and apparent adherence to contemporary service philosophies (Jones, Felce et al 2001: p 345).*

Bradley (1994) charts the changes in thinking which have provided the rationale for practice in the intellectual disability field over the last four decades. The era of **institutionalisation, dependence and segregation** which ended in the 1970s was governed by norms which were primarily medical. Intellectual disability was equated with sickness, and separate services were developed to provide care and protection.

The **developmental model** of the 1970s linked the experience of disability with opportunities and environments which foster learning and development. It resulted in a critique of the inadequacies of institutional living, and ushered in the era of deinstitutionalisation and community integration. Group homes and sheltered workshops were physically integrated in the community, but the emphasis remained on the provision of **specialised services in segregated settings**. An emphasis on "training" in these settings, including at home, also meant that adults with an intellectual disability lived their lives surrounded by professionals who were paid to be there (Bradley 1994; Snow 1989).

The recognition that deinstitutionalisation should be more than just a change of address (Bradley 1996; O'Brien and O'Brien 1994), has led to a new set of assumptions about how services should support daily living. This set of assumptions "acknowledges that people with intellectual disabilities are capable of making choices about their own lives, respects their rights to do so, and focuses on individualized supports and empowerment" (Bradley 1996: p xi).

## **Moving beyond the residential continuum model**

Following the process of deinstitutionalisation, residential support services have traditionally been based on a "continuum of services" model in which a person might move from more restrictive services (eg, an institution) to less restrictive services (ultimately, one's own home). While a range of residential services now exist in New Zealand for people with an intellectual disability, **group homes** (in which several

people with an intellectual disability live together in a house with a paid staff person) have emerged as the typical place in which supports for daily living are based.

The “residential continuum model” which has supported the development and maintenance of the group home concept, is based on the concept of the “Least Restrictive Environment” (LRE). This term has its origins in North America and is not often used in New Zealand, however the idea that some form of restriction is necessary for people with an intellectual disability is common in both residential (Brook 1999) and education (Ballard 1996) settings in this country. Taylor (2001) argues that **the LRE concept is fundamentally flawed as a conceptual framework for the design of support services for people with intellectual disabilities**. He suggests that an appreciation of the limitations of the LRE and continuum model is important if service providers are to design services and supports which are truly community inclusive.

Emerging in the 1960s as a conceptual framework for a continuum of placements for children with disabilities in education, the Least Restrictive Environment has been used to describe a continuum of residential placements from most restrictive (public institutions) through to least restrictive (homes in ordinary neighbourhoods). Taylor describes four of the LRE’s most serious flaws as follows:

1. **The LRE continuum confuses segregation, on the one hand, with intensity of services, on the other.** The continuum concept equates segregation with the most intensive services, and community integration with the least intensive services, yet historical evidence shows the most segregated settings provide the **least intensive** services. Segregation and integration on the one hand and intensity of services on the other should be seen as separate dimensions. Any health-related, educational, or habilitative service that can theoretically be provided in a segregated setting can be provided in an integrated setting. The debate over institutions versus the community is not, he suggests, a debate over whether some people require intensive services and supports. It is a debate over whether some people must forfeit their place in the community in order to receive services.
2. **The LRE continuum sanctions infringements on human rights.** The LRE could be seen as a seductive concept in that it suggests that governments should act in a manner that “least restricts” the rights and liberties of individuals. However, the LRE principle can equally be seen to be **sanctioning** infringements, because it implies that the question is not **whether** the rights of people with an intellectual disability should be restricted, but **to what extent**.
3. **The LRE continuum is based on a “readiness” model.** Inherent in the continuum concept is the idea that people with an intellectual disability must prove themselves to be “ready” to move on to a less restrictive, more community integrated residential setting. In reality people do not move smoothly through the continuum, and even if they did, the series of starts and stops inherent in such a model would destroy any sense of “home”.

4. **The LRE continuum directs attention to the physical settings rather than to the services and supports people need to live successfully in the community.** A major criticism of support services in the intellectual disability field is that the response to identified support needs is often to build a building:

*The LRE continuum emphasises facilities and physical environments. Services are confused with bricks and mortar. As a consequence, “independent living” – the “least restrictive” step in the continuum has often been associated with minimal services, even neglect. Instead of focusing on buildings and facilities, we should be working to make sure that supports are sufficient to enable people with developmental disability to live in ordinary homes, neighbourhoods, and communities. New approaches such as supported living are designed to accomplish this (Taylor 2001: p 21, emphasis added).*

An emphasis on physical environments has led to a preoccupation in the literature and amongst service providers with **size** of residential facilities, when it is self-evident that smaller settings will have the potential to provide more personalised care. Taylor also points out that the research already shows that smaller units (1-5 people) have a significant impact on self-determination and opportunities for privacy. Unfortunately, this preoccupation with size has taken attention away from “the need to support people with developmental disability in **ordinary homes** as opposed to “home-like” facilities” (Taylor 2001: p 21).

It is important to remember that the continuum model was developed at a time when people with an intellectual disability and their families were offered segregation or nothing at all. The continuum was used to create opportunities for community integration where few existed. The discussion to this point suggests that the context today is quite different. Current concerns are for daily living services and supports which promote not just community presence but, more importantly, **community membership and participation**. This idea has important implications for the design, location, operation and ownership of homes for adults with an intellectual disability.

## Moving beyond group homes

Group homes were originally thought of as being one step in this continuum of services, a midpoint between living in an institution and full community integration (including social integration) and independence (Carnaby 1998; Howe et al 1998; O'Brien 1994; Van Dam and Cameron-McGill 1995). Group homes have traditionally focused on “care and treatment” of people with an intellectual disability. While they were originally designed to teach people skills that would result in their moving on to the next “less restrictive” setting, this continuum concept appears to have failed people with an intellectual disability (Howe et al 1998).

Van Dam and Cameron-McGill (1995) have argued for a shift beyond group homes because the reality has been that most people moving into group homes have remained there. Brook (1999) agrees that in New Zealand the group home has become an end-point, not a step in a continuum to less restrictive residential environments for many people with an intellectual disability. In Australia, Van Dam and Cameron-

McGill suggest, the group home has been perceived as the “only possible living arrangement for people with an intellectual disability who require ongoing support” (p 7), despite their inherent problems. The promise of new and supportive community relationships has not always been realised, either. While the term “community” has been used to evoke warm emotive overtones, the reality is that the community has not been uniformly welcoming to people who are vulnerable (Carnaby 1998). The move from an institution to a smaller group home in the community has not always meant that people have become truly a part of their community. Loneliness and relative isolation from neighbours and others remain issues for many people with an intellectual disability both in New Zealand (Brook 1999) and elsewhere (Marquis and Jackson 2000).

Group homes have been criticised on a number of counts. Such criticism does not rule out four or five people with a disability living together **if this is an arrangement which suits those people**. However, problems may arise where service systems **only** allow this option, and do not cater to the needs and wishes of people who want other living arrangements (Allard 1996; Van Dam and Cameron-McGill 1995). A common concern is incompatibility:

*People are expected to live for many years with three or more people to whom they are not related and with whom they might have nothing in common other than their disability. They are expected to cope and behave ‘appropriately’ in this living situation no matter what differences and falling out they may have with the other people living there (Van Dam and Cameron-McGill 1995: p 7).*

While legislation and policy might emphasise choice and individualised planning, Brown (1994) suggests that people in group homes are likely to find it very difficult to move between living settings or agencies without causing major administrative problems:

*Small is not beautiful if it means that you cannot ever move on or move back... The rigidity of housing provision for people with intellectual disabilities means that relationships and gender are not taken into account as a dimension of decisions about groupings or about facilities... Within group homes people with learning disabilities may have to continue to live with someone when they would prefer not to and be prevented from moving in with someone else when they do... (p 140).*

Group homes have also been criticised for placing limits on personal development. Questions have been raised about the practice of group homes in which people were not offered any real control of their daily lives (Lord and Pedler 1991). Van Dam and Cameron-McGill (1995) suggest that their rigid structure and focus on group needs means that individuals may not be able to pursue their own interests (including coming and going as one pleases, cooking one's own meal, pursuing one's own leisure interests). Individuals may find it difficult to make their own decisions, and staff and the service itself may exert excessive control over the lives of individuals. Residents who are unhappy with their living arrangements may have no way of changing them, and may express their discontent in ways which others interpret as behaviour problems:

*A service system where the group home is the only available living option maintains the features of institutional practice... (it) still congregates people rather than paying attention to them as individuals and an effect of this congregation is that people are still segregated because service practices such as rigid routines inhibit individual involvement in the community (Van Dam and Cameron-McGill 1995: p 9).*

Concerns have also been raised about the limited extent to which people living in group homes have experienced supportive social relationships. Friendships between people with disabilities outside of family or human service workers remain limited and contact with the general public remains at a superficial level (Emerson and Hatton 1996; Perry and Felce 1995). While there are increasing numbers of friendships and relationships between people with disabilities and other non-related people in the community (Amado 1993; Meyer et al 1998) many people with an intellectual disability in the community report that service workers provide their most frequent and enduring contacts and access to other relationships thus impacting on one's sense of self (Schalock and Genung 1992 cited in Marquis and Jackson 2000).

### **Changing from facilities to supports: An alternative model for daily living support**

Taylor (2001) argues that the LRE continuum model has no place in current thinking about daily living support. The assumption that there should be a range of service options which vary in integration and opportunities for independence (or restrictiveness, self-determination and so on), and that severity of disability will determine a person's living situation should be challenged. If they are not, then approaches such as supported living, home ownership, self-directed supports, and individualised funding will simply become new slots at the least restrictive end of the continuum, and adults with an intellectual disability will continue to be denied the ability to take control of their own lives. Taylor suggests that this is not the way ahead, and that "What is needed are not new slots, but changes in how services and supports are conceptualised" (p 29).

The experience of "community living" between the 1970s and 1990s shows that the slavish focus on professional services and specialised "programmes" for people with an intellectual disability has been to the exclusion of supports that enhance social presence and relationships. Bradley (1994) suggests that "surrounding people with professionals inadvertently isolates them from friends, family and community" (p 20) and that the focus in adult services needs to change. In response, the 1990s have seen the emergence of a new era of community membership, marked by a focus on functional supports to enhance inclusion and quality of life as defined by **both physical and social** inclusion.

Families today have benefited from a state provided education for their children, many of whom have attended ordinary classes in their local school (although some segregated special classes, units, and schools continue to exist in some parts of New Zealand). Few families who have supported their children to participate in the community want to see their sons and daughters as adults moving into residential and other settings (such as vocational and leisure "facilities") which separate them from

their local community. Within this context, Bradley (1994) supports Taylor's (2001) view that a reconceptualisation of services and supports for daily living involves a fundamental change in thinking:

*Instead of thinking about how to surround people with services in specially designed and constructed homes, the movement should be toward moving support to where people live. Instead of concentrating on how to make the individual adapt to the environment, ways of adapting the environment and supports to the individual should be explored. The concept of functional supports offers an alternative to the continuum of services and the obsession with programme slots. Rather than focussing on putting people into community programs, this developing focus emphasises creating a network of formal and informal supports that a person with a disability needs to meet day-to-day demands (Taylor 2001: p 20).*

Borrowing from the work of Taylor, Racino, Knoll and Lutfiyya (1987), Bradley (1994) describes the keystones of this new model of daily living support as “commitment to community and families; human relationships; functional programming and individualization; and flexibility and individualized supports” (p 23). Bradley (1996) cites work by Bradley and Knoll (1995) which identifies four major attributes of this new way of thinking about services:

- **The primacy of the community** - the belief that people with an intellectual disability can and should live in the community as full participating members. The role of service providers is to remove barriers to full participation.
- **Emphasis on relationships** - People with disabilities have the same needs for social relationships as any other person. Service providers need to ensure that people make social connections and become fully integrated into the life of the community. Supporting social relationships ensures that people with disabilities will have natural supports in their communities.
- **Person-centred supports** - Rather than fitting people into existing programme “slots” the emphasis in services should be on designing supports to respond to the unique situation of each person in their community. This means living in a home, not a programme, and working in a job, not a vocational facility. Programme planning should include the person with a disability, family, friends, service providers, and advocates.
- **Choice and control** - Rather than assuming that professionals know best, the right of the person with a disability to make choices is paramount. This means being able to make choices about where and with whom one lives, how one spends one's time, and how one wants one's supports configured. The task for service providers is to assist people with disabilities to make informed choices and to ensure that meaningful choices are available.

## **Summary**

Significant changes in thinking have occurred in relation to supports for daily living. Following the period of institutionalisation prior to the 1970s, the developmental model linked the experience of disability with opportunities and environments which foster learning and development. Group homes in the community were established, and services emphasised the importance of “training” in these settings. The lives of people with disabilities were dominated by professionals who made decisions about what individuals needed to learn.

A new paradigm or way of thinking in services is based on assumptions that people with an intellectual disability are capable of making choices about their lives, and respects this right to do so. The role of service providers is to plan with the person and to focus on individualised supports and empowerment. This approach assumes that all people can be supported in the community, and rejects the principle of the “Least Restrictive Environment” in designing support services.

Past efforts have seen an emphasis on supports as home-like “facilities” rather than supporting people in ordinary homes. This has resulted in the proliferation of group homes in New Zealand and elsewhere. Group homes have been widely criticised on a number of counts: they traditionally focus on care and treatment rather than empowerment and self-determination for people with disabilities; they have become an end-point rather than a step towards less restrictive residential options; and people with disabilities have failed to experience the relationships with others which mark community membership. Incompatibility has become a common problem for residents and opportunities for personal growth and development have been limited.

More recent concerns are for daily living supports which promote not just community presence, but also community membership and participation – a concern that people are not just “in” the community, but are also members “of” the community. A change from “facilities” to individualised planning and supports is advocated in the literature of the 1990s. Rather than building specially designed homes for which individuals must adapt, the focus is on adapting the environment and supports to the individual. Both formal and informal supports are advocated, along with a commitment to individuals, their families and the community.

## CHAPTER THREE

### WHAT TYPES OF SUPPORT MIGHT PEOPLE WITH AN INTELLECTUAL DISABILITY NEED FOR DAILY LIVING?

This review is concerned with **the nature of supports and the related models of service delivery** needed to meet the goals of community membership and a meaningful life for adults with an intellectual disability in residential settings. The types of support provided to adults in their home will depend upon how service providers think about “community membership” and “home life”. Current thinking in daily living supports, sees a move away from the idea of supporting people in “residential services” to providing personalised supports to people in the place in which they feel “at home”. This chapter considers some of the areas of a person’s life in which support may be needed, then looks at personalised, individual planning which is the cornerstone of a person-centred approach to designing supports for daily living. It focuses particularly on **supported living** as a current approach which uses flexible and individualised supports in an attempt to overcome some of the limitations of group homes.

#### A citizen perspective in support systems

In line with current thinking about the nature of supports, Ericsson (1996) advocates a move away from the model of housing whereby a house has a primarily educational/developmental focus with opportunities for “training” people with an intellectual disability. A person’s house should instead be viewed as a “home”, with the focus on possessions, social relations, and emotional security (Ericsson 1996). This alternative model for housing supports a “citizen” perspective on people with disabilities, as opposed to the “competence perspective” associated with houses as training grounds.

Thinking about the role in which people with disabilities are cast raises important issues for service providers. A “competence” perspective casts people with disabilities in the role of a pupil or patient, with an emphasis on support or education and care. Seen in this way, **preparation of individuals for participation in society** becomes the goal of support services. Allard (1996) argues that some types of person centred planning perpetuate this notion that professionals must “cure or fix” people with disabilities before they are ready to live the kind of life they want to live.

In sharp contrast, the “citizen” perspective views people with disabilities as having the same rights and obligations as other citizens, including the right to live and receive support **in** the community. An important concern is the person’s influence over their own life, and the basis of service provision is **the person’s own idea of what is a good life**. Supports and services on individual terms are needed, and Ericsson (1996) suggests that if a person’s **own wishes** are the starting point, the premises and environments of the service organisations are not likely to be where they will choose to live.

What constitutes “a good life” and “supports and services on individual terms” will depend on the experiences, needs, and background of the individual person. It will be

culturally determined. In New Zealand, this means recognising at the outset the different concepts of disability held by Maori. It also means supporting the development and management of kaupapa Tangata Whenua initiatives and services so that Maori “have the dignity of choice between mainstream or kaupapa Tangata Whenua services to support people with disabilities and their whanau” (Kingi and Bray 2000: p 26). A priority also needs to be placed on understanding how other ethnic groups talk about disability. Huakau and Bray (2000), for example, emphasise that the Pacific concept of family based care needs to be upheld and that disability services must “...communicate with disabled Pacific people and their families on an individual level, so that the family as well as the individual person's needs are identified” (p 49). To be effective, they suggest, “...disability services need to recognise what is appropriate for Pacific people in terms of support, communication, and education... the responsibility for support for Pacific family members must be located in the Pacific community as well as disability services so that these issues can be worked through in a safe and supportive environment” (p 49).

### **Supports to be a member of the community and to have relationships**

Supports for daily living need to respond to current concerns that adults with an intellectual disability can still be segregated while living “in” the community (Bradley 1994, 1996; Brook 1999; Marquis and Jackson 2000; Van-Dam and Cameron-McGill 1995; Wolfensberger 1972). People's homes are located within communities. In order to understand the meaning of “home” it is important to also consider the wider community context in which adults with an intellectual disability reside.

The reader is referred to a more detailed discussion of the notion of “community” in the associated literature review on “Community participation for adults with an intellectual disability” (in particular the section entitled “What is community participation?”). For the purposes of this review, a multifaceted definition of community is used in recognition of the multi-faceted nature of community life. It is useful to think of the community as a geographical place which includes the ordinary and varied activities of other citizens. The “community” may also include sub communities and “communities of interest”. “Community” should not be narrowly viewed as a location which is not an institution (Walker 1999). McKnight (1988) also points out that in defining “community” it is important to distinguish between community institutions (eg, large structures such as government health systems and social service agencies) and community associations (family, friends, neighbours, and also local associations, churches and civic groups).

Many definitions of community involve the three interrelated concepts of **“place, people, and a sense of membership or belonging”** (Walker 1999). This three-part model suggests that benchmark questions about community participation, then, might include the following:

- Do adults with an intellectual disability have a “sense of place” in the community and indeed in their own home (a sense that this is “my home”)?
- Are they involved in a variety of social networks (including networks which make one's house a home)?

- Do they feel a sense of membership or belonging to a community or communities (and does their home reflect the activities, relationships and possessions which mark this membership)?

Service providers may be some way from meeting this definition of community participation for people using residential services. Studies which compare the experiences of people with an intellectual disability with those who do not have disabilities show that people with an intellectual disability are disadvantaged when it comes to community participation and developing social networks (Marquis and Jackson 2000; Myers et al 1998). On the whole, people with an intellectual disability, including those who have always lived in the community, have a “distinct social space”. They live and work with other people with an intellectual disability, have few non-disabled friends, and experience only brief, superficial contact with others (Myers et al 1998; Walker 1999). Walker’s (1999) interviews with three men and four women with an intellectual disability between the ages of 24 and 60 reflected very limited positive experiences associated with a sense of place in the community. People commonly spent time in places designated for people with disabilities rather than for the public; in public rather than private places; and in places which involved business transactions rather than social interactions.

While most people in the community have natural supports evolving out of friendships with others, people who have been in the service system for years frequently have lost those supports to professional intervention (Bradley 1994; Marquis and Jackson 2000). A commitment to physical presence in the community, then, needs to be accompanied by “tangible social connections in the community. Being part of the community means that individuals have enduring relationships with people other than those paid to be with them” (Bradley 1994: p 23). Friendships and close relationships with family can bring with them natural systems of support which can complement and sometimes replace formal supports.

Staff working in support services may find it challenging to think of ways to support friendship development, yet this is an area which should not be ignored. Loneliness and a lack of friendships and supportive relationships have been associated with both mental and physical health problems in children with disabilities (Pavri 2001; Wolke 2001), and negative social experiences at school can have a lasting impact into adulthood (Ballard and McDonald 1999). Supporting friendship development and the development of other supportive relationships needs to become a matter of priority in planning for children with disabilities in early childhood, primary and secondary schools (Meyer et al 1998; MacArthur and Gaffney 2001), as well as in the daily lives of adults (Traustadottir 1994). The reader is referred to the related literature review on “Relationships for adults with an intellectual disability” for a more detailed discussion of this topic.

A key element in current models of support is a **commitment to the community as the place where people should live and have a right to live** (Bradley 1994). It is the task of support staff to help remove barriers that prevent community participation. Services under this model are not labelled as “community-based”, because there is no alternative to the community. Bradley also stresses that a commitment to community means **providing support to people with disabilities in their families**. In the same way that removing people from their home communities to specialised services

disrupts natural supports, removing people from their families “ignores the commitment of the family, disrupts family connections, and deprives the child (and adult) of the experience of growing and developing in a family unit” (p 23).

## Support to have a home

The term “home” has been frequently misused and misapplied to a wide range of residential settings for people with an intellectual disability over many years. Yet it is essential that stakeholders in residential services do have a clear understanding of what constitutes a “home” if supports involve the development of genuine homes for the people they serve:

*...Accommodation for people with intellectual disabilities is one of the most significant areas of service provision in terms of overall government budgets, legislative and regulatory direction, and the number of staff employed. At a more fundamental level, the creation and experience of home is an important contributor to a person's humanity and their positive social perception by others (Annison 2000: p 251).*

Typically many adults with an intellectual disability “eat the bread of others and know only the way that goes up and down stairs that are never their own” (O'Brien 1994: p 1). They either live in their parents' home, or:

*... they occupy a bed in a place established to offer supervision and treatment. In most instances, opportunities to hold one's own lease require the ability to succeed with minimal assistance. Problems usually send a person with a lifelong disability down the steps of the service continuum to a bed in a more restrictive facility (p 1).*

Annison (2000), in his review of the intellectual disability, architecture and environmental psychology literature, describes home as a “**multi-faceted concept.**” He concludes that no single element makes a place a “home” (p 251), but if any **one** of these essential elements is missing, there is potential to turn a home into a “non-home”. In providing genuine homes, and evaluating homes for people with an intellectual disability, then, service providers need to ensure that their approach is also multi-faceted. Annison groups the attributes of “home” identified in the literature according to their contribution to meeting people's basic needs:

- Attributes of “home” which meet people's fundamental needs (needs for food, water, warmth/shelter):
  - suitable physical/material structures and environment for the individual's purposes
  - safety - ensuring a safe environment
  - extent of services seen as a necessary part of home
  - spatiality - adequate room for essential activities and their separation
  - centre of fundamental activities such as sleeping and eating

- Attributes of “home” which meet people's intermediate needs (needs for safety, security, affection/love, belongingness, social acceptance and self-esteem):
  - emotional environment - place where there is love and affection
  - happiness - the experience of happy events and general feelings of happiness, positive atmosphere
  - relationships - type and positive quality of relationships and the ability to control them and exercise choice over who one lives with
  - friends and entertainment - people visiting, the social core of the home, the opportunity and ability to offer hospitality
  - belonging - comfort, relaxation, and familiarity contribute to this
  - knowledge - familiarity with the physical and social environment of the home
  - permanence - the continuity of the home
  - meaningful places - because of specific events which took place there
  - privacy - being able to have the level of privacy desired and freedom to do what one desires
  - security and control - sense of security, control of the area- who enters and what they do or where they go, ability to create a refuge for oneself, choice of what is done and when it's done
  - reflection of one's ideas and values - view of self and others' view of self, indicator of personal status, recognition in socially valued roles, personalisation of the home
- Attributes of home which meet people's growth needs (needs for creativity and self-actualisation, justice, goodness, beauty, order, unity):
  - responsibility for the home, including homemaking tasks, home improvement tasks, and home ownership or tenancy
  - self expression - behaviour in and manipulation of the place; acting upon and modifying dwelling; opportunities for self-expression and development; choice of, and opportunities for new and different activities
  - critical experiences - related to growth and development of the individual
  - time perspective - relating the self to the past, present and future via home preference to return - as an ordering point in space
  - architectural and decorative style - appeal to the individual's sense of the aesthetic
  - choice of dwelling
  - work environment -working at home

Annison does note, however, that much of the research informing this understanding of “home” involves people without disabilities, and that many people with an intellectual disability have a range of additional and different needs for support which might impact upon their own experience of “home”. He suggests, then, that:

*...further research is required to identify and describe the manner in which people who have an intellectual disability experience and conceptualise home, or indeed, whether the concept is meaningful or useful to them, and, if so, in what ways. There is also a need to develop valid, reliable and efficient*

*instruments to measure the presence of home in residential service settings and if not, the extent to which those various attributes considered essential to transform a residential service setting into a home are present (p 261).*

Notions about what constitutes a home are also intensely personal, an extension of the individual's personality, and a reflection of their history and experiences. Above all, it is a place to be comfortable, free and secure (Mansell and Ericsson 1996). Bennett (2001), for example describes home as:

*... more than a house. Home is like a pair of jeans that time and body heat have tailored into a second skin. At the points where you bulge the jeans have faded. When you take them off they relinquish their shape slowly... They would fit no-one else. And the same is true of a home... I bought my first house at 30... I can remember standing in the hall of that ramshackle house and thinking that for the first time in my life I could kick a hole in the wall and not have to explain the damage. It felt strangely like freedom... I am comfortable in this house. Its parts have arranged themselves to suit me ... Home tells the truth of me... Home is self and self is imperfect. Home has fingermarks about the light switches, and in the cupboards lies the junk of dead dreams - the exercise machine, the books of self improvement, the forgotten enthusiasms. What makes a house a home is not the stencilled wallpaper or the macrameed plant holders, or the Belgian blinds, but the passage of time. It moulds the occupant and the building into one... Home is more than a building. Home is an extension of the self, the occupant's unique and thoughtless signature on a scrap of land.*

These ideas about what makes a home may challenge some service providers and staff, to re-evaluate the benchmarks currently used to determine and evaluate residential supports for the people with an intellectual disability they serve.

### **Support to develop as an adult and to learn skills**

People with an intellectual disability, like others, need opportunities to develop as adults and to learn skills which will support their lives as autonomous, self-determining, independent and interdependent community members. The disability literature contains numerous examples of approaches to teaching functional skills which will enhance people's daily lives (eg, Wyer and Halliman 1994). These range from practical skills such as cooking and shopping (eg, Giere, Rudrud and McKay 1989; Schloss et al 1996) through to personal skills such as those which enhance and make safe people's sexual life (eg, Johnson, Hillier, Harrison and Frawley 2001); those which promote communication and supportive social relationships with others (eg, McDonald 2000); and those which protect people from abuse (eg, Sobsey 1994). Other literature reviews in this series address skills acquisition in some of these areas.

It is not the purpose of this review to cover this wide ranging material although it is important to stress that there is a large body of literature which shows that adults with an intellectual disability, including those who have multiple and challenging disabilities, can learn skills which will enhance their autonomy, independence, and ultimately their life in the community. This literature is based on an understanding of

adults with an intellectual disability as competent people, and has direct implications for support staff in relation to planning for daily living and supporting the development of individual skills and competencies.

Bradley (1994) advocates a functional approach when determining individualised learning goals for adults with disabilities:

*The demands of an agency or the nature of a program should not dictate the individualized goals for people with disabilities. A functional approach concentrates on developing the skills that are required by the demands of each individual's life situation. The interdependence of housemates or workmates and the demands of each individual's daily routine dictate the components of his or her functional program (p 24).*

A functional approach to assessment and learning tries to understand how adaptations can be made to assist a person to gain control over their everyday life. Adaptations may be mechanical (such as a communication device) or may involve the support of another adult. A functional approach “should assess the necessity of acquiring skills against the roles that these skills will play in enhancing community presence and integration” (*ibid*). Klein (1992) describes the overemphasis on “programming” in people’s homes during the 1970s and 1980s when people with an intellectual disability were perceived as having deficits requiring remediation through the teaching of a wide range of ‘skills’. “Useless programming” (p 305) meant that in people’s ‘homes’:

*...we attempted to find things that people did not know or needed to improve upon... people became “subjects” in an experiment we called ‘active treatment’ ... most of the time the programming was based not on what people wanted or desired, but on what was required or desired by others... as we begin to support people to live in their own homes we must focus on their abilities and uniqueness... offer assistance to people to meet their personal goals for a positive future, rather than programming for useless tasks that contribute little to a meaningful life (p 306).*

Meyer (2001) reiterates this point, emphasising that it is pointless teaching skills which will make little difference in the person’s life. Careful decisions need to be made about priorities for change in an individual’s repertoire. The research literature has focussed almost exclusively on teaching skills to children and adults with disabilities, and has paid little attention to the social or cultural barriers that disabled children and adults face every day (Davis and Watson 2001; Meyer 2001). The individual’s physical and social environments (eg, social interactions initiated by staff and others; the person’s “home” environment) should also become the focus for change. Staff can, for example, be taught to interact with adults in ways which support communication development (McDonald 1997), and structure home environments so they offer multiple opportunities to learn and use new skills (Heller et al 2000).

In the area of behaviour challenges, a functional approach is concerned with the “full context of an individual’s life” rather than a narrow behavioural focus on antecedents (what happened before) and consequences (what happened afterwards). It takes into

consideration the broader context in which the challenging behaviour arises, and considers the communicative function that behaviour might serve for that person. Staff working with people with challenging behaviours need to be particularly alert and sensitive to individuals' attempts at communication (McDonald 1997). Staff also need to think about ways to teach new, adaptive functional skills that satisfy the same need as the problem behaviour, while also serving a real purpose in daily life (Bradley 1994).

### **Support through individualised, person-centred planning**

Individualised planning is a critical part of functional programming, bringing together all of the people needed in a cooperative team to develop a plan of action which will contribute to the person's future quality of life, including family and friends. The planning process identifies what is important to the person with a disability, how that person wants to live, and what needs to be done to help the person move towards that life (Bradley, Ashbaugh and Blaney 1994). Whitney-Thomas, Shaw, Honey and Butterworth (1998) emphasise that in order to be "person-centred" the focus person needs to drive the process. Ways need to be found to ensure that the process adheres to the person's needs in terms of style, structure and meaningfulness of the planning process.

Proponents of individualised or person-centred planning assume that individuals with disabilities have the ability to make and express choices, and the focus is therefore on the preferences, talents, and dreams of the individual (Whitney-Thomas et al 1998). This is an assumption which differs from the more traditional, deficit-focused medical model that has driven traditional human services in the past, and it is important that the service system does not restrict the choices and options available to the individual. The planning approach requires both formal and informal support systems and resources (Whitney-Thomas et al 1998). The cornerstone of person-centred planning is the development of *new* services and supports to reach identified goals, as opposed to planning on the basis of existing resources and services (Becker et al 2000). Planning meetings include the person with a disability, friends, family and those who provide support, working together to achieve desired future goals (Becker et al 2000). However, Whitney-Thomas et al (1998) stress that the process is about more than meetings:

*...it is an ongoing process of social change. The effectiveness of a plan depends on a support group of concerned people who make a plan a reality by learning to solve problems, build community, and change organisations over time. These planning processes typically take place separately from formal educational or adult service plans but provide direction to those planning processes (p 119).*

A variety of person-centred models have been developed and are described in the literature (eg, lifestyle planning; life plans; whole life planning; future planning; person-centred planning), and a range of materials are widely available to guide staff in planning for the future learning and development of the people they support (Greasley 1995). Such approaches to planning provide:

*“...a useful framework for facilitating discussions about present and future needs, skills and opportunities, and personal interests and wishes. The extent to which this is achieved will depend on the quality of the design and the values underlying the approach to individual planning (Greasley 1995: p 360).*

Individualised planning should reflect and respond to the person's individual circumstances, including the transition periods which mark adult development. Planning for adults in later life, for example, can reflect the changing focus of later life experiences, and allow older adults to make their own decisions about work, leisure, or some combination of the two (Heller, Miller, Hsieh and Sterns 2000; Mahon and Goatcher 1999). At the other end of the adult lifespan, planning can focus on “building a future” as young people make the transition from school to adult life (Whitney-Thomas, Shaw, Honey and Butterworth 1998).

Malette et al (1992) report that individualised planning has been used successfully with a range of people with disabilities, including people with multiple and challenging needs. However there appears to be a limited amount of empirical research which evaluates services' use of such approaches.

The actual implementation of lifestyle planning approaches by service delivery agencies, was evaluated by Becker et al (2000). Twelve staff members from three service provider agencies were interviewed about the implementation of “Essential Lifestyle Planning”, a form of person-centred planning. The three services responded in different ways to the implementation process. One service believed the approach had helped their service to move in the direction it wanted to go in, and made the most progress in meeting the goals of the study. A second service became enthusiastic about the process once the potential benefits to the people they worked for became clear. A third service felt overwhelmed by the process and unable to deal with the required changes in service provision.

The study highlights essential areas of staff support needed for effective change in services moving towards individualised planning and supports. Ongoing staff training, more time to plan, and technical assistance, particularly in the area of individual budgeting, were highly valued by staff. Several staff wanted written guidelines for handling funding for individuals with an intellectual disability, and some suggested that staff may need to build up their skills for making community contacts. Staff support for the process, particularly at the management level, was seen as critical to the success of person-centred planning. While this study focused on staff developing person-centred plans for daily living, it did not focus on the implementation of those plans. The authors point out that “...staff members may find it easier to identify supports than to actually make things happen for individuals and their families” (p 393). To determine whether person-centred planning processes do make a positive change to the lives of people with an intellectual disability, studies are needed in which individuals with disabilities themselves, their families and friends are asked to describe the long-term impact of person-centred planning on people's daily lives (Becker et al 2000; Heller et al 2000).

Through a series of four case studies (two adults and two children), Malette et al (1992) followed the development and implementation of the “Lifestyle Development Process” (p 180), a form of lifestyle planning. The process moved through an initial

planning stage, assessing and remediating barriers to participation in community settings; assembling meaningful routines and schedules (developing daily and weekly schedules that included goals and objectives related to where the person would live, work, go to school, and spend leisure time); developing specific intervention strategies; and evaluating the effectiveness of the process. The findings of the study support the use of person-centred planning, with all four participants in the study engaged in a greater number of community-based activities. The two adults in the study were engaged in integrated work places for the first time in their lives, and were more actively engaged in community activities with others who were not paid to be with them. There was, however, a lack of substantive change in social networks for these adults, suggesting the need for a specific focus on improving this aspect of their lives.

Person-centred lifestyle planning approaches may not always be perceived as being relevant across the lifespan, however. Older people with an intellectual disability may be short changed when it comes to the promise of a 'home for life' (Heller et al 2000, Thompson 2000). Under the rationale of economy of scale in the UK, there is a pattern of older people moving from smaller homes which use a person-centred approach focused on **independence**, to larger older people's homes in which services focus on growing **dependence**. Thompson suggests that this pattern is indicative of an underlying belief that older people no longer deserve the models of care and quality of life, which service providers have been striving to offer following the closure of institutions. For people with an intellectual disability in this age group there is a danger that "we may just be replacing one institution with another" (p 23). Services supporting older people with an intellectual disability should ensure that support strategies continue to address people's changing health, mobility, activity, family and social needs.

In a study by Heller et al (2000), a later-life planning programme was used to teach older adults with an intellectual disability about making choices, current and potential living arrangements, work options and roles, health and wellness, use of leisure and recreation, use of informal and formal supports, setting goals, and making action plans. The study showed the planning programme to be an effective means for teaching older adults about later-life issues. Adults gained knowledge in the areas of work and retirement, health and wellbeing, residential living arrangements and leisure activities.

The role played by others in the planning process was found to be critical to long-term success. Barriers to meeting goals for adult participants included, for example, inadequate family and staff support. Families did not always have time to help their relative, or did not think that the person's goals were appropriate. Inadequate staff support included staff who did not have enough time to support the person, did not think the goal was appropriate, did not think that helping the person meet a goal was part of his/her job, and/or did not cooperate or coordinate with other staff or agencies to help the person. Inadequate residential and work options were also barriers to people meeting their goals.

Unlike an earlier study by Mahon and Goatcher, (1999), Heller et al (2000) did not find an improvement in life satisfaction as a result of later-life planning, suggesting that a follow-up of only one month following the implementation of the programme

was too short a time in which to assess long-term benefits. They suggest, therefore, that further research needs to examine life satisfaction over longer periods of time.

Planning for adult daily living should also be part of the transition from adolescence to adulthood, yet Kerr (2001) suggests that even at this critical point in a young person's life, poor links exist between an adolescent's school and home environment on the one hand, and adult services. He argues that this period is critical to planning because:

*...transition may be a time of opportunity, when inclusion of those with severe disabilities within real community life can be achieved, if service agencies respond creatively to young people's needs and deploy resources in ways which do not limit them to specialist options (p 170).*

For this to happen, services need to separate the desired ends (such as choice of accommodation, valued daytime activity, relationships with others) from the necessary supporting activities (such as transport, aids and appliances, personal and nursing care):

*In order to meet this challenge it is important that systems are in place for transferring information from childrens to adult services, to enable the latter to plan for the future needs of young adults. This becomes essential when there are patterns of new, changing or substantial needs coming through (p 171).*

### **The role of support staff – ‘Minding’ or maximising quality of life?**

To what extent do services providing support see their task as maximising quality of life? Will adults with an intellectual disability be given the opportunities they need to grow and develop through the lifespan? Will staff see their support role as ‘minding’ or as involving careful planning and active support for quality lifestyles? Recent studies suggest that despite the availability of relevant information and materials, service providers do not always adopt good working practices in this area (Emerson et al 2001; Heller et al 2000; Parley 2001; Spreat and Conroy 2001; Taggart and McConkey 2001).

In a study of the perceptions of 98 front-line staff working in 42 adult residential and day care facilities, Taggart and McConkey (2001) found a distinct shortage of good practices in relation to person-centred planning, and assessment of challenging behaviours and mental health problems. They concluded that services were more likely to adopt a ‘minding’ model as opposed to the client-focused model of active support’ (described in more detail in the following chapter) advocated in the current literature on supports for adults with an intellectual disability. An ‘active support’ model comprises a number of procedures and practices for developing particular working methods that encourage staff to be proactive in involving and supporting the person with a disability in his or her daily living environments.

In this study, more traditional service-centred ‘care plans’ were commonly used, while person centred planning approaches advocated in the current disability literature were rarely used. Staff in general had few opportunities for training and ongoing

professional development, and there were marked inconsistencies in staff working practices across hospital, residential, and day care services. Inconsistencies also existed between management assumptions about staff working practices and what front-line staff actually did. The authors suggest that the challenge for service providers is to find ways to ensure that 'good practice' based on person-centred planning and 'active support' (described in detail in the following chapter) guides staff working approaches, and that there are consistencies across the settings in which people with disabilities live their daily lives.

Other studies raise similar concerns. Emerson et al's (2001) finding that adults living in supported living arrangements received less habilitation planning and teaching than their counterparts in small group homes, suggests that some support staff may not see assessment and teaching as part of their role, even when the model of support (supported living) emphasises a **person-centred** approach (Howe et al 1998; Parley 2001).

Parley (2001) found some improvement in services when staff implemented a person-centred approach to residential care and support. Nursing staff in hospital wards for adults with an intellectual disability were found to be more respectful to clients and there were improved opportunities for people to make everyday choices. Little progress was made in involving people with disabilities in planning their own care, however, with power and control exercised predominantly by staff. The implementation of person-centred planning by staff with a nursing focus in a segregated hospital setting may present some challenges. The author concludes, for example, that person-centred planning is difficult to achieve when the focus is on nursing practice, rather than on the multiple environments in which most people live their daily lives.

Follow-up and comparative studies of the experiences of people living in institutions and those living in the community, suggest that while community placement provides a much improved quality of life, some areas of people's lives remain poorly supported. A study looking at people with an intellectual disability in Australia one year after moving from an institution, showed that while there was some improvement in adaptive skills (particularly self-care, shopping and domestic skills), no changes were apparent in the areas of physical development, vocational activity, language development, self-direction, and social behaviours (Young, Ashman, Sigafoos and Grevell 2001). The authors suggest that for gains to occur in these areas, support staff may need to take a more active approach in teaching skills, rather than simply providing opportunities for learning to occur. Stancliffe and Avery (1997) found that people who had moved to community homes had more opportunities to exercise choice than did their peers who remained institutionalised, but opportunities to exercise choice were still found to be relatively low in both settings.

In relation to people with the most challenging disabilities and high support needs, Spreat and Conroy (2001) observed that people living in the community in Oklahoma experienced more community integration than people in institutions, and had either equal or higher levels of adaptive behaviour growth. Institutional placement offered few benefits in excess of community placement across the measured variables, and the authors conclude that public policy supporting community living for this group is empirically supported:

*Community placement must be considered presumptively valid for persons with profound mental retardation... the most severely challenged groups of persons with mental retardation are served well in the community (p 110-11).*

Nonetheless, some interesting findings in this study point to a need to address accessible funding support, and the focus of staff support for this group in community settings. People in institutional settings, for example, had higher daily levels of productivity (involvement in vocational or academic activity) than those living in the community. People living in the community had more unmet needs (12% of those living in community residences), the most commonly cited unmet need being for assistive technology to support communication. This is of particular concern because people are unable to communicate their choices, desires, needs and preferences without this support, and suggests that effective case management, planning and resource allocation is needed to address this issue (Spreat and Conroy 2001).

People living in community residences also found it more difficult to access medical services than those living in institutions. While such services are readily available in institutions (in the form of on-site physicians) it was not clear from this study whether such access was more difficult than it would be for others in the community who do not experience disabilities. On this point, the authors suggest that “legitimate medical needs that require greater than ordinary access to medical staff should be arranged prior to community placement” (p 111). They suggest that nursing staff can be hired to work in community homes and regional medical centres can be accessed. While the issues raised above are addressable for people with very challenging needs, the authors suggest that future research needs to focus on three specific areas: productivity and its linkage to life quality in the community; unmet needs and access to medical care; and forms of support other than small group homes.

## **Summary**

Current thinking sees a person’s house not primarily as a training ground, but as a “home” with a focus on possessions, social relations and emotional security. Daily living supports need to respond to this broader understanding of “home”, which is based on a “citizen” perspective in which people with disabilities share the same rights and obligations of others, to live and be supported in the community.

What constitutes “a good life” and the associated supports to achieve this goal, will be culturally determined. Different concepts of disability held by Maori and Pacific people need to be recognised and the development of indigenous initiatives and services supported.

A multi-faceted definition of “community” recognises that the community involves a geographical location, community institutions, community associations, and a sense of place, membership and belonging (Walker 1999). Many people with disabilities living in the community experience a distinct or separate social place, with few opportunities to participate in the community and develop social networks. **People need supports for daily living which allow them to experience community membership**

Supports are also needed to **have, own and experience a home**. “Home” is a multi-faceted and very personal concept. A home meets people’s basic fundamental, intermediate and growth needs. **Supports for daily living need to recognise this personal definition of home and not assume that homes must be restrictive places or places owned by others.**

Adults need supports to learn skills which will support their lives as autonomous, self-determining, independent and interdependent community members. A functional approach ensures that skills are taught on the basis of an assessment of the person’s daily routine, and focus on enhancing community presence and participation. **Skills taught should be those which are personal goals, and which make a difference to the person’s life, and not those which others may find convenient or desirable to teach.**

Daily living support should include the use of individualised, person-centred planning to identify what is important to the person with a disability, how that person wants to live, and what needs to be done to help the person towards that life. Person-centred planning requires the development of **new services** and supports to reach identified goals for the person, as opposed to planning on the basis of existing resources and services.

While the research literature supports the use of individualised planning, little evaluative research was uncovered for this review. What has been done suggests that adults become more active participants in the community, although it is not clear that access to social relationships will improve without a specific focus on this aspect of a person’s life. Staff implementing this approach need managerial and service system support to implement the approach effectively, and transition points in adults’ lives (school to adulthood, and old age) are identified as critical but often forgotten stages of adult life for person-centred planning to be implemented.

Finally, adults need daily living support through a service and staff philosophy which promotes the maximising of quality of life as opposed to ‘minding’. Recent empirical literature suggests that service providers do not always adopt good working practices in this area. Inconsistent approaches are described, between service and management philosophy and staff practices. While empirical research shows marked improvements in adaptive behaviour and quality of life for those adults moving from institutional to community homes, some areas of people’s lives remain poorly supported. These areas need to become the focus of daily living support services.

## CHAPTER FOUR

### CURRENT BEST PRACTICE IN DAILY LIVING SUPPORT AND SUPPORTED LIVING

#### Principles underlying best practice

Concerns in the early 1990s for adults with an intellectual disability to be able to make choices, have some control over their own lives, and become **members** of the community have focussed efforts on **supporting people in their own homes**. Knoll and Racino (1994) see this shift in thinking away from institutional models as a reflection of the fact that, “the supports paradigm is once and for all in and of the community” (p 301). ‘**Supported living**’ has emerged as a preferred model for daily living support, with its emphasis on mobilising the unique array of supports each person needs, to live in his or her own home and participate in the life of the community (Knoll and Racino 1994).

Supported living requires that service providers think differently about the ways in which people receive support, giving priority to what works best for the individual. This means not being constrained by past or present options. It also means building a commitment amongst service providers, to responding to people through personalised supports (Fitzpatrick 1996). Some writers emphasise the importance of a set of key principles which underlie the practice of supported living.

- **Flexible service structures** - Services need to make sure that they are not constrained by what is currently being provided or what has normally been done in the past. This means a shared commitment within services to looking at what is ideal for each person using the service, and then working to achieve that ideal. Services structures need to be flexible and non-bureaucratic, capable of responding on an **individual** basis rather than group or house basis (Fitzpatrick 1996; National Council on Intellectual Disability 1994; Van Dam and Cameron McGill 1995).
- **Flattened management structures** - Key decision makers need to remain close to the individual being supported, and have the authority to deploy resources in ways which respond to individual circumstances (Fitzpatrick 1996; National Council on Intellectual Disability 1994; Van Dam and Cameron McGill 1995).
- **Flexible staffing** - Staffing needs to be negotiated between the individual and service, rather than the individual having to conform to the demands of the service. Staff roles also need to be flexible enough to respond to individual's needs for support. Set roster hours (eg, 3.00 pm. - 9.00 pm.) are not likely to allow staff to be responsive to the **individual's** needs. Instead schedules can be devised so that staff are at work at times that suit the changing needs of the individual. Staff might work with a number of different people in a number of different locations in one day (eg, 7.00-9.00 a.m. with one person to assist with showering and breakfast, 9.00-1.00 with another person to assist with shopping etc.). Flexible delivery of support in this way means that people do

not need to attend day services if they are not working, they simply live their lives, some working, some not.

- **Flexible provision of housing** - Services need to ensure that they are not locked into particular properties, as this limits the ability of the service to consider alternative arrangements for people. As people's housing needs may change, services need to be able to dispose of some housing and seek new alternatives. O'Brien (1994) argues that the typical service practice of tightly linking the funds and the personnel for the necessary assistance to the operation of a facility, restricts most residents from moving into their own homes. Allard (1996) suggests that funding needs to be individually - not programme-based.
- **Separation of housing and support** - the provision of housing and support need to be seen as two separate considerations. If a service is locked into a particular location, it is less able to consider a range of options for individuals. Instead support tends to be channelled into the house no matter who lives there. Support needs to be attached to the individual, and move with them into whatever living situation suits them. This suggests that services will need to be free to change households if necessary, and redeploy resources in whatever way is needed. Separating issues of housing from issues of support in this way has other advantages: it encourages a more "person-centred" approach to assessing and providing for individuals' support needs; it emphasises diversity in housing options; relationships with family and friends become a major concern in the design of housing and support (Brook 1999); and homes can aspire to reflect the personalities and cultures of the people who live there (Brook 1999).
- **Access to generic services** - individual support systems recognise the capacity of generic community services to ensure that community presence is not just a token presence. Community recreation and leisure settings offer the opportunity to mix and relate with non-disabled peers and to receive natural rather than paid staff supports. Individuals may also be able to use generic services such as cleaning services (paid for by the individual or by the support service), which ultimately reduce staff time.
- **Individual freedom to move about the service structure** - People should not be required to 'fit the system'. Rather, individuals should be able to access whatever service and facilities best support their changing needs and aspirations. This requires a commitment by service providers to continually increase the effective control people have over the supports they receive and the choices they make.
- **Utilising other personal supports and co-residents** - family and friends may be able to assist with outings, buying clothing and household goods etc. These are natural supports which also enhance and strengthen relationships. They can blend creatively with formal supports to meet individual's needs in less bureaucratic ways (Allard 1996). Van Dam and Cameron-McGill (1995) also describe benefits for individuals in the right situation who share their home with a co-resident. Co-residency involves finding a flatmate without a

disability and offering them a reduced rental in return for companionship and specific tasks which vary according to the needs of the person with a disability. This approach may not be for everybody, although it has been found to work well when it is what the person with a disability wants and needs. If the co-resident has major responsibilities, the service may offer an allowance and free accommodation.

The ideas presented above suggest that supported living is not only achieved through structural changes within organisations and the redistribution of resources. Supported living also implies a need to review relationships between people with disabilities, staff and families, to challenge old ways of working, and to commit oneself to new and better ways of providing personal supports. O'Brien (1994) suggests that service providers, family, friends or allies cannot support a person with a severe disability in establishing and enjoying a household without reviewing and renewing the nature of their personal relationship with that individual:

*Support only results from a long-term relationship that communicates a strong sense that the person with a disability deserves a decent home and the assistance necessary to live there with dignity, as well as a willingness to respect and align with the person's emerging sense of self and developing ability to define and pursue individually meaningful objectives (p 5).*

### **Supported living – Bringing individualised, person-centred, and flexible supports together**

Flexible supports such as individualised housing and work options, encourage choice and autonomy in adults with an intellectual disability, including adults with multiple and challenging disabilities (Bradley 1994; Brook 1999; O'Brien 1994). In the area of residential “services”, **supported living** involves adults with disabilities making their own choices about where and with whom they live, and for how long, and involves supports being provided which sustain that choice (Allard 1996; Bradley 1994; Brook 1999; Fitzpatrick 1996; Howe et al 1998; O'Brien 1994). Several examples of supported living in practice are described in the literature in North America (eg, Ferguson et al 1997; Hulgan 1996; Howe et al 1998); the United Kingdom (eg, Broderick 1996; Emerson et al 2001); and in Australia (eg, Astbury 1997; Van Dam and Cameron-McGill 1995).

#### **What is supported living?**

Supported living is described in the literature in a variety of ways. Some writers emphasise general principles relating to (often undefined) ideas about “quality of life”. Fitzpatrick (1996), for example, describes supported living as being:

*... about complete lives. It is about providing appropriate levels of support for people with a disability who need it, to enable them to lead purposeful and dignified lives in the community... (it) is about providing a quality of life where there is room for personal growth and development, where the opportunity for social relationships and participation in socially valued activities is made*

*available... it is the responsibility of service providers to make these opportunities real by developing the community supports necessary to meet individual needs and interests (p 21).*

While this definition talks about making available “opportunities” in people's lives for growth and development, other definitions emphasise both the physical and social aspects of having one's own **home** (eg, Howe et al 1998; O'Brien 1994).

The term supported living (or supportive living) has been used to describe **the broad context which is needed for person-centred approaches to lifestyle planning and support.** Key principles of supported living include “having choices” and restructuring of formal residential agencies to become “service providers” (Allard 1996). In a review of the literature Howe et al (1998) describe the wide range of different perspectives on what constitutes supported living.

- Finding and securing a home that is not agency owned or agency-operated and then providing the flexible supports that people need to live successfully in the community.
- People with disabilities living where and with whom they want, for as long as they want, with whatever support is necessary to make that possible.
- Rejecting the notion of a continuum of residential services, with its attendant focus on “care and treatment” designed to teach people skills that will result in their moving to the next less restrictive residential setting, in favour of supporting people to experience community presence and participation in homes of their own.
- Rather than fitting people into existing facilities that offer pre-packaged services of a particular kind and level, supported living involves developing support that is matched to a person's specific needs and preferences, and changing that support as a person's needs and preferences change.
- Supported living seeks to ensure that a person's preferences are honoured with regard to where and with whom the person lives, and in terms of the person's lifestyle activities.
- Supported living fosters and honours a person's choices without sacrificing health and safety.
- The nature or severity of someone's disabilities should not exclude that person from being a recipient of supported living services.

In essence, then, supported living is the term which has been used to describe finding and securing a home which is not agency owned, and providing the flexible supports people need to live in that home and community. It is not facility based, and it does not require people to fit into programme slots or vacancies (Allard 1996; Howe et al 1998; Fyffe 1999). It is a “philosophy and an approach”, rather than “the answer or some new magic” (Allard 1996: p 110). It is a way of viewing people and their families, and of assisting them in ways that enable them to receive the supports **they**

need to live in the home they want, with whom they want, and for as long as they want.

Most supported living programmes used a form of person-centred planning process which emphasises strengths, not deficits, and included five elements:

- listening to the individuals or their representatives
- identifying their preferences and core values
- addressing the issues that the disability presents
- developing a vision
- mobilising community resources to make the vision a reality.

In America, the states of Maryland, Florida and Wisconsin have encouraged supported living agencies to adopt this type of planning process or a related version of it. In these services, individual choice and control were emphasised across all aspects of daily living and were integrated into service design and plans. People were given meaningful choices about where they wanted to live and with whom, and how they controlled their own housing. The agency did not own or lease the person's home; in some cases they acted as guarantor on a lease; if the agency did own the home the agency worked hard to transfer ownership to the person with a disability. However, for agencies that were heavily capitalised through both owning or renting properties, providing home ownership to people with disabilities was a significant barrier.

### **How effective are supported living services?**

There are few published formal evaluations to date of supported living in practice. It should also be noted that in comparing outcomes between residences which have different service philosophies and approaches, it is very difficult to control for differences between the people who live there in terms of (for example) their age; length of time living in that setting; previous residential history; and adaptive behaviour. While some studies attempt to control these variables, the influence of unknown confounding variables cannot be ruled out. This is a major methodological problem inherent in virtually all research undertaken in the field of residential supports for adults with an intellectual disability (Emerson et al 2001).

One recent study suggests that problems inherent in group homes can be overcome with a shift to supported living services (Howe et al 1998). Howe et al (1998) compared the experiences of 20 people living in traditional residential services (typically group homes) in Oregon with those of 20 people living in supported living services. They concluded that people living in traditional residential services had qualitatively inferior lifestyles when compared with people receiving supported living services. People living in supported living arrangements were more likely to own or personally rent their home; have housemates (or no housemates) according to their own choice; be actively involved in the development of their support; and be the decision makers about their daily affairs.

In terms of community-based activities, people living in supported living services participated more often and in a greater range of community activities. Compared with their peers in traditional residential services, the community activities they

engaged in were much more likely to be preferred activities in line with their own personal interests, and activities were enjoyed with more and a wider range of people.

A more recent study (Emerson et al 2001) suggests, however, that the Howe et al study may have confounded type of service (supported living or traditional residential services) with facility size. The reported mean number of co-residents in supported living settings was 1:6, compared with 1:6.9 for traditional services. Since better outcomes are associated in the recent research with very small homes (Stancliffe 1997), it is difficult to be certain that the better outcomes were due to supported living services and not to smaller group size.

Emerson et al (2001) undertook a similar study in the United Kingdom in which information was collected on 63 adults in supported living residences, 55 adults in small group homes, and 152 adults in large group homes. Compared with participants living in small group homes, those in supported living residences had greater choice, and greater choice over where and with whom they lived. They also experienced a greater level of participation in community-based activities. These gains were reported with no increased cost associated with supported living, findings which are consistent with those of Howe et al (1998). Participants in supported living residences also experienced higher staffing ratios, higher ratios of care staff, better internal procedures for allocating staff support on the basis of resident need, more frequent contact with lawyers, and were more likely to have had a hearing check.

Emerson et al's study (2001) pointed to some other issues of interest, however. Unlike Howe et al's (1998) study, they did not find that supported living resulted in benefits in the area of social relationships. Such benefits seemed instead to be a function of the number of people with disabilities living in a home rather than service model. They also found some negative outcomes associated with supported living residences. People living in supported living settings were less likely to have a designated key worker, less likely to have an Individual Habilitation Plan, and were supported in settings which had poorer internal procedures for assessment and teaching.

## **Housing**

Fyffe (1999) and others (eg, Brook 1999; Fitzpatrick 1996; Van Dam and Cameron-McGill 1995) stress that **in supported living it is important to draw a distinction between housing and support**. This means distinguishing between the physical characteristics of housing for people living in the community, and the nature of the support required from families, friends and staff to support that housing option.

### ***Physical aspects of housing***

It is important to remember that ideas about home can begin with a structure - a house. John Byrne (1996) is the parent of a young adult son and the Director of Special Projects for the Queensland Department of Public Works and Housing. Byrne adds a slightly different perspective to the issue of home for people with an intellectual disability, arguing that the diversity of housing types or designs has not kept pace with the new diversity of needs in the community:

*Not everyone needs or wants the traditional detached family house on the quarter acre block... What we need is a range of house sizes (from bed-sits to 1,2,3,4, or more bedroom dwellings) and with a range of garden sizes... what we need is a much wider range of choices, including detached, duplex and attached houses, apartments and units, not to mention group forms of houses such as boarding houses (p 96).*

From a planning and urban development perspective, he argues that finding the right place is important for everyone, but it is crucial for people with an intellectual disability. Because the choice of housing in society continues to be narrow, Byrne acknowledges that not every adult with an intellectual disability will be given a chance at an independent lifestyle that meets their personal needs and desires. He raises a challenge to service providers, families and advocates:

*If we want the best housing for these people (and especially if they are our children), then we must become strong public advocates for the development of a much greater range of housing types in our community (p 8).*

Consistent with the discussion above, he argues that rather than forcing people into institutional options, the emphasis needs to be on providing people with the housing they need in the right place, and with access to the right facilities. This means having fair access to a home of your own which meets your needs; access to inclusion in your wider community and privacy and control; and access to the different parts of your life.

### ***Looking for a home***

Looking for a home for a person with an intellectual disability is a sensitive task, and Mansell and Ericsson (1996) suggest that there is a need for a **model** to create individually tailored housing so that people's unique needs can be met. While some people may be able to make independent decisions and choices, others will need the support of an advocate, particularly if they find it difficult to express themselves and their interests. These authors suggest that in looking for a home, service providers can be guided by questions in relation to:

- the type of house
- settling into a particular community
- what the person wants to do during the day, in the evenings and at weekends
- where the person wants to live
- who the person wants to live with.

These questions should be the subject of many discussions, not just one meeting. Finding the answers requires negotiations where realistic short-term decisions must be reached, so supports and services can be made available. Decisions may then be made on:

- place
- district and neighbourhood

- type of housing
- access to adequate personal support (decisions on support will require that questions be raised about staff training, working methods, and perspectives ie, competence vs. citizen perspectives)
- the contribution of family, friend, and advocate support
- secure relationships with neighbours.

### **The role of support staff - Engagement, relationships, ratios and training**

The current focus on individualised, person-centred supports means that service providers need to define a new role in their daily work and take a new perspective on their relationships with people with disabilities. Knoll and Racino (1994) argue that:

*It has taken a generation of struggle with the meaning of concepts like choice, control, quality of life, personal satisfaction, and community membership to begin to understand the power of the program/facility-centered model and the extent to which it reflects a way of thinking that is fundamentally alien to the way human beings wish to live (p 301).*

There are major implications for staff working directly with people with disabilities, in particular Knoll and Racino (1994) suggest that:

*Nowhere is the reality of the supports paradigm more evident than at the level of **direct interaction between the person with the disability and his or her service provider**. In fact, it is at this micro level that the new way of thinking was defined... For it has been in personal one-to-one interactions that the inherent and unresolvable tension between a program-centred model and the hopes and dreams of an individual must be confronted... a new, distinct role that focuses on community support is indeed evolving... (and) the development of a systematic approach to educating support personnel is crucial to continued progress (p 301).*

They conclude, however, that while many organisations and individuals have changed their vocabulary to fit in with supported living, the style of individual professionals remains substantially the same:

*The basic values of personal choice, control, individual quality of life, valued roles, and full community participation for people with developmental disabilities do indeed require the fundamental transformation of words and practice inherent in the supports paradigm (p 302).*

The promise of these basic values will be lost, these authors suggest, unless service workers are re-educated or developed in line with this new way of thinking about supports for daily living. This process includes having the skills needed to undertake the far-reaching changes that lie ahead.

### ***House size and staff ratios***

It might be expected that people with greater dependency would need more intense and consistent support, and therefore higher levels of staffing. Research in institutions, however, has shown that people can expect contact from staff only a few times in an hour and for less than a minute on each occasion (Felce 1996).

According to Felce, the “myth of understaffing” is that low interaction is due to staff shortage, yet increases in staff have not necessarily been accompanied by proportional increases in staff interactions with residents. Staff have been found to spend more time in organisational duties and less time interacting with residents, when greater rather than lower levels of staff are on duty, suggesting that improving staffing ratios **alone** will not guarantee improved supports for people with an intellectual disability. A study by Emerson et al (2000) supports this conclusion. Although staff ratios in community-based group homes were 115 percent higher than those provided in a more institutionalised “residential campus”, there was only a minimal increase in the level of staff contact.

Higher ratios of staff to residents do make a positive difference, however, in settings where there are **overall low** numbers of people with disabilities and staff. This is particularly true when ratios allow staff to work for reasonable periods of time in a supportive 1:1 situation with residents. The size of a home in terms of the number of residents, is known to be related to the degree of personal control and resident autonomy. Smaller homes provide more opportunities for personal control, involvement, decision making and choice making (Heller et al 1999; Stancliffe 1997; Stancliffe et al 2000). Smaller homes also foster greater community integration, probably because they are more accessible to the community and offer more opportunities for residents to become involved in community activities.

Stancliffe et al found that people supported in semi-independent living arrangements exercised more personal control than those living in group homes. People living alone exercised the highest levels of personal control, whereas those living in 4-person households exercised the least. Differences in self-determination were also evident. People who lived semi-independently showed the best developed self-determination skills, attitudes and knowledge, whereas residents in group homes did not perform as well. People living in semi-independent living services also experienced a living environment which was more conducive to individualisation and to resident and staff autonomy; staff were more skilled but provided fewer hours of support per resident; and residents had more money available for discretionary spending.

Opportunities to exercise control through choice making, however, may be affected in different ways by the presence of staff. Stancliffe (1997) found that the number of residents in a home and staff presence are both important predictors of choice, but the relative importance of these two variables may vary. Staff presence can in fact have a **limiting** effect on residents' opportunities to make choices. In his study of semi-independent and group home residences, periods with **no staff** provided greater opportunities to exercise choice freely. For people with moderate to high skill levels like the people in this study, Stancliffe argues that full choice and autonomy may be exercised more freely or be required more frequently when authority figures are not around. Clearly, however, people with more complex disabilities and higher needs are

likely to need more support to exercise choice, and may need constant staff presence to assure other important outcomes relating to autonomy and safety.

For the people in Stancliffe et al's (2000) study, higher levels of personal control were associated with increased adaptive skills; fewer behaviour problems; improved self-determination competencies and an improved living environment. From a rights perspective, however, Stancliffe et al warn that the strong relationship found in their study between personal control and adaptive skills is a cause for some concern. Does this mean that people who have fewer adaptive skills (more complex disabilities) will be less self determined, less able to make choices and exercise control over their lives? They argue that this is not necessarily the case. Carefully designed and responsive individual support systems can still be used to enhance personal control among people with more severe disabilities, although more support and assistance will be needed to ensure that people are able to make choices and access their preferences (Avery and Stancliffe 1996; Howe et al 1998).

Organisational change towards supported living services carries with it some important implications for the size of homes; the ratio of staff to residents; and, equally importantly for the type of staff required and their training (Felce 1996; Mansell and Ericsson 1996; Myers et al 1998; O'Brien 1994; Stancliffe et al 2000). To understand how to provide effective support for ordinary living, Felce suggests that we do need to find out what level and quality of staff individual interaction will result in resident participation and independence.

### ***Staff training***

The literature suggests that the quality and training of staff working in supported living services is critical. Knoll and Racino (1994) stress that the disability field must re-educate itself and develop new workers who are "imbued in this way of thinking and have the skills needed to undertake the far-reaching changes that lie ahead" (p 302). Without this, there is a danger that services will continue to operate in traditional ways. For people living in staffed housing with high support needs, in particular, the outcome is very dependent on what staff do (Felce 1996).

*Discussions about support also involve discussions about how staff interact with people with disabilities and each other, on what activities and how staff are employed, trained and supervised (Fyffe 1999: p 182)*

The emerging literature on community support challenges the idea that low staff skills are all that is needed to implement community support. Staff require expert skills to be able to implement active support and promote individual decision making. When adults with an intellectual disability have a voice in making decisions in their home (including making choices and decisions about both personal and policy matters) their skills for independent living are enhanced and they are much more likely to be involved in community activities (Heller, Miller and Factor 1999). Unfortunately, these researchers found that while residents were able to make less important choices and decisions (eg, what to wear, what to have for dinner, when and who to entertain, the type of decor in the home), on average staff members made all of the

administrative decisions such as moving residents out of the home, selecting new housemates, hiring and firing staff, and addressing safety issues.

Staff training is not always valued or seen as a priority and even when it is valued, disparities can exist between what management in service organisations expect to occur in theory and what actually happens at a practical level among front-line staff in residential settings (Balcazar et al 1998; Taggart and McConkey 2001). Taggart and McConkey cite a study by Whitworth et al (1999) which showed that front-line staff often continued to ignore formal programmes of intervention, even though training was provided, and that a conflict of interest sometimes existed between management and front-line staff.

Felce (1996) describes the role of staff as complex. They are important mediators between the opportunities to lead an ordinary lifestyle in the community, and the taking up of those opportunities by individuals with severe disabilities who lack independence in many areas. A major concern at managerial level in an organisation, then, is how staff are recruited so that they have the necessary skills and attitudes. It is action at the managerial and operational levels which will determine best practice in staff training and working methods; quality monitoring; and staff management. It is important for service providers to recognise that the values held by staff, their training, their perceptions of their role, and their perspectives on and interactions with people with disabilities are just as important as staffing ratios.

Of equal importance, service management plays a key role in promoting and supporting front-line staff's adherence to the service's espoused goals of community inclusion. In a study of 518 daily-living support staff representing 130 disability support services, Balcazar et al (1998) found that staff generally had a high level of knowledge about the values of community inclusion. They also adhered to the philosophy of inclusion, in that they knew about the importance of providing opportunities to engage in community daily activities and about clients' rights to receive services and supports. However staff were much less knowledgeable about providing clients with opportunities to **make choices**, which is a cornerstone of personalised approaches to daily living support.

Balcazar et al's (1998) study also showed that staff who had more knowledge about community inclusion philosophy were more likely to report their service's adherence to that philosophy. Importantly, staff who perceived that their service held tightly to and put into practice philosophies of inclusion were more satisfied with their jobs. These findings are "consistent with the view that staff training and the development of effective ways to instruct new employees in new service approaches is important, particularly when considering the high turnover rate among direct care staff" (p 460).

The organisational culture of a service is also important. In a survey of 450 staff, Hatton et al (1999) concluded that whilst individual staff may hold relevant sets of values, the impact of those sets of values on people with an intellectual disability is likely to be mediated by the organisational cultures within which staff work. Hatton et al suggest that values training may be less important than trying to encourage a productive organisational culture throughout a service. Staff in this study described such a culture as "high in rewarding staff, tolerant/staff oriented and fostering social relationships, and low in demands on staff" (p 215). Where services have a culture of

supporting staff wellbeing, they suggest, there may be a greater willingness by staff to achieve a high-quality service.

### ***Staff relationships and interactions with residents***

The pursuit of quality in ordinary homes entails more than just the provision of an ordinary environment. It requires that service providers think carefully about the nature and quality of the relationship between staff and people with an intellectual disability:

*It involves changing performance away from traditional care models... and creating an alternative which emphasises resident participation. It also involves changing performance away from the traditional allocation of activity to residents on the basis of their ability to carry out activities independently, and creating an alternative which emphasises the absence of exclusion of residents from participation and the provision of support to help those people who lack skills to accomplish activity successfully (Felce 1996: p 133)*

The way in which staff support and interact with people with disabilities is important. Jones et al (2001) argue that inadequate support from staff, and low activity among people with an intellectual disability is an enduring problem. Measuring the level of engagement in typical daily living activities has been one way of evaluating whether community services provide an improved environment and resident quality of life. Research by Emerson et al (1999), Felce and Perry (1995), and Felce et al (1998) (all cited in Jones et al 2001) has shown that the extent of resident engagement in activity is related to the person's level of adaptive behaviour. People with higher levels of adaptive behaviour have been found to participate in typical social domestic, personal and leisure activities for the majority of the time, while people with lower levels of adaptive behaviour are more likely to be unoccupied for much of the time.

Felce (1996) argues that the primary fault in the behaviour of direct care staff is **a lack of sufficient social interaction with residents**. This point is reiterated in McDonald's (1997) New Zealand study on staff responses to individual's communication attempts. People with lower levels of independent behaviour and greater communication challenges usually receive fewer positive and responsive interactions than their more able peers, and they receive more routine custodial care.

However, more recent research suggests that the problem of inadequate staff support may have less to do with low rates of attention, and more to do with the **quality of attention** (Jones et al 2001). Felce et al (1999) found that the majority of staff attention given to residents in community homes was in the form of conversation, which made little contribution to enabling residents to participate in an activity. While people with more severe disabilities require greater levels of staff support, these authors concluded that they did not typically receive it.

McConkey, Morris and Purcell (1999) also looked at staff interactions with people with an intellectual disability in residential and day services and found few opportunities to engage equally in a conversation. Staff overly relied on verbal communication; preferred to use directives and questions, and most failed to adjust

their language to the person's level of understanding. The authors suggest that staff need to adopt a wider range of ways of communicating which are responsive to individual's non-verbal signals and to their own attempts to initiate communication.

The quality of interactions between service staff and adults with an intellectual disability is important, because adults have pointed out that their most frequent and sustaining relationships are with staff. Staff also provide them with entry into other relationships, and these relationships have a bearing on one's sense of self (Marquis and Jackson 2000). In this sense:

*...the interpersonal relationships between service users and workers in human services have potential to support the development of a sense of identity and connection with others, or alternatively to suppress the development of positive relationships (Marquis and Jackson 2000: p 413).*

In a series of studies on staff: resident interaction and resident engagement Felce (1996) found that engagement and activity levels were a function not only of the structure of the service, but of the service's detailed orientation, procedures, staff training and management practices. In one home, staff used a supportive approach, with an emphasis on instruction, demonstration, prompting and guidance for people with substantial disabilities so they could be involved in the routine aspects of their daily household lives. This level of staff engagement did not happen in a vacuum - it was reflected in the service orientation, structure and procedures. Meaningful engagement and activity with people with disabilities was considered central to the role of staff, and this was written into the service's operational policy and staff job descriptions. The orientation of the service itself can have an impact on the way in which staff understand and play out their roles in community homes. For example, Howe et al (1998) found that staff in traditional residences (such as group homes) were more likely to provide **instruction and training**, whereas staff in certified supported living services were more likely to devote their time to **support and supervision**.

Staff training in specific strategies can enhance staff engagement with residents, and promote overall activity levels. Jones et al (1999) used '**Active Support**' with staff in five community residences serving 19 adults with severe disabilities. The residences were part of a deinstitutionalisation programme, and all had undeveloped ways for ensuring that residents had adequate opportunities to take part in activities. 'Active Support' comprises a package of procedures which include activity planning, support planning, training on providing effective assistance and engaging in supportive interactions. The prime focus of Active Support is on creating the conditions that make homes places where people with severe mental retardation can live as opposed to being accommodated. Active Support combines five elements that have been shown separately to be related either to the extent of attention residents receive from staff, or to their participation in the activities of daily living. These elements include:

1. staff members plan opportunities for resident activity proactively
2. staff plan their own division of responsibility for supporting planned resident activity (clear allocation of staff members to duties and working alone with small resident groups)

3. when supporting participation, staff supplement verbal instruction with gestural or physical prompting, demonstration, or physical guidance as necessary
4. staff give the majority of their attention to residents when residents are constructively occupied
5. staff monitor the opportunities provided to individuals each day.

For people with severe disabilities and limited independence, they suggest that three critical factors are necessary if people are to have genuine opportunities to participate:

- (a) available activity
- (b) available staff support
- (c) the matching of the level of assistance given by support staff, to that required to participate successfully.

The planning element within Active Support is directed towards increasing the occasions when the first two factors are present. Practical training is directed towards increasing staff skills to achieve the third factor.

As a result of the training, staff assistance and resident engagement in domestic activities significantly increased in all houses. Staff continued to use the strategies, and improvements came without increasing staff ratios (which were approximately 1:4). Jones et al (2001) later replicated this study. This later study involved 303 staff working in 38 community residences who were trained in Active Support approaches in an attempt to increase the assistance given to 106 adults with a severe intellectual disability. As in the study by Jones et al (1999), the study showed significant increases in the receipt of assistance, engagement in domestic activity and total engagement in activity when staff used Active Support.

The authors conclude that Active Support appears to provide a means of meeting the goal of supporting people with few independent skills to participate in the daily round of activities that typically occupy us all. They stress also, that the intention of Active Support is not to be coercive and limit opportunities for **choice** by people with an intellectual disability. Rather it is “to offer people who currently may be disengaged through no choice of their own, an opportunity to participate in some form of typical, constructive pursuit” (p 355).

Staff organisation and working methods (eg, staff working practices, the service's policies, household routines) could also be important for residents' personal control (Stancliffe et al 2000). In their study of personal control and autonomy in different residential settings, Stancliffe et al found that these aspects of daily life may be even more important than staff ratios or even staff attitudes and skills. Modifying daily routines to make them more flexible and individualised would, they suggest, support personal control. Staff can also use Active Support to encourage self-determination in residents with an intellectual disability by involving them as much as possible in the construction of their own activity plans, and attending to their own preferences and aspirations.

Staff also need to share values which are consistent with the philosophy and process of supported living. O'Brien (1994) and Racino (1994) challenge staff, parents and

friends to establish long-term relationships, which communicate a strong sense that the person with a disability deserves a decent home and the assistance necessary to live there with dignity and pursue individually meaningful objectives. This means challenging the notion in some services of people with disabilities as "clients" or recipients of services. When people are viewed as clients, they are given little autonomy or responsibility, and problems are blamed on the person rather than on the support system (Peter 1999).

Racino (1994) describes a service provision agency which has reinterpreted its role in terms of personal commitment and networks between staff and clients. The roles and relationships of neighbours and roommates who might also be paid by the agency were examined to promote relationships which were different from those of staff. One staff member explained that:

*We are trying to support a more normal relationship, even though in reality they are giving a service and they are getting something in exchange, but it is not quite the same. So the way that we support that is quite different. We try to encourage, not govern as we would staff, not regulate, not as much agency involvement (p 12).*

Paid flatmates and paid neighbours generally received room and board for providing some kind of support to the person with a disability with written agreements unique to each situation.

To ensure that people are both **physically and socially** a part of their community Meyer et al (1998) suggest that the role of some staff may "extend beyond facilitating the social participation of individuals to being a key component within someone's social network... (being seen) not just as a source of support, but as a 'friend'" (p 402). Close relationships such as this may not always happen naturally, however, and there may be potential for a conflict of roles when a person is both a friend and a member of staff responsible for the person with a disability. Nonetheless, home environments can be places where social relationships are encouraged and sustained. Staff can facilitate this process by ensuring that people are able to maintain contact with friends, family and relatives (eg, through ready access to telephone and transport), and have the autonomy and control needed to ensure their own privacy.

Meyer's suggestions are supported by Marquis and Jackson (2000), who spent two years getting to know and interviewing 50 adults with an intellectual disability aged between 21 and 96. Their aim was to gain insight into people's daily lives at home, and they identified the major theme from their research as "Human serving more than doing a job" (p 416). Participants in the study consistently referred to the importance of **interpersonal qualities** associated with the service as opposed to the tasks of providing care:

*Themes emerging from analysis of the data from interviews with people with disabilities suggested that quality interactions provided experiences that were responsive to the individual rather than the 'service condition'... participants provided consistent examples of relationships with service workers as 'more than doing a job' in the communication and acts of concern which they*

*perceived to be oriented towards their continued viability as developing people and also towards personal well-being (p 416).*

Ross, a man with both a physical and intellectual disability in the study described the importance of relationships with staff in this way:

*Having someone you get along with is more important than doing the job. It's important to have someone here who understands me and talks to me like any other person. Some people... they kind of shut off from you. You get that feeling, from different ones that I'm a job (p 416).*

Adults with disabilities in this study were insightful about the way in which staff conveyed attitudes about their work and their acceptance of the adults they supported. They emphasised that staff need to have “the right attitude” (p 417), fostering feelings of attachment and inclusion, if they are to contribute to people’s quality of life. Staff who had “the right attitude” had relationships with adults with disabilities which were equal, and included a sense of being liked, valued and respected. These staff were described by adults with disabilities as a “friend, mate or buddy” (p 417), and engaged in normal social communication, ‘normal-talk’ and self disclosure.

Other aspects of relationships with staff contributed to adults’ quality of life. Being part of “the inner circle” in which adults with disabilities shared their lives with staff (eg, through self-disclosure; through relationships with staff’s children and grandchildren) was highly valued, as was being “like one of them” where relationships were characterised by personal involvement rather than professional distance. Some adults described negative relationships with marked differentiation between “staff” and “clients”. People experiencing this relationship described staff who adopted “an instrumental approach which fulfilled the task of body and environmental care with minimal personal interaction” (p 420). Simon, a man with a physical disability placed in a home with another man who had challenges communicating with others, described the negative impact of this relationship:

*It's awful. They don't talk and they are just watching the clock all the time. I'm just a part of their duty. They're just there for the money... I feel they don't like me because they don't answer me when I talk to them (p 421).*

These authors conclude that while services might promise support which enhances autonomy, the promise is not always delivered. For adults with disabilities using services, relationships with staff may be crucial to the development of personal identity and self worth, particularly where other relationships with family and friends are lacking. Their quality of life, then, is significantly impacted by the attitudes and actions of staff who relate with them on a daily basis. Marquis and Jackson conclude that:

*As a minimum ‘quality’ outcome, human services must ensure that service workers are sensitive to the relational context and needs of people who spend most of their lives in service environments. Mission statements of human service organisations and job descriptions of service workers need to articulate the importance of relational ethics in human service objectives and ensure*

*people with disabilities themselves have opportunities to provide insight into their service experiences (p 422).*

Allard (1996) notes that in a five-state study on supported living in the United States, staff did not see people with disabilities as “clients” or “residents”, but as community members, people they had responsibility **to**, not **for**:

*Staff in the best supported living programmes talked about individuals and told stories, they did not present organisational charts or assessment forms... staff in these programmes spent a long time getting to know the individuals whose lives they are helping to support; they listen to them carefully, either through their verbal or other means of expression (Allard 1996: p 104).*

Getting to know the person and their family was considered by some staff to be an appropriately intensive and lengthy process, extending into years.

## **Summary**

Supported living has emerged in the literature as a preferred approach for daily-living support. Supported living is based on an assumption that quality of life is enhanced when the unique array of supports each person needs, to live in their own home and participate in the life of the community are brought together. Service providers need to change their thinking about supports and their models of service provision to fit with the philosophy and practice of supported living.

Definitions of supported living vary in the literature, with some emphasising opportunities for individual growth and development, and others emphasising having one's own home. However, key principles are **having choices** and restructuring residential services to become **service providers**. Finding a home which is not agency owned and providing flexible supports needed to live in that home and community are key elements of this approach.

In the area of residential services, supported living means people make their own choices about where and with whom they live and for how long, and involves supports being provided which sustain that choice.

Few empirical studies have been undertaken to compare the outcome of supported living with more traditional residential services. Supported living provides people with greater choice and a greater level of participation in community based activities. Benefits in the area of social relationships were found in one study, but not in the other.

Housing should be seen as distinct from support. Housing needs to be physically appropriate to the person's lifestyle and needs, and should be selected by the person themselves with the necessary support.

Person-centred supports require that service staff redefine their role in their daily work, and take a new perspective on their relationships with people with disabilities. Higher ratios of staff to residents make a positive difference in settings where there

are overall low numbers of people. Smaller homes provide more opportunities for personal control, autonomy and choice making, and are more accessible to the community. Staff training is critical – how staff interact with people with disabilities, how staff are employed, trained and supervised impacts on outcomes in services.

Staff relationships and interactions with residents are important. Empirical studies show that staff often provide inadequate levels of support. Inactivity is common, with interactions being primarily conversational. Adults with communication challenges typically miss out even at the level of conversation. Meaningful engagement and activity with people with disabilities needs to be integral to a service's overall orientation, structure and procedures. Services with an organisational culture which supports staff well-being may find that staff are more willing to achieve a high quality service.

**Active support** is a strategy which enhances staff engagement. Empirical research has shown that staff trained in active support gave more assistance, engaged people more in domestic activities, and spent more time engaged in joint activities with people with disabilities. These gains came without an increase in staff ratios.

Staff relationships also need to reflect a commitment to people living in decent homes with the support needed to live there with dignity and pursue meaningful objectives, including social relationships with friends, family and others. People with disabilities stress the importance of interpersonal qualities in staff and ask not to be seen as “a job”. Getting to know the person and their family is essential.

## CHAPTER FIVE

### WHAT DO WE KNOW ABOUT THE VIEWS AND PREFERENCES OF ADULTS WITH DISABILITIES IN RELATION TO SUPPORT FOR DAILY LIVING?

An increasing number of research studies are giving adults with an intellectual disability themselves an opportunity to speak about the quality of their own lives in the community. This is particularly true for people who have made the transition from institutional to community living (eg, Astbury 1997; Booth, Simons and Booth 1990; Hunter 1997; O'Brien, Thesing and Tuck 2001; Senescall 1997). These stories reflect a general enthusiasm about new homes and lives in the community with few if any disadvantages noted, and no desire to return to the restrictive environment of the institution.

#### Moving out of the institution

A decade ago, Booth, Simons and Booth (1990), followed the relocation of 36 adults with an intellectual disability from institutions to homes in the community. People in the study stressed the importance of ‘doing for yourself’ in their new homes, and the greater freedom and fewer rules and restrictions compared with living in an institution, a point reiterated in recent New Zealand studies (O'Brien et al 2001; Senescall 1997). Better relationships with relatives, carers and other residents were also important reasons for preferring the new placement. In O'Brien et al's (2001) study, one participant described the supportive social relationships experienced in the community:

*I'm very happy with my life... I've got wonderful friends who love me – they really look after me. I like living here. I've got lovely friends. Why I am really happy is nobody is picking on me or nasty to me... I'm more independent and I like not to be depending on other people (p 80).*

However Booth et al (1990) point out that in their study it would be wrong to give the impression that “all was sweetness and light” (p 133). By the second round of interviews carried out one year after moving into the community, two people had left the staffed houses they shared with four others partly because of relationship difficulties. Relationships with others were still reasonably limited, and while some people had become very actively involved in their local community, Booth et al conclude that:

*...for most of the hostel movers contact with people apart from staff and family remained largely at the level of nodding acquaintance: ‘Next door neighbour, she's nice... She once gave me cigarettes, that were good of her (p 135).*

People living in their own homes or flats expressed no desire for change, but those living in hostel-type housing were less satisfied. Despite initial comments about fewer rules and regulations than in the institution, people now were more likely to complain about staff intrusiveness and interference in the smallest details of their lives. Many

were “champing at the hostel bit” (p 137) and seemed to prefer some form of accommodation based on ordinary housing.

### **Dissatisfaction with group homes**

Ten years on, the literature reflects a growing sense of discontent with “residential services” amongst some adults with an intellectual disability, their families and advocates, with criticisms levelled at group homes in particular (Ellis et al 1997; Froese et al 1999; Fyffe 1999; Senescall 1997).

People with disabilities themselves may have few opportunities to comment on their own living arrangements, and when they do, their perspectives may surprise even significant others in their lives. Froese et al (1999) interviewed people with disabilities and significant people in their lives about their relationships, living arrangements and daily care needs. Of the 53 people with disabilities interviewed, 53 percent expressed a desire to live elsewhere, while only 26 percent of significant others thought that a move might be preferable. Sixty-three percent of people with disabilities wanted to live in their own home. The gap between people’s desires and reality is apparent given that 68 percent lived either with their parents or in group homes, and 32 percent lived alone or with a friend. Froese et al concluded that people in this study had little or no voice in decision making, and were dependent on public service systems that did not allow participation in life choices such as where to live, with whom, and when to make desired changes.

In an article aptly entitled “Whose home is it?”, a group of Australian Self-Advocates described those elements of group homes (referred to as Community Residential Units or CRUs) which threatened their right to “enjoy a life the same as anyone else” (p 17). They described not being allowed out after 10pm because of staff cutbacks; having to ask permission to buy anything over \$5, and having to collect their money from head office; being unable to take responsibility for paying their own rent; not knowing where their money goes; having to ask staff’s permission to bring a friend home or use the telephone; not being allowed to stay at home when sick; having no say in who their flatmates or roommates would be; not being allowed to cook; and being forced to go to bed before ten o’clock. In effect, there are large differences in service quality within community-based residential services, with some community-based services providing a quality of life which is similar to that found in a large institution (Fyffe 1999).

In a New Zealand study, Senescall (1997) interviewed five people with an intellectual disability about their lives in the community following life in an institution. Most of the participants had satisfying lives in the community and viewed their future positively, although some described aspects of their daily life with which they were dissatisfied, including feeling unsafe in the neighbourhood; being socially isolated from family and others in the community; boredom; poverty and concerns about not having enough money; and a lack of meaningful, paid work. Senescall stresses that in welcoming people from institutions into the community support staff need to address the basic needs of the human condition for “friends, intimacy and meaningful work” (p 139).

Horner (1994) also found that people who moved out of an institution into group homes in a New Zealand city were not always well supported. While their relatives agreed that the move into the community brought major benefits, they often described their disabled relatives' relationships with staff as "disadvantaging":

*The staff often appeared to be involved in carrying out their organisational and other duties. There seemed to be little time available for talking with the residents. For example, residents wanting to talk to staff when they arrived home often got the response: 'Go and put your bag in your room', or 'get in the bath shower now'... the need for people to be managed in this way did not result in a home-like setting. The point here is that it is quite possible to create all the limitations of an institutional environment in the smaller setting of a community home. Just because a residence is 'in the community', does not necessarily mean that it operates with good staff training and practices (p 168).*

Matthew Ellis' mother, sister and brother (Ellis et al 1997) argue that services providing daily living support have for too long focussed on deficits in adults with disabilities. They suggest that services need to have a positive, competency-based emphasis, rather than working from a deficit model. Matthew's brother James suggests that:

*Human services (in Australia) seem to only look at the negative things in a person's life and then say, 'the person can't walk so let's put her in this or that activity'. Instead they should be looking at the positive things about the person and saying, 'let's help him get better at this (p 145).*

The group home experience raised concerns for Matthew's family. Libby, Matthew's sister described dropping Matthew off at his group home after a day out:

*Often when we arrive, there are staff who don't know Matthew and he gets upset and I have to stay for a while. Throughout Matthew's life in the group home, large numbers of staff only stay for six weeks, or six months or a year. That's the real problem for Matthew (p 141).*

Finding a better way to support their son and brother had become a goal for Matthew's family, when they finally sat down together and decided, "No, it's not good enough" (Ellis et al 1997: p 142). They had entered into discussions with the service provider to "radically change" Matthew's life and to get the service to do something which was "different to a traditional group home" (p 142). In their search for a new approach Matthew's family wanted:

- a small service so that everyone from the top down knows the people using the service
- use of 'outside' resources rather than resources within the service structure
- stability of support staff and a commitment to their work
- fewer rules, less complexity, capacity to change and be flexible
- individual supports for people with no congregation of people
- families considered as leaders and partners – opportunities for families to learn and grow alongside support staff and other service workers.

Ferguson et al (1997) shared similar concerns for their son in his final years at school, as they began to plan for Ian's first experience as a young adult in his own home:

*...the residential options we had seen failed to show us the kind of non-bureaucratic support, stable relationships, and individual attention that we believed Ian would need and prefer. So many group homes seemed burdened with depersonalised regulations, underpaid and unenthusiastic staff and barren or shabby settings. They often reminded us of the large institutions that we had fought to empty for twenty years (p 194).*

### A new life – supported living

Some people with disabilities and their families have achieved the kind of goals aspired to by the Ellis family (see for example, Astbury 1997; Cummings 1997; Hulgan 1996; Ferguson et al 1997). Ferguson et al (1997) describe the Personal Support Agency (PSA) process involved in setting up a supported living arrangement for Ian, a young man with a significant intellectual and physical disability, in a home of his own. The PSA system involves the employment of a “personal manager” who is an employee of the person whose life he or she is helping to manage. Personal managers may do anything from handling the person’s finances to choosing the person’s wardrobe, and tasks can range “from the fundamental and personal to the seemingly trivial and impersonal” (p 192).

The PSA approach relies on a definition of ‘support’ as an adjective, as opposed to a fixed service. While a service might offer a range of different types of support, such as residential, vocational, educational and even ‘family’ supports, the Fergusons argue that many families know that a service is not necessarily supportive:

*Instead, support should be locally varied, defined by the users, and based in natural contexts rather than artificial settings. The symbolic way we capture this is to switch the word order and make ‘support’ the adjective that modifies the basic domain of life. Surely this is the logic behind the shared syntax for policy innovations such as ‘supported employment’, ‘supported living’ and ‘supported education’. We simply want to add one more shift from – ‘family support’ to ‘supported families (p 198).*

Finding the right person with the right values and level of commitment to act as support person was important both for Ian and for Bob, a 20-year-old with multiple disabilities (Astbury 1997) and for Luke, a 23 year old man with an intellectual disability (Broderick 1996). Using Personal Futures Planning (PFP), Bob’s grandmother initiated the move from a group hostel to a home of his own so that he could experience a home like most young men his age, and live closer to his family. A critical ingredient in the process has been the “involvement of the people who knew him intimately, wanted the best for him and were committed to a vision for his future. The screening, matching and training of support staff (carers) was comprehensive, with a particular focus on finding “a person who is ‘right for Bob’, not right for a person with high needs” (p 186). Individual carers needed to have skills and attributes to provide the care Bob needed, and the employment arrangements were put in place with as much flexibility as possible to adapt to the carer’s family and other

circumstances. In this way carers were encouraged to see their support for Bob as more than ‘just a job’.

Similarly, Luke moved into a flat after spending his days at home with his parents. He and his flatmate, Donald, spend two evenings a week together and every second Saturday (Broderick 1996). Donald does not play a role in Luke’s direct care but shares time socially with him, and helps with the upkeep of the flat. He lives rent free. A team of three workers provide most of the support he needs and sleep over at the flat. Donald will soon share this role. The move to flatting was guided by a person-centred planning process with Luke and his family, with the help of a keyworker at his day centre.

## **Summary**

Research which interviews people with disabilities living in the community, shows the importance of being able to do things for oneself, and having more supportive and stronger relationships with family, staff and others. People living in their own homes or flats are generally happy about their lives, although those living in group homes are much less satisfied. Concerns over power and control and poor treatment by staff are commonplace amongst people with disabilities, and their families. Meeting the basic human needs for friends, intimacy and meaningful work remain key challenges for service providers.

Descriptive examples of supported living in practice in the literature show that person-centred planning, key workers, careful selection of staff and flatmates can combine to offer a quality life in the community.

## CHAPTER SIX

### WHAT ARE SOME OF THE CHALLENGES AND BARRIERS FACED BY SUPPORT SERVICES SEEKING BEST PRACTICE IN PERSONALISED SUPPORTS AND SUPPORTED LIVING?

#### **Structural changes to residential services and moving to a more flexible system**

Changing to personalised support systems and supported living means reviewing and changing service policies, philosophy, structures and systems. It also means reviewing and modifying the way staff think about, interact with, and provide support to people with an intellectual disability in their homes. Changes at all these levels suggests that there will be challenges.

Reporting on moves towards supported living policies and programmes in the United States, Allard (1996) stresses that a shift towards “supports” implies a structure which is **not** characterised by professional bureaucracies or governed by regulations, formal rules and documentation, centralisation and hierarchies. Instead, services need to adopt an “organic” control model which is designed around **values, informal norms of behaviour and interpersonal communication**. This implies structural changes in residential services within organisations as follows:

- using a different approach to planning for the individual - one that includes attention to lifestyles and or “futures” issues, that is, a focus on individual “gifts” and capacity instead of deficits and remediation of those deficits
- changing the way in which human service organisations are structured to respond to individuals and to create flexible and tailored supports to meet their lifestyle choices
- empowering and valuing not only people with disabilities but also staff that will be part of this new social order.

A policy decision by staff in the Oregon Office of Developmental Disability Services to develop supported living services led to a revision of the Oregon Administrative Rules (the standards formulated by state agency personnel describing how the agency will meet its mission within the context of state and federal laws). Supported living was now acknowledged as a publicly funded option. The revised rules reflected that agency's understanding of supported living, and its rejection of a readiness model in residential services (that is, the idea that people can only live in supported living arrangements when they have proved themselves “ready” to do so):

*The goal of supported living is to assist individuals to live in their own homes in their own communities... Supported living is not grounded in the concept of “readiness” or in a “continuum of services model” but rather provides the opportunity for individuals to live where they want, with whom they want for as long as they desire, with a recognition that needs and desires may change over time (Oregon Administrative Rules, Chapter 309, 041-05060, 1997, cited in Howe et al 1998).*

Wayne Community Living Services in Detroit, Michigan (WCLS), transferred from a “well-oiled” system of group homes to a more personal way of supporting people based on the principles of self determination (Dehem and Chapman 1997). Fundamental to the process of change was the idea of shifting control from interdisciplinary teams to “support circles driven by the person with the disability, and assisted by those he or she requests to be involved” (p 9). Authority was also shifted directly to the person as they control their own resources; choose their own supports and providers; and evaluate the whole process. Fundamental changes have occurred not only in how WCLS sees itself as an agency, but also in how the organisation is funded and operates. This has meant shifts in the following areas:

- from a service system to a provider of supports
- from placing people into segregated group housing to assisting them to live where and with whom they want
- from team planning for people, to individuals being assisted by those they trust in identifying how they can achieve their own personal dreams
- from an agency that determines how it will spend its financial resources to serve people, to an agency that puts money and other available resources in the control of the individuals themselves
- from an agency that sets its values and evaluates its performance on process and professional standards, to one that focuses its mission, and measures its success, on the satisfaction of the people for whom it exists
- from a position of power and control to one that empowers and transfers authority to people with disabilities and their families, by shifting the control of its resources to them.

Findings from a Five State study on supported living in the United States (Allard 1996) identified some prerequisites to the development and acceptance of supported living:

- a philosophical commitment to the underlying components of supported living
- growth of supported employment initiatives (which influenced where people lived)
- State Developmental Disabilities Councils were instrumental in promoting systems change through start-up grants
- legislation on supported living was enacted.

### **Some limits and vulnerabilities of individualised support arrangements**

Kendrick (2001) a long-time advocate of flexible, individualised supports and supported living models for adults with an intellectual disability, issues some warnings about the risks associated with these models and practices. He suggests that certain quality issues must be attended to if individualised options themselves are to remain valid. He identifies the following key categories of concern:

1. *The possibility of irrelevant but nonetheless individualised supports –* Supports need to be relevant to the individual person being supported, however it is possible for supports to be badly conceived at the outset. Several

core errors may be made in this regard, including failing to understand and getting to know the person well; over-reliance on fixed models and practices; meeting the needs of other parties rather than the person; and a failure to give authoritative standing to the person and those who know him or her well.

2. *Otherwise valid supports are not implemented properly* - The implementation of individualised supports can result in error, breakdown and perversity. Organisations need to hold to a set of disciplines which enable implementation errors to be foreseen, prevented or at least corrected. Kendrick lists relationship, value, attitudinal and staffing variables which are likely to contribute to well implemented individualised supports.
3. *The realities of personal and community life even when being supported well in individualised arrangements* – Kendrick emphasises that even when an adult is satisfied with the supports they receive, life goes on and struggles will remain in various aspects of their life. Rejection by some in the community may be unavoidable, but may be less burdensome if one receives the right assistance and support. Individualised supports may also create some problems for adults which might not have arisen in more conventional services. For example, some adults may experience onerous and overwhelming responsibility for managing their own supports; a ‘place of one’s own’ may mean personal social isolation; finding one’s identity may be difficult; some may become vulnerable to predatory interests in the community and abuse; there may be discontinuity because of casual and rotational staffing; and expanded freedom and choice may come without support to manage it.

Kendrick emphasises that “it is not individual support options that are the source of quality but rather the foundation of commitment to the person that must animate them from the inside out” (p 16). He returns to the quality of service personnel. Staff at all levels of a service using individualised supports need to realise that “it is not the individualised arrangement which will predict good outcomes, but rather the quality of the people involved in creating its essence” (p 16).

### **The cost of supported living**

Some recent attempts have been made to establish the cost of providing supported living services compared with that of more traditional models of residential support such as group homes. It appears that using supports in flexible ways need not mean increased cost, particularly when change is associated with an emphasis on the redistribution of resources and tapping into existing resources external to the service (such as family, friends, co-residents, and generic community services and supports) (Emerson et al 2001; Van Dam and Cameron-McGill 1995).

In a comprehensive study of the cost of supported living residences, Emerson et al (2001) collected information on 63 adults in supported living residences, 55 adults in small group homes (1-3 residents) and 152 adults in large group homes (4-6 residents). No statistically significant differences were found in service costs once these had been adjusted to take account of participant characteristics. For similar

costs, these authors conclude, supported living residences offer distinct benefits in the areas of resident choice and community participation.

Dehem and Chapman (1997) agree that seeking out and utilising generic community resources and services is an important aspect of supported living. Wayne Community Living Services (WCLS) in Detroit, for example, provides supports for 1700 people with an intellectual disability in housing, employment and other service areas with a \$123 million budget. WCLS collaborates with the person and their support circle to utilise generic resources and “in-kind” or “trade-off” supports. Resources which are available to others, such as food stamps, housing vouchers and public utility programmes for low-income earners are used to offset some costs. In addition, WCLS are committed to the fundamental right of all people to have connections to family and friends, and they recognise the collateral financial benefits:

*If family and friends could replace paid staff the equivalent of one eight-hour shift per week, the amount of money that could be redirected to other needs would be \$7 million per year in an agency the size of WCLS. Think of the value, both in human and financial terms, of replacing group homes with shared housing with family and friends (p 11).*

Van Dam and Cameron-McGill stress that in their own organisation changes in living situations occurred gradually over several years and were achieved without additional funding. They also argue that in their experience, keeping people in unsatisfactory living arrangements can cost the organisation more in the long run because of the need for intensive staffing support in response to behaviour problems. Case studies of redistributed resourcing for supported living illustrate service change without increased costs.

The cost of unsatisfactory living arrangements might also be measured in relation to staff burnout. Decreased job satisfaction is highly associated with staff burnout, while staff burnout is associated with a reduction in the quality of services to people with disabilities (Shaddock et al 1998). In contrast, community residential staff who hold favourable views towards their jobs find satisfaction through their interactions with residents and families, the nature of the work itself, and supportive relationships with co-workers (Ford and Honnor 2000). Staff in this South Australian study frequently expressed values which reflected respect for the residents with severe disabilities they supported, and appreciation of them as individuals who are capable of learning. A lack of involvement in decision making, feelings of isolation, being unable to utilise their skills, and having limited feedback about their work were identified as areas of concern. This suggests that staff need opportunities to be involved in decision making, to update and use their skills and knowledge through staff training, to network with other staff, and to receive constructive feedback.

Howe et al (1998) looked at public support costs as part of their comparison of certified supported living services and traditional residential services in Oregon. When the study was carried out, the mean amount of state funding provided to each person per month was \$US2144 for supported living, compared with \$US2066 for traditional living services. They concluded that there was no statistically significant difference in costs between the two types of service, and that supported living was

therefore a cost-neutral strategy for improving important aspects of lifestyle quality for people with an intellectual disability.

Bleasdale (1995) describes the experience of “Supported Living”, a “drop-in” support service for people with an intellectual disability in Sydney, Australia, which developed out of a deinstitutionalisation project.

Beginning in 1982 with six three-bedroom community homes in four suburbs, it now meets the needs of 22 people between the ages of 25 and 70 living in 19 properties within 14 different suburbs. Key workers operate with considerable autonomy and through a close working relationship to support people.

The service operates individualised funding. While this fits well with the philosophy of the organisation it has also brought some tensions. Smaller services like “Supported Living” are put at a financial disadvantage and are forced to move their attention from the service users to management issues. This is because the funding model used only allows a notional cost per hour for face-to-face support. Also, people living relatively independently with weekly drop-in support are consistently being presented with information about the organisation which serves to identify them as members of a group of service users, not individuals. Identifying people as group members in this way conflicts with the service's concerns that each person has the opportunity to express what independence means to them, an approach which requires flexible evaluation and funding systems.

Jay Nolan Services (JCNS) (Hulgan 1996), a non-profit organisation providing a range of services to 65 people in 13 group homes in Los Angeles made the transition from group homes to supported living in two years. The agency entered into an agreement with the state that it would make the transition without additional funding, although some additional funding was sought for the period of transition only. At the time the cost of running group homes was very high, and the agency anticipated that while some individuals would be costly to support, people would be happier in their own homes and have fewer behaviour problems, thereby requiring less support. An agreement was made to receive funding in a lump sum to allow for more flexibility, and the overall cost of supporting people has in fact decreased over time.

In an Australian study of resident outcomes and costs of group homes (3-7 people with full-time support) and semi-independent living arrangements (1-4 people with part-time support), Stancliffe and Keane (2000) concluded that:

*Per person staff support hours and per-person recurrent (non capital) expenditure on accommodation support services were significantly and substantially higher for group home participants... Given that semi-independent participants achieved similar or better outcomes with less staff support and at less cost, it was concluded that semi-independent services were more cost effective than group homes.*

Participants from group homes were closely matched with those from semi-independent living arrangements on the basis of their level of independence, adaptive behaviour and behaviour problems. This meant that there were considerable similarities between the people living in semi-independent residences and those living

in group homes. It should be noted that semi-independent living did not necessarily mean supported living in this study, although some people appeared to experience some elements of supported living services. People living in semi-independent residences received on average 10.5 hours of staff support per week, compared with an average of 42 hours for people living in group homes. This study involved people with moderate and low support needs only and findings in relation to people with more complex disabilities and higher needs for support are likely to differ.

In terms of policy implications, the authors conclude that:

*...the very large cost differences between group home and semi-independent settings suggests that people's accommodation services were not needs based, given that support needs... did not differ significantly by group. This study is consistent with several previous studies showing that variations in community living staffing and/or expenditure were not significantly related to resident characteristics (p 302).*

If service providers aspire to equity in provision of community living services based on support needs, this study suggests that considerable restructuring of funding and services is needed. Few of the people in this study received individualised funding, however, and the authors are therefore unable to show whether individual funding might result in a needs-based service. While the study suggests that reduced cost should not be a reason for determining where people with low and moderate support needs should live, it does support the idea that these people:

*...should be given the opportunity and support to live semi-independently if they choose. To date such opportunities have been too rarely available in NSW (p 313).*

### **A careful or careless approach to change?**

While supported living is now recognised as a desirable approach to residential services and supports, O'Brien (1994) warns that change towards supported living can involve major challenges for service providers and, if approached carelessly, can pose threats for people with disabilities:

*Growing enthusiasm creates a favorable but dangerous climate for change. The vision of individuals with severe disabilities living with support in their own home contradicts most current policy and practice. Moreover, work to realize this vision brings significant new problems, risks and uncertainties (O'Brien 1994: p 2).*

Threats include “dumping” people into squalid or dangerous settings in the name of “getting people into their own places”, or attempting to resolve the tension between the vision and current practice by re-labelling existing facilities as private homes. Steering between these two threats means paying particular attention to three dimensions of what it means for people to have their own homes:

- (a) individuals with severe disabilities have their own homes when they experience a sense of place
- (b) when they, or their agent, control their home and the support necessary to live there
- (c) when they experience security of place by holding the valued role of home owner or tenant (p 2).

Fyffe (1999) also acknowledges that failure to adequately support individuals in community settings can occur in two main ways. Staff may not know how to support community participation so that individuals may be more isolated and have fewer friends than in larger scale facilities. Secondly, a lack of sufficient support may mean that families are asked to provide support with little assistance. Passive approaches to community support (the idea that support involves “just being there”), and the pressure for economic restraint (relying, for example, on poorly trained and cheaper staff) have, according to Fyffe, combined to undermine the effectiveness of some community support models.

With careful preparation, however, converting quickly from group homes to supported living can be achieved. Jay Nolan Services (JCNS) (Hulgan 1996; Hulgan and Walker 1997) is a non-profit organisation providing a range of services to people with autism and an intellectual disability in Los Angeles. Growing tensions among parents that residential services to the 65 people living in JCNS group homes were not responsive to individual’s needs, created the impetus for change. The organisation recruited Jeff Strully, a parent and well known advocate for responsive supports, as its Executive Director and embarked on a period of change aimed at only providing supported living services in the space of two years. While not initially intending to close down all group homes, inconsistencies soon became apparent between supporting people in their own homes on the one hand (which involved new practices and ways of organising) and existing practices on the other.

JCNS’s success in making such quick changes was attributed to several opportunities and strategies:

- the JCNS board (which consisted mostly of parents) was personally committed to providing state of the art services
- Jeff Strully worked on the commitment and skills of a small team of staff who met with families to address concerns and plan
- early in the planning process, the agency clarified the issue of decision making power by supporting both individuals and their families
- the agency helped families to learn about supported living from other families
- families who did not want supported living were assisted to find alternatives for their sons and daughters
- there was an expectation that staff would be either “in” or “out”, and consequently there was a high level of staff turnover during the transition. New staff were hired on the basis of their commitment to supported living
- JCNS made an agreement with the state that it would make the transition without additional funding. They also managed an agreement to receive funding in a lump sum to allow for more flexibility. The overall cost of supporting people has decreased over time

- additional sources of funding were made available to facilitate the moving process, including reduced rents from the State's Department of Housing.

The focus for this agency now has shifted to developing ways of identifying and responding to individual's needs and preferences.

### **Will people with disabilities have a voice in planning?**

The aim of supported living is to give a voice and autonomy in decision making to people with disabilities. Bewley and Glendinning (1994) warn, however, that organisations, while paying lip service to the input of people with disabilities may raise organisational and practical barriers which prevent people with disabilities from representing their views to service planners. In particular, careful thought needs to be given to how and by whom the voices of people with more complex disabilities and communication challenges can be represented.

### **Small is beautiful?**

It may also be more challenging for large service organisations to move towards supported living services, with some smaller organisations acknowledging that size is sometimes in their favour (Bleasdale 1995; Fitzpatrick 1996; Hulgan 1996). Fitzpatrick (1996) suggests that "L'Avenir", an innovative housing support model in Winnipeg, Canada, illustrates the benefits of a "small is better" approach. L'Avenir provides housing support for twelve people with severe disabilities in a variety of situations and in a variety of different ways. The emphasis is on supported active decision making in decisions that affect their own lives, and on flexible support according to need. Living arrangements include houses, units, and apartments with support provided by live-in staff or paid housemates. Funding combines government funding and fund raising, and the Board which serves the twelve individuals acknowledges that challenges have arisen, particularly in encouraging other service providers to provide what the individual needs, rather than what the service requires.

### **Policy and organisational barriers**

Service structures themselves may make it difficult for a person with a disability to own their own home. For example, if services tightly link funds and personnel for necessary support to the operation of a facility, most facility residents will not be able to move into their own home (O'Brien 1994). Growing demands for residential services may also mean that funding is sunk into new facilities. In this environment, there is a disincentive to service providers to reduce the number of people "bound to facilities" (O'Brien 1994: p 5).

Welfare policies may also interfere with individuals' goals to buy their own homes. O'Brien (1994) points out that in North America, for example, payment for assistance through the welfare system does not allow individuals to save more than a small amount of money.

In some cases there may be a discrepancy between the vision of what would be most suitable for the person and what available funding will actually buy. Holburn and Vietze (1999) suggest that finding alternative sources of funding for individualised arrangements often requires developing relationships with local employers, bankers, realtors, experts in housing development, and city planners:

*Multiple funding streams are usually necessary. This will call for creativity in finding solutions to funding that meet the needs of the person. Ideally funding experts should be joined with support people in problem solving (p 122).*

## **Availability of appropriate housing**

Both O'Brien (1994) and Byrne (1996) point out that in most housing markets an undersupply of physically accessible housing can combine with very small amounts of money for adaptations to keep many people trapped in group homes. In addition, a limited range of housing alternatives means limited choice for people with an intellectual disability whose needs dictate specific features in a house (Byrne 1996). This suggests that service providers changing to supported living approaches may also need to advocate for the construction of a wider range of housing options in society.

## **Summary**

Services wishing to change to individualised planning and support, and supported living need to make changes to:

- service policies and philosophies
- service structures
- service systems
- staff roles
- staff values in relation to people with an intellectual disability
- the way staff interact with and provide support to people with an intellectual disability.

Structural changes include using future critical planning based on individuals' strengths; creating flexible and tailored supports to meet individuals' lifestyle choices and valuing and empowering people with disabilities and staff.

Studies of services which have moved to Supported Living (Allard 1996) show that a successful transition happens in a service where there is:

- a philosophical commitment to the underlying components of supported living at all levels of the service
- a growth in supported employment initiatives
- enacted legislation on supported living.

For individualised supports to provide a quality life, some quality issues need to be addressed. Supports need to be relevant to the person, properly implemented, and recognise the (sometimes negative) realities of personal and community life.

Research to date suggests that individualised planning and supported living does not mean increased cost, partly because existing resources beyond the service should be sought (friends, family, generic community resources, and supports). Some additional funding may be needed to cover the transition period.

Because Supported Living can involve major challenges for service providers, changes should be undertaken carefully. Threats to achieving Supported Living include “dumping” people in dangerous settings; simply re-labelling group homes as private homes; and poor support for community participation and membership, resulting in social isolation. It is critical that people with disabilities are central to the process of decision making and are able to have a voice. The research literature suggests that, in general, this area is still poorly addressed by staff.

A challenge may be the size of the organisation, with smaller organisations reporting that their size has made transition to supported living easier. This issue has not yet been pursued by empirical research.

Organisational barriers may interfere with a smooth transition. Where funding is tightly linked to the operation of a facility, owning one's own home may be difficult to achieve. Growing demands for residential support may encourage services to sink money into new facilities, rather than individualised support structures. Multiple sources of funding may need to be sought if existing funding does not match the vision for the individual.

Finally, physically accessible, practical and well sited housing may be unavailable, suggesting that service providers may need to advocate for a wider range of housing options.

## CHAPTER SEVEN

### IMPLICATIONS FOR DISABILITY SUPPORT SERVICES AND GENERIC SERVICES IN NEW ZEALAND

#### Have changes in thinking resulted in changes in practice?

The current literature on supports for daily living emphasises the rights, choices and preferences of people with an intellectual disability as central to the experience of community living. Attention has also turned to the issue of community membership, with questions being raised about the extent to which group homes have supported the development of strong networks and friendships in the community (Amado 1993). Group homes have been criticised for their tendency to produce “community institutionalisation” (O’Brien and O’Brien 1994), offering people with an intellectual disability few if any choices or control over their daily lives (Lord and Pedlar 1991). This has resulted in an emerging awareness of the need for more individualised, person-centred approaches to planning and providing support in the community (Pedlar, Hutchison, Arai, and Dunn 2000), and a move away from programme or facility-based models which simply reinvent institutional living in the community.

To what extent, then, have these changes in thinking impacted on practice in services which support people with disabilities? Smith (1994) suggested seven years ago that the ideological impact of the new supports paradigm had not reached agency practice, with the bulk of public dollars spent on people with an intellectual disability in North America paying for services focused on teaching skills and competencies and behaviour management. More recent research covered in this review shows that key issues of choice and community participation remain largely disregarded at the service level (Bradley 1996; Stancilffe and Avery 1997; Taylor 2001).

Internationally, there has been little empirical work demonstrating how the service landscape has changed in recent times (Pedlar et al 2000). These authors cite one paper by the Roeher Institute (1996) in Canada which “provides empirical evidence of a shift toward smaller living arrangements, especially in certain regions of the country” (p 332). The New Zealand situation is no different, with an absence of research on service models and on change processes in services. At an observational level, group homes remain the most common form of residential support for people with an intellectual disability in New Zealand despite their serious limitations, although there is some recognition of the need for change (Brook 1999).

An ongoing study by the Donald Beasley Institute reiterates the point that many people with an intellectual disability continue to live in a place which cannot be considered a “home”. The ACC funded project on injury prevention for adults with an intellectual disability found high levels of intentional injuries in residential services through client-to-client aggression (Bray et al 2002). It should be remembered that attributes of home identified in the literature include those which meet people’s needs for safety, security, affection, belonging, social acceptance and self esteem (Annison 2000). It seems reasonable to conclude that the service landscape in New Zealand has not changed significantly, and that residential services generally do not reflect the best

practice advocated in the current literature. A significant change in service orientation is indicated.

A recent Canadian study (Pedlar et al 2000) found that some shifts are occurring in the service landscape, from traditional congregate care to smaller homes and more individualised supports. Change had mostly occurred through the efforts of parent and self-advocate movements. As in New Zealand, the majority of services were in the non profit, rather than private-for-profit sector, with the nonprofit sector providing the most innovation in areas such as advocacy, community and self-advocate education, facilitation of self-help groups, and information resource functions. The range of services across the country was considerable and innovations included more individualised approaches to planning and funding as well as efforts to involve individuals with disabilities, families and community members on agency boards and committees.

Group homes remained the most common form of residential support, with almost half of the 801 services surveyed accommodating people in this way. A third of services provided smaller, more individualised living options such as apartments in the community. The major funding approach continued to be programme funding, making it difficult for many services to develop individualised approaches to support. Individualised funding was utilised in one-third of the agencies. Service brokerage was used by less than one-fifth of agencies, despite its suitability to more individualised and person-centred supports.

How then can services in New Zealand begin moving towards personalised models of daily living supports for people with an intellectual disability?

### **What needs to change?**

Moving to personalised supports requires major adjustments to service structures, and shifts in the structure of services entails change at multiple levels (Pedlar et al 2000). The majority of residential services in New Zealand are provided by large organisations. Some writers have described changes in their own services which suggest that change may be easier to effect in smaller rather than larger organisations (eg, Bleasdale 1995; Fitzpatrick 1996; Hulgan 1996). Nonetheless, this claim has not been addressed by empirical research, and while large organisations may face more challenges, large-scale organisational change takes place in a wide range of sectors and has its own research base. Any planned changes to large New Zealand services should be guided by best practice in this field.

### **Committed leadership and a shared philosophy**

Strong and insightful leadership is a key element in the process of change (Ashbaugh et al 1994; Kirakofe 1994). Kirakofe refers to leaders as “paradigm pioneers” whose commitment to the goal of person-centred supports is second to none. Bringing others involved in the service agency alongside so that there is a shared vision is a key part of the organisational change strategy.

Knoll and Racino (1994) suggest that the process of change is underpinned by a **key philosophical adjustment** so that terms like “community-based alternatives” and “home-like environments” are rejected:

*Once the segregation of the past is finally rejected the field can assert that: 1) there are no community-based alternatives, the only alternative is the community, and 2) service systems should not develop homelike environments for groups of people; rather they should figure out how to support individuals in their own homes... In other words, the supports paradigm is once and for all in the community (p 301).*

New Zealand policies and services may be some way yet from achieving a shared vision about person-centred supports for daily living. At the basis of this may be a poor understanding at many different levels (from policy through to practice) about what constitutes person-centred planning and supports. This review has emphasised the philosophical and practical components of this approach. It should be appreciated that the Needs Assessment approach currently used to provide access to support systems for people with an intellectual disability in New Zealand is **not** the same as the personalised planning which is strongly advocated in the current literature. The New Zealand Needs Assessment approach is currently under review by the Ministry of Health, and any new approaches which might be pursued should be guided by the now considerable literature available in this area and described in this review.

### **Changing the structures, role and function, and culture of service providers**

Moving towards person-centred planning and supports requires significant changes in the role and function of agencies or services providing supports for daily living. Such changes should be consistent with and guided by best practice as identified in the current literature. The literature supports the use of more decentralised, less formal, and more fluid or organic structures to foster the development of person-centred supports. This means a move away from highly centralised, formalised and mechanistic structures typical of many organisations and systems (Ashbaugh et al 1994). An organic model is nonhierarchical, with authority based more on knowledge, competence and expertise. It is characterised by face-to-face communication, shared values and support and empowerment of front-line staff to problem solve.

In a description of agency change associated with the relocation of people from a large institution to group homes in Western Australia, Cocks (1997) stresses the importance of addressing the roles and functions of the service provider as central to any change process. Such roles and functions need to be coherent with the needs of those people who use the service. In this service agency, the formulation of position papers and the eventual development and endorsement of a set of governing principles, comprised the first step in a series of consultative processes with key agency stakeholders. This was followed by the development of a basic strategic plan for the agency incorporating statements of mission, governing principles, and a beginning process of policy development and revision of the agency's formal constitution. The process culminated in an examination of the agency's service management structures, and the development of a new structure that would be

consistent with service users' needs and the intended future roles and functions of the agency.

The transition process involved the participation of key stakeholders, particularly families and staff through their involvement in Personal Futures Planning processes, workshops and consultations. The wider literature reviewed here, however, also strongly supports the active involvement of people with disabilities themselves. The lowering of internal barriers to change by encouraging a "culture of internal critique" (p 175) in which those involved could appreciate both the efforts and achievements of the past as well as the need for change. A learning environment can be fostered in which there are planned opportunities to reflect on the change process, to share concerns and celebrate successes (Kirakoff 1994). Cocks (1997) stresses also that the change process was characterised constantly as requiring sufficient time to be done properly and to ensure that key stakeholders understood the changes.

### ***Staff training***

Staff training at all levels is also critical if support services are to realise person-centred approaches to support. The review suggests that front-line staff need to be skilled workers who focus on getting to know the people they support and their families. Staff need to be supported to understand the philosophy, principles and practices of the service they work for, and be able to translate these into their everyday interactions with people with disabilities. Ashbaugh et al (1994) argue that staff need to be "more humble, knowledgeable and resourceful" (p 500). Staff need to accept direction from people with disabilities and their families; listen with respect; be able to analyse power relationships; collaborate with families and communities to retain existing natural supports and build more; and have skills to help people to recognise and gain confidence in their own abilities. There are clear implications for staff training, and there is an argument that formal training should be encouraged:

*The jobs of front-line workers will be enlarged. They must have the basic knowledge, temperament and capacity to grow into their jobs through experience, sharing and collaboration. And they must be well supported by other staff in the organization up and down the line (Ashbaugh et al p 501).*

### ***Systems which are consumer centred***

The literature reviewed reinforces the critical role played by service users and their families. Ashbaugh et al (1994) suggest that there must be ways for consumers to be heard and assert themselves at both the service agency level and the service system level. Traditional services have given people with disabilities and their families limited influence. They suggest that the case manager/service coordinator role can work well provided their efforts are directed towards person-centred planning processes based on the person and his or her social, vocational, and living preferences. They warn that in the United States, cumbersome paperwork associated with intake and eligibility criteria, service verifications, and client and service information for payment and accountability purposes have shifted the case-worker's focus away from the person with a disability. It is therefore important that case-

managers be given the caseload, support, and authority they need to act in the best interests of service users and their families, free of needless regulation and paperwork.

Any process of change should also recognise the importance of people with disabilities and their families as agents of change. The literature reviewed reflects the key role played by service users and families in galvanising support to move towards person-centred approaches. Organisations providing services need to support people with disabilities to think for themselves and value their rights to demand good service. Ashbaugh et al (1994) emphasise the success that comes from family- and consumer-rich collaborations organising for systems change.

If services are to be truly consumer and family based, changes may need to be made at the level of evaluation and accountability in services. Current standards for monitoring services, for example, may need to be reviewed and revised in light of the current focus on person-centred supports, and in response to the call for a better understanding about what constitutes a person's "home" (Annison 2000). In New Zealand, we do have a tradition of the involvement of consumer and families in service evaluation by the Standards and Monitoring Service (SAMS).

### **Implications for social policy and funding**

The review suggests that supports for daily living cover a diverse range of areas, crossing sectors. An intersectoral approach to service delivery is, therefore, strongly indicated. The New Zealand Disability Strategy offers strong support for such an approach, offering an important starting point for moving towards systems and structures which are person-centred. However the reality is that disability supports tend to be separate from, rather than part of generic policy development. While disability issues do need special attention, there is a danger that this special attention means that disability issues are then omitted from generic policies. One example of this issue in practice, is the lack of any clear way to support disabled parents in New Zealand, in their daily living needs as **parents**.

In their review of Canadian services, Pedlar et al (2000) stress that for positive daily support innovations to continue, support is needed at both a Government and service level:

*...more responsive and comprehensive action is required from government and service providers... the federal government can support consistency through promotion of sharing between provinces and agencies of information about innovative programs and funding arrangements (p 339).*

Public policy makers at government level also have an over-riding obligation to ensure that government funds are used prudently and in accordance with legal requirements. In fulfilling this legitimate role government agencies may impose regulatory requirements, which have the effect of restricting the flexibility of response at the point of service delivery, when such flexibility is a cornerstone of person-centred supports (Gettings 1994). It is important, therefore, that public accountability can be met while still allowing people with an intellectual disability to make their

own life choices. Gettings offers some key principles governing the design of quality assurance systems which meet this goal.

- Quality assurance should promote, on an individual basis, expanded opportunities for independence, productivity, and community inclusion.
- Consumers should be empowered to make their own life choices. The assessment of the extent to which people are satisfied with the supports they receive should be integral to any programme of quality assurance.
- Where services receive government funding, regulations should specify minimum safeguards to protect individual's health, safety, and wellbeing based on a quality assurance/ enhancement plan.
- Quality assurance/enhancement plans should be a part of every individual's support plan, and should be tailored to their individual needs and circumstances.
- Government policies should emphasise the use of multifaceted strategies for monitoring the quality and appropriateness of the services and supports provided to people using intellectual disability services, rather than relying on a single, uni-dimensional compliance monitoring process.
- Any government or local quality assurance plan should promote the provision of superior services rather than meeting minimum compliance standards.

Changes in both social policy structures and public attitude are also advocated if people with an intellectual disability are to achieve a truly participatory citizenship. Stainton (1997) argues that social policy needs to move away from paternalistic thinking in which people are viewed as lacking the ability to participate in the community and being in need of 'care', if not control. He suggests also that social policy wrongly perceives people with an intellectual disability as a unitary body defined by levels of impairment. Consequently public policy has tended to:

*...preclude participation through segregation, isolation, and low expectations and provided support on this false class of need, ie, 'the needs of the severely mentally handicapped' or 'the needs of the mildly retarded'. There is little room in this equation for the 'I' of the citizen to emerge as either a specific individual citizen or as a participant in the state or civil society (p 25).*

If this historical trend in public policy is to be reversed, Stainton claims, these assumptions must also be reversed. Instead, **participation, individuality, and equality must be assumed**. While inclusion in education for children with an intellectual disability reflects this process, there is still a long way to go. Stainton argues that **policy must allow for individually determined choices about how, when and where daily living support is provided**. Policy developments which allow direct, individualised funding, and access to advocacy which allows individuals to choose how their needs are to be met are critical. These approaches "provide the means for the individual citizen to participate and grow as an individual citizen rather than a part of some excluded putative class" (p 26). However, ideas about 'equal' citizenship need to be clarified. If equal means 'getting the same as everyone else' it can become the basis for 'dumping' and lack of support (Stainton 1997; Bray and Gates 2000). This 'difference dilemma' refers to the problem that what people need to achieve an equal citizenship differs with each individual. Hence 'equal treatment'

does not satisfy the claim for equal citizenship since different people require different types of support to achieve the same capacity for participation (Stainton 1997: p 26).

Changes in public policy are fundamental because public attitudes will only change, Stainton suggests, when the terms of participation in society change:

*When people are allowed to be full participants in life, when they share the same rights, schools, workplaces, and communities as any other citizen, they will be seen and treated as equals. It is not surprising that, in societies which have excluded, vilified and labelled people with intellectual disabilities, they have come to have a negative value in those societies. We have created a fertile bed for negative attitudes. It is only by reversing this legal, structural and social exclusion that attitudes will change and the social basis of citizenship, mutual respect, will emerge (p 26).*

**Funding arrangements** need to have the capacity to support individualised, person-centred approaches to planning and supports. This means reconfiguring funding systems away from facility based models and shaping them around flexible, customer-driven services and supports (Smith 1994). Gettings (1994) argues for a restructuring of existing methods of organising, delivering and financing services so that the person with an intellectual disability becomes “the hub, rather than the hubcap of the service delivery process” (p 169). This process of restructuring will, he suggests, pose some major challenges for the field.

Most funding for residential services in New Zealand is in the form of a residential subsidy paid directly to the provider, not to the person with a disability. The level of this funding (simplistically determined as level 1, 2, or 3) is decided by a Needs Assessor on the basis of a very simplistic tool which is **not** designed for this purpose. While there are some ‘individualised funding packages’, these are approved only for special cases. The special case nature of such packages means that their implementation can be complex and slow moving. Clearly this approach is not personalised planning. A better assessment tool and overall approach is needed to identify individualised needs for support. This review offers a range of solutions. Most importantly, though, the literature suggests that staff involved in this process need time to get to know the person, their family and others involved in their daily life, if a truly personalised support system is to be put in place.

Individualised funding approaches are particularly well designed to meet the characteristics and requirements of these approaches (Pedlar et al 2000; Smith 1994; Stainton 1997). Pedlar et al conclude in their review of Canadian Services that at the provincial level, funding alternatives need to be examined:

*The government can play an important role in ensuring that individualised funding is linked to individualised planning through the establishment of funding criteria. Further, funding arrangements need to promote and encourage options such as smaller collectives of support focusing on one or two individuals, along the lines of microboards. In such approaches, a small group of people come together to provide an individual who has a disability with care and support, utilizing individualised funding that is allocated on the basis of individual need and administered on the microboard (Pedlar et al 2000: p 339).*

Dollars are more likely to shift to person-centred supports if the new paradigm is considered to be affordable at government level, and spending is comparable to that of more traditional models of support (Smith 1994). Some recent research in this review suggests that person-centred supports and supported living is indeed fiscally viable while also improving people's overall quality of life (eg, Dehem and Chapman 1997, Emerson et al 2001; Racino 1994; Van Dam and Cameron-McGill 1995;). Racino (1994) reports that while some supported living arrangements in New Hampshire are costly, others are not because the level of supports needed by individuals varies. In looking at costs, she suggests, it is important to compare the average costs and not simply look at the expense of a single situation. In New Hampshire, one agency providing supported living services is spending the same money on average, in the new personally designed situations, which are better suited to people. From a fiscal perspective, Smith (1994) argues, person-centred supports offer two potential advantages over traditional models:

1. they allow services to be tailored to individual's needs and thereby make the most efficient use of available dollars by purchasing only what is needed rather than a predetermined package of services.
2. there is a reduced reliance on paid staff through the integration of natural supports into person-centred support strategies.

### **Achieving a sense of “community” and “home”**

Having a comfortable sense of belonging in the community and in one's own home has been identified as a critical area of focus for support services. Pedlar et al (2000) argue that there is a need for service providers to promote “‘softer’ services, such as building social networks, community education and advocacy – activities that appear not to be a priority among for-profit service providers” (p 339). In response to the comments of the people with an intellectual disability in her study, Walker (1999) offers some strategies for service providers and others to increase people's sense of place in the community.

- **Promoting safety, familiarity and identification**

People had experienced considerable uprootedness in their lives in order to receive services, resulting in a sense of loss and separation from community. A sense of safety and familiarity can be returned by assisting people to receive services in their own homes, neighbourhoods and communities of their own choice, a place in which it is possible to establish one's “roots”.

- **Promoting a sense of being known and accepted**

The kinds of places people spend time in are important in providing opportunities for relationships with others. Many people in this study had little opportunity and support for social relationships and companionship with people with and without disabilities. Intentional efforts need to be made to assist and support people to be part of shared social contexts and networks in both public and private places.

- **Promoting adaptations**  
Issues such as cost, convenience and compatibility are common to people choosing the places they go to. People in the study were supported primarily in certain locations and in certain groups of people, rather than in places and with people of one's own choice. People were afraid to explore new places if they were uncertain about the availability of support. Promoting adaptations means changes in staff roles and service systems. It means working with community members and organisations to explore ways of interweaving natural and formal supports so that people have increased choices and control over the type of support they receive.
- **Promoting choice, autonomy and control at home**  
Heller et al (1999) conclude that offering opportunities to exert choice and control in residential settings is an important way to support the dignity of residents. There are clear implications for service providers. If notions of autonomy, dignity and personal control are important to a service organisation, then the size of a person's home, who they share that home with, and the values and actions of the staff who provide support should be addressed as matters of priority at all levels of the organisation. Ascertaining which variables in a person's living environment are related to personal control should also help service organisations to identify the full range of desirable approaches in residential services. This seems particularly true for people with more severe disabilities.

But this is not just a matter of changing staff behaviour. Stancliffe et al (2000) stress that these approaches will include wider changes including organisational change; policy review; regulatory reform away from restrictive and overprotective practices; and a review of staff training. Organisations may need to review their own processes for evaluating services and supports, and seek new approaches which take into consideration residents' own ideas about what makes a home. Examples include alternative evaluation systems such as "Quest" (Oakes 2000) and qualitative service-user centred approaches (eg, Carnaby 1998). Quest evaluates the **structure** and **process** of residential supports. The structure includes the resources and systems that provide opportunities for people and the process is the point of delivery, where a staff member interacts with the resident. Quest gathers important information about the structure of the residential service (the Service profile); the quality of the opportunities available to people who receive the service (the Support Questionnaire), and the interaction between staff and residents (the Observation profile).

## Implications for research

Empirical studies of services which have changed from traditional services to person-centred approaches are needed. Gettings (1994) remarked seven years ago that attention needs to be given to examining local services which are attempting to employ the community supports paradigm:

*There is a need to review systematically the experiences of these programs and glean from them the lessons that can be learned. Unfortunately... the*

*Government... invests little money in critically evaluating the impact of promising new programmatic strategies; as a consequence, past mistakes are repeated while worthwhile new approaches are not. This situation must be reversed if the transition to a person-centered service delivery system is to be achieved (p 169).*

This situation appears to remain current in 2001. While there are a few descriptive individual case studies of person-centred programmes, only two North American empirical studies comparing the outcomes of person-centred supports with more traditional residential programmes were located for this review, and New Zealand research in this area appears to be non-existent. If New Zealand disability services are to move towards person-centred supports local research needs to be seen as an urgent priority. This must include indigenous research which considers issues of particular relevance to Maori and Pacific Island people.

Research on daily living support needs and approaches to providing supports also needs to reflect a ‘user view’ which focuses on social and environmental barriers rather than personal impairment. McKenzie (1996) argues that “Designing a more inclusive society cannot proceed without more reliable information about the quality of life of people with disabilities compared with the rest of the community” (p 120). The knowledge base which contributes to the development of disability services in New Zealand and elsewhere “needs to take account of the subjective experience of living with a disability and the inter-personal and societal relationships that accrue therefrom” (p 120).

However, a social model of disability suggests that it would be wrong to focus only on the contribution of an individual’s impairment when considering the development of daily living supports. Coles (2001) argues that everyone involved in service provision should participate in Disability Equality Training “which challenges assumptions about the cause of disabled people’s difficulties and introduces the idea that society, its attitudes and its human and physical structures create such difficulties” (p 509). Research which looks at the development of personalised supports should also consider wider societal barriers to the achievement of this new support paradigm.

## **Summary**

The current literature on Supports for Daily Living strongly advocates for a person-centred approach to planning and supports. It appears that services in New Zealand and elsewhere remain largely focused on the traditional model of facility funding and group homes, although there has been little empirical research to demonstrate overall changes in service orientation. A significant change in service orientation towards person-centred approaches in New Zealand seems indicated.

Moving to personalised supports in New Zealand requires major adjustments to service structures and changes at multiple levels. The large size of organisations providing residential services in New Zealand, may mean that the change process brings additional challenges.

The change process needs to focus on:

- a better understanding at all levels (policy to practical) of the philosophy and practice of person-centred supports and supported living in New Zealand
- a committed leadership and a shared philosophy related to person-centred supports at all levels
- changes in the culture and structure of services which are consistent with best practice in person-centred support systems
- staff roles and function, with a priority placed on staff skills and training
- the development of systems which are truly consumer centred.

Social policy needs to reflect the unique status and experience of people with disabilities. While some separate policy is needed, there is also a need to ensure that people with disabilities are included in generic policy. Public policy can support person-centred supports by emphasising participation, individuality, and equality, rather than deficits and notions of ‘care’, and by allowing for individually determined choices.

Funding needs to be flexible at the point of delivery and have the capacity to support individualised approaches to planning and support. Current funding in New Zealand based on Needs Assessment is inconsistent with this approach. There is a need for a more personal approach to assessment and for improved assessment tools.

Support services need to focus on ways to support individuals to achieve a sense of “community” and “home”. This includes looking at ways to promote safety, familiarity and identification in the community; and promoting choice, autonomy, and control at home.

Research is needed in New Zealand to improve the knowledge base on residential services. In particular little is known about the range of services provided, or about local innovations which reflect moves towards person-centred supports and supported living. Research needs to include a ‘user view’ and issues relevant to Maori and Pacific Island peoples.

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