

5. The View from Australia: Australian legislation, service delivery and quality of life

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This chapter will present an historical development of Australian services for people with disabilities in the context of disability legislation that has supported the funding of services and provided guidelines for their delivery. It will provide a review of research that has examined the effects various government policies have had upon program outcomes for people with disabilities, especially ways in which these policies have affected the quality of their lives.

The philosophies and principles that have driven the evaluation of Australian disability programs have not been dissimilar to those of many other Western countries. While there have been quite strenuous attempts to demonstrate that changes in service delivery have led to significant improvements in the quality of life of people with disabilities, it will be shown that many of the advances have been more apparent than real. Despite what appear to be honest attempts to give people with disabilities more control and say in the way they conduct their lives, there is in Australia a superficial grasp of what quality of life really means. Perhaps in our efforts to

provide better program outcomes for people with disabilities we have overlooked an injunction provided by Knoll (1990, p.235) who suggested that "the definition of program standards and quality is a process that transcends empiricism. This process ultimately appeals to the fundamental values of society."

The vast Australian continent (77 million square kilometres) is populated by approximately 17m people — nearly 65 per cent of whom live in the capital cities of the six states and two territories. The majority of the population live in two coastal regions, the largest along the south eastern seaboard and the smaller along the south western coast. Almost three quarters of the Australian land mass is relatively uninhabited.

Australia has a federal system of government with the six individual states and two territories having their own legislatures; a situation somewhat similar to Canada and the United States. However, the Australian parliamentary structures are based upon the British Westminster system.

Despite its relative geographical isolation, Australia has been significantly influenced by the philosophical and legislative

developments in the field of disability services experienced in older and more populous western countries. Consequently, similar patterns of service delivery and community attitudes towards people with disabilities have emerged in Australia's relatively short history of white settlement spanning two hundred years.

Typically, the presence of a disability was viewed as a tragedy and something to be avoided. Not surprisingly, the person with the disability was identified primarily as being synonymous with the impairment. Hence the person with the disability incorporated the negative connotations that were ascribed to the condition evidenced by the derogative terms such as "the retarded", "the epileptic", "the cerebral palsied", etc.

With the emergence of welfare systems by the federal and state governments, the needs of people with disabilities and their families were recognized through the provision of invalid pensions, rehabilitation programs, nursing homes and, for those more severely disabled, institutional care.

It is noteworthy that the Australian Federal Government enacted legislation in 1910 to provide the first invalid pension scheme for people with disabilities. The Social Services Act of 1947-77 broadened the range of pensions, benefits and allowances and led to the establishment of the Commonwealth Rehabilitation Service. This Service essentially provided a medical-ly oriented rehabilitation program to people with physical or sensory impairments in a number of large hospital-like centers situated in the capital cities of the various states.

The role nongovernment agencies could play in the provision of services was recognized by the provision in 1967 of Federal

Government funds that subsidized the establishment of educational, residential, vocational and day activity programs.

There was little, if any, recognition that the people with the disability had the right to comment upon the types of services provided or, indeed, the impact the services were having upon their lives.

The combination of the welfare and charity models saw a rapid increase in congregate residential and vocational programs throughout Australia in the post World War II period; especially in the 1960s and 1970s. Nongovernment agencies were subsidized by the Federal Government on a \$4 for \$1 basis for capital expenses and between 50 and 100 per cent for salary costs. The introduction of the Handicapped Persons Welfare Assistance Act in 1974 extended the subsidies to activity therapy centers for people unable to be placed in sheltered workshops.

Despite one of the stated goals of sheltered employment being preparation for open employment, only a miniscule number of disabled workers ever transferred to regular community-based jobs. Prior to the 1980s there was little contemplation of community-based residential programs for people who were in the several large state conducted "mental hospitals," which catered for people with severe intellectual disability or psychiatric illness.

However, during the 1970s Australia was being influenced by a number of social and philosophical forces, including the world-wide emergence of the independent living movement for people with a physical disability and the growing acceptance of the normalization principle for people with intellectual disabilities as enunciated by Nirje (1969) and Wolfensberger (1980). The

election of a reformist Federal Government in 1972 provided a change in the essentially conservative climate that had permeated the welfare services in Australia. A clear example of the reformist role the national government was to increasingly play in disability policy was in the area of special education where the Federal Government endorsed its commitment to the integration of children with disabilities into the mainstream educational systems by the provision of significant funds for teacher training, research, and the assumption by the government school system of nongovernment schools for children with severe disabilities. The proclamation of 1981 as the International Year of Disabled Persons provided a further impetus for governments, consumers and service providers to re-examine their attitudes towards the way services were being provided to people with disabilities.

Don Grimes, the Federal Minister for Community Services, in 1983, sponsored three initiatives that were to have a profound effect upon disability service delivery in Australia. The first was the funding of an Australian chapter of Disabled Peoples' International, the second the establishment of the Disability Advisory Council of Australia that consisted of people with disabilities or their advocates, and the third was the setting up of the Handicapped Programs Review.

The latter has been acclaimed as a landmark development in the Australian disability scene. The review which involved a nationwide consultation with people with disabilities, their families and service providers, culminated in the publication of *New Directions. Report of the Handicapped Programs Review* (Grimes, 1985) and the

enactment of the *Disability Services Act* (1986) that replaced earlier disability legislation.

The focus of the review and the subsequent Act was the promulgation of seven positive consumer outcomes as a basis for program development for people with disabilities. The key outcomes were:

- A place to live
- Paid employment
- Competence and self-reliance
- Community participation
- Security
- Choice
- Positive image

Grimes (1985, p. 13) summarised the focus of the review as follows:

The Commonwealth Government should set and promote philosophical directions to create an atmosphere and environment which will ensure equality of access and opportunity for all Australians, free from unnecessary restrictions on the individual.

People who have disabilities share the same rights as all other people. The recognition of equal rights of people with disabilities will be assisted by the provision of programs which are based on the needs of disabled consumers.

Not surprisingly, the Handicapped Programs Review has shown the paramount concerns of people with disabilities to be the achievement of particular goals such as choice, security and independence in their daily lives and the extent to which government provisions can facilitate the realisation of these goals.

It is clear that government activity should be focused to a greater extent on the consumer. The principle of positive consumer outcomes should be the basis of program development for people with disabilities. Such a principle will enable the development of a system which concentrates on the consumer. The particular consumer outcomes which are felt to be desirable will vary according to societal values at any given time and on the type of service being considered. Shaddock (1990) has conceptualized the consumer outcomes advocated by the *Review* within a model of quality of life that incorporates the relationship among philosophy, goals, services and outcomes along the lines of the work of Schalock (1987) (see Fig. 5-1).

These initiatives of the Federal Government in the 1980s were paralleled by similar developments in several of the Australian states and territories, either by way of major government reports and/or legislation. The developments at the state level were primarily concerned with residential accommodation for people with severe intellectual or psychiatric disabilities and resulted in a commitment to community-based living arrangements for numbers of these people, although large institutions for people with disabilities still exist throughout Australia.

The Disability Services Act (1986) basically took the initiative for the planning and execution of disability services away from the service providers and attempted to shift them to consumer groups although, as will be pointed out later, the shift was essentially from the service sector to the bureaucratic machinery of government. Incorporated into the Act were seven principles and fourteen objectives that were to become the basic yardstick against which programs and services would be measured (see Appendix 1). In a

statement to the Australian Senate in 1986 Senator Grimes commented:

The Principles recognise that people with disabilities are individuals who have an inherent right to respect for their human worth and dignity, and, irrespective of the origin, nature, type and degree of disability have the same fundamental rights as do other members of society. This applies to the realisation of individual potential; to involvement in decision-making in matters affecting their lives; to the pursuit of grievances and rights; and to services which offer the least restrictive alternative in the achievement of these ends.

The Objectives relate more directly to service delivery and cover aspects such as a focus on consumer benefits, integration of services into regular service structure where possible, and a community-based focus for specialist services where these are required.

Adoption of the Principles and Objectives will have some very practical consequences for service delivery. They will demand new standards of accountability by service providers to their disabled clients. They will require a new emphasis on the rights of privacy and confidentiality. They will herald a drawing to close of an era in which regrettably it has been possible for single organisations, in some cases without any accountability, to control the entire life of a person with a disability.

The legislation supported the following categories of service:

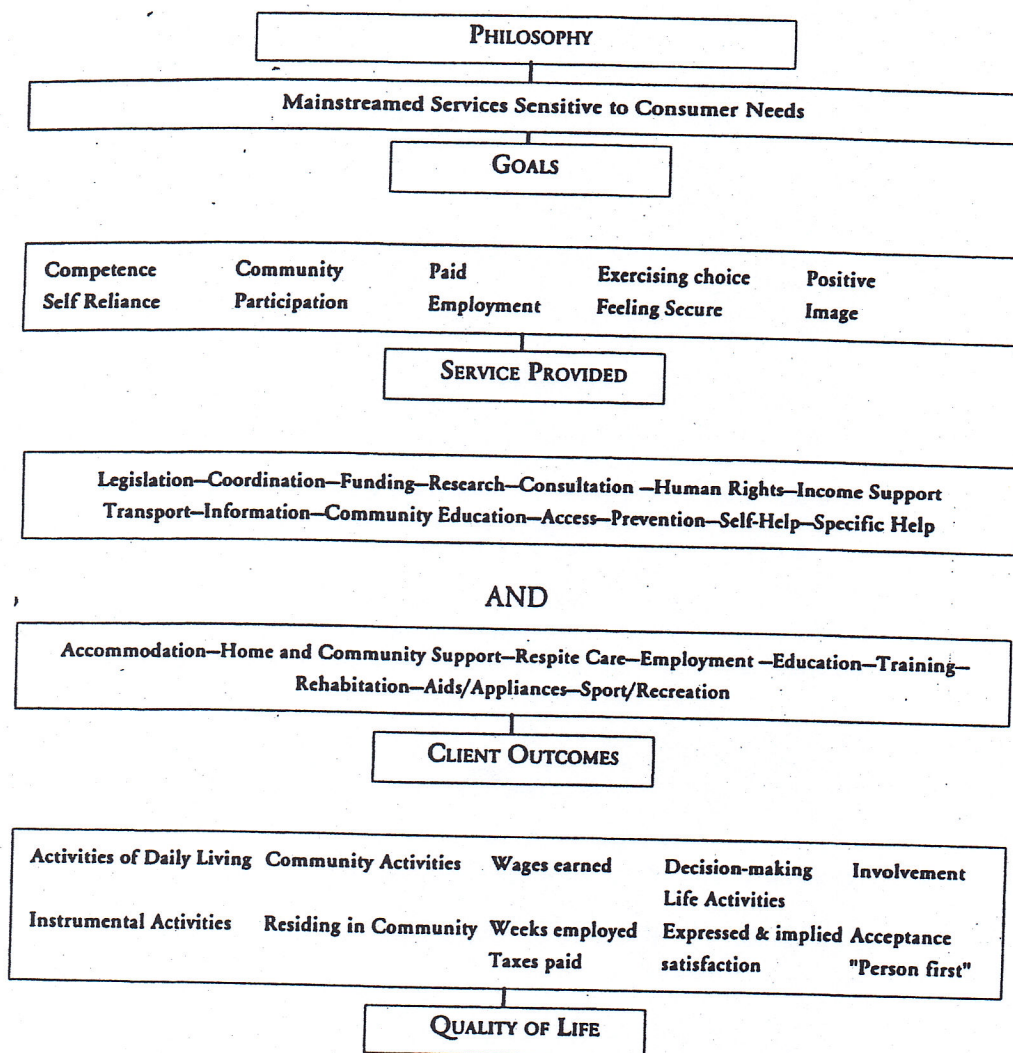


Figure 5-1. Relationships among philosophy, goals, services and outcomes (Adapted from Schalock, 1987, and Handicapped Persons' Review, 1985)

- Accommodation support;
 - Respite care
 - Supported employment
 - Competitive employment, training and placement
 - Independent living training
 - Advocacy and information
 - Recreation; and,
 - Services for people with a print disability
- Embodied in the Act was a timetable for existing service provisions to transit to

the approved service types. The acceptance of the Act and its implementation for changes in the outcomes of programs was not without its difficulties. Opposition came in part from families who resisted the notions of community-based living and working programs and from service providers, especially sheltered workshop managers, who complained that there were insufficient funds being provided to enable them to establish community-based employment programs.

The Federal Government countered this resistance by sponsoring new vocational programs that emphasised community rather than sheltered environments. In spite of a very energetic program to extend these new services, they currently serve only a very small proportion of the disabled population. One of the contributing factors for this slow expansion, suggests Morath (1992), is that change has been bureaucratically driven rather than being a cooperative effort led by the service sector.

Two more recent initiatives have been the introduction of the Disability Reform Package and the Commonwealth/State Disability Agreement. The key components of the former, that came into operation late in 1991, include a replacement of the Invalid Pension by a Disability Support Pension and a cooperation between three Federal Governments: Social Security; Employment, Education and Training; and Health, Housing, and Community Services, to provide a more integrated and streamlined service to people with disabilities. The major thrust of the Disability Reform Package is to enable more people with disabilities to enter or re-enter the workforce, with a specific emphasis upon younger disabled people.

The Commonwealth/State Disability

Agreement is a joint agreement between the Federal, State and Territory Governments to streamline the delivery of disability services nationally. The key ingredient of the agreement is the assumption of the responsibility for funding vocational programs by the Federal Government and accommodation services by the respective State and Territory Governments. Before the Federal Government provides additional funding to the States and Territories, each has been required to enact complementary legislation to the *Disability Services Act* (1986), especially embracing the Principles and Objectives. The stated goal of the Agreement is to rationalize the delivery of services to people with disabilities and to enable these people and their families to be more involved in making decisions about how services work.

It is interesting that Senator Grimes, the architect of the *Disability Services Act* (1986), in reviewing the progress that Australia has made since its implementation, recently commented that there were two concerns about the processes that had ensued. These were concern about *rigidity* and concern about *over-caution*. He noted that,

The Principles and Objectives that were set out in the Disability Services legislation in 1986 are as clear and as sensible as can be found in most places. But I must remind those involved...that they are but standards and guidelines to help us in the development of programs to assist people to fulfil their developments in society. They can never be immutable. (Grimes, 1992, p.5)

Grimes, who has recently returned to Australia having been the Ambassador to

The Netherlands, has recognized the negative side of the bureaucratically driven changes in disability services and the "political correctness" movement which has polarized the conservative and reformist streams of thinking.

In respect to the second concern of over-caution, Grimes has identified the excessive caution "which overtakes politicians and policy makers, and the bureaucratic process, for fear that they will be criticized when something fails" (Grimes, 1992, p6). Here Australia faces a critical problem. As one of the major driving forces for change and reform has been government and its bureaucracy, the issues have become highly politicized. Enterprising initiatives by individuals and individual organizations have been seen by some as attempts by governments to foster favored programs to the detriment of traditional service types.

To some extent there has been a reluctance by government agencies, both state and federal, to sponsor research programs that might examine the processes and outcomes of a variety of disability services. Driven by economic rationalist policies, governments have tended to employ economic and business consultancy firms for research programs. Grimes (1992) also noted this trend in his comment that,

consultants are used to delay the implementation of programs when the real reasons are budgetary or even political....I have the greatest respect for accountants, economists and management specialists in their place but, if they are left alone to produce solutions to problems, they have an unfortunate tendency to forget they are dealing with

individuals and not just numbers or beans. (p.7)

There has been an economic emphasis in research especially evident in the vocational area, to the detriment of research that is both process and outcome oriented. Outcome research that has examined both the subjective and objective dimensions of quality of life has not been high on government agendas.

Nevertheless, there have been some enterprising pieces of research in Australia that have addressed the specific effects that programs have had upon the quality of the lives of people with disabilities. These encompass areas such as choice and decision-making; personal competence and self-reliance; and community participation. Following the model developed in Figure 5-1, each of these will be described and commented upon in the context of the emergence of disability policy in Australia.

Choice

Having the right and the opportunity to make choices is expressed or implied in most conceptualizations of quality of life. These rights also feature in the Disability Services Act (1986) which emphasizes choice and participation in decision-making. The principles and objectives of the Act state that, like other members of Australian society, people with disabilities have the rights to "participate in decisions which affect their lives" (principle 5), to "the least restriction of their rights and opportunities" (principle 6) and to "pursuit of any grievance" (principle 7). Objectives 11 and 13 focus on the provision of advocacy support, where necessary, to assist with

decision-making and participation in the planning and operation of services. This emphasis on self-determination has been paralleled by the growth of the self-advocacy movement in Australia in recent years. Advocacy is an approved service type under this Act and a number of self-advocacy groups, funded under the Disability Services Act, are in operation throughout Australia.

The legislation contains admirable statements of rights. However, Australian research into choice and decision-making has not always indicated that these rights are available in practice to people with an intellectual disability. In retrospect, one of the weaknesses of the Disability Services Act was the lack of enforcement mechanisms when consumers felt that their rights had been infringed. Unlike the United States, Australia does not have a system of constitutional rights and freedoms enforceable at law.

What has the Australian research told us about choice and decision-making by people with an intellectual disability?

Choice in Institutional, Segregated and Community Settings

Kent (1990) found that staff ratings of residents' opportunities for decision-making were positively related to residents' self-expressed satisfaction with their life, thereby underlining the importance of choice in relation to satisfaction and subjective quality of life. She found that staff ratings of resident decision-making indicated that institutional residents were allowed to make decisions about fewer matters than those who lived in community group homes or at a farm-based residence (regarded as being between the institution and the community). Barlow and Kirby (1991) compared the residential satisfaction of adults with mild

intellectual disability living in an institution with former residents of the same institution now living unsupported in the community. Almost half of the institutional group lived in houses on the grounds of the institution and the institution was said to have "relatively few restrictions." Barlow and Kirby found few differences in satisfaction between the institutional and community groups, but community residents were significantly more satisfied with their *autonomy* than institution dwellers. In responding to a question about the best feature of their accommodation, almost twice as many community residents (47%) as the institutional group (26%) nominated "the freedom." Jiranek and Kirby (1990) reported somewhat similar findings concerning employment. They found that workers with an intellectual disability in open employment reported greater satisfaction with their freedom to make decisions at work than was the case for those who worked in a sheltered workshop. In another work-based study, Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne (in press) observed differences in the number of choices made in different settings. Consumers in "community access" programs made significantly more choices than those in sheltered workshops and small businesses. Taken together, these findings suggest that choice and personal autonomy may be more available in integrated and community-based settings in Australia.

Availability of Choice

There is a considerable variability in findings about choices available to people with an intellectual disability in community accommodation. This variation may relate to a number of variables including

staff's perception of the consumer's intellectual ability, the gender of consumers and the actual freedom available in different settings. For example, a significant association has been found between staff's perception of the consumer's level of intellectual functioning and number of choices, with people considered to be more intellectually able being given, or making, more choices (Shaddock, Bennett, Dowse, Guggenheimer, Stancliffe, Zilber, 1992). Although no gender differences in relation to choice-making in residences were found in the above study, Shaddock, Zilber et al. (in press) found a significant association between gender and choice-making in work settings, with males making more choices than females.

Different settings appear to offer varying levels of freedom. For example, Shaddock, Bennett et al. (1992) surveyed decision-making by adults with intellectual disability in private homes, group homes, hostels and institutions. Carers were asked to observe and record who made day-to-day decisions during the week and on weekends. Although carers recorded that consumers made more decisions on the weekend about when to get up, whether to take a shower, when to come home, etc., it was evident that people were denied the opportunity to make their basic decisions in all settings. Similarly, Parmenter, Briggs and Sullivan (1991) reported low levels of choice availability amongst younger (11-21 years), recently deinstitutionalized individuals with low moderate or severe intellectual disability living in group homes. The majority of these consumers had little or no say about routine daily events such as meals, the clothes they wore, the television programs they watched, spending money, participating in group activities and telephoning

family and friends. On average across these six items 16 per cent of consumers had "a lot" of say and another 15 per cent had "some" say.

In contrast to these findings, Stancliffe (1993), using an almost identical assessment instrument (taken from Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988), reported much higher levels of choice for adults living in group homes or semi-independently in supported apartments. In each of the six routine decision-making areas listed above, Stancliffe's subjects almost all (an average of 87% across items) reported that they could make the choice whenever they wanted. A further 11%, on average, said they could make these decisions sometimes. Independent staff ratings of these consumers on the same items yielded similar results. Another study, using a different assessment procedure, was conducted by Jenkinson, Copeland, Drivas, Scoon and Yap (in press), who looked at choices available to 20 adults with mild or moderate intellectual disability who lived in community group homes. They asked about specific aspects of seven major life areas, as well as family and advocate involvement in decision-making. Because of the somewhat different assessment procedure, Jenkinson et al.'s results are not as readily comparable with those reported above. Jenkinson et al. found an average of 55 per cent of consumers said they made the decisions (34% according to staff ratings).

Markedly different levels of everyday choice appear to have been available to the various groups studied above. Overall, the variability in findings suggests that community living by no means guarantees the availability of even quite mundane choices about one's daily life.

In Stancliffe's research, the areas in which people had less choice were those involving more major life decisions such as who to live with and what work to do. Similarly, when 140 choices observed in the Shaddock, Zilber et al. study were analyzed according to critical dimensions of choice, it was found that nearly all related to concrete here and now options and had minor life impact. Jenkinson et al. reported quite similar findings and, according to staff reports, the majority of consumers did not make their own decisions about their living situation and living companions (none were perceived to make this choice), choice of workplace and work done (18% made this choice) and choice of doctor (24%). It appears that people with an intellectual disability have differing degrees of access to different types of choices. These data provide support for the notion that such individuals are less likely to have the opportunity to make certain major life decisions independently.

One shortcoming of the Australian research on the availability of choice has been a lack of comparison data with the choices available to non-disabled Australians in similar circumstances. It seems self-evident that Parmenter et al.'s and Shaddock, Zilber et al.'s subjects had considerably less choice than the norm, but no data are available to determine whether the greater freedom of choice available to the adults living semi-independently studied by Stancliffe (1992, 1993) was within ordinary expectations. Stancliffe (1992) noted that many of his subjects who lived in apartments reported having limited choice about matters such as having pets, because their lease precluded it or they needed to seek their landlord's permission. This situation

was no different for non-disabled tenants in their building and it seemed as if their freedom to have a pet was no more restricted than their neighbors.

Choice and Service Provision

In Australia, the predominant model of community living service is the group home, with full or part-time staffing. The limitations on choice imposed by this form of group living were explored in participant observation studies by Stancliffe (1991) and Bennett, Shaddock and Guggenheimer (1992). Both studies found that a range of individual preferences regarding meals, household routines, leisure, etc., could not be met because of the needs of other residents or of the group as a whole. Interpersonal conflict arose partly because moving into a group home brings with it the necessity of living with the others who already reside there, even if they are not the people with whom one would otherwise have chosen to live. Staff are faced with the difficult task of responding to the choices of more assertive individuals and encouraging choice-making by less assertive people in the home. Parmenter et al. (1991) reported that community excursions undertaken by group home residents were usually supervised *group* activities. This suggests that there was little room to indulge or develop individual preferences. Stancliffe (1992, 1993) found that there were a number of areas where residents of supported apartments had more choice than their counterparts in group homes.

Bennett et al. (1992) drew attention to issues associated with choice and "duty of care" in group homes. It is expected that staff will look after the health and welfare of consumers in group homes and promote

choice. However, consumers may be unaware of the consequences of their choices so trial and error learning could be dangerous. There are no clear guidelines for carers about when it is legitimate to stand back, allowing the person to learn from consequences, and when they should intervene to protect the person (and themselves). It appears that the lack of clear directions for staff on the extent of their responsibilities in relation to consumer's choices and their consequences helps to maintain overly conservative practices in Australia. Perhaps the dominance of the fully staffed group home as the principal option available for community living should be re-examined, if true choice is to be available and individual preferences are to be pursued.

Individual Service Plans

One of the main formal mechanisms for participation by consumers in decisions about the services they receive is through direct involvement in the individual planning process. Several authors have described procedures for the evaluation of such plans (Hudson & Cummins, 1991; Shaddock & Bramston, 1991).

Australian research evidence reveals a mixed level of compliance with the individual planning process and a low level of consumer participation. Some organizations are struggling to come to terms with developing individual plans and the gap between legislation and implementation has been apparent wherever such plans have been evaluated. Stancliffe (1988) reviewed an entire service system made up of 20 group homes and 86 residents. He reported that only 33 per cent of the residents had any written program at all, with a mere 10 per cent having a genuine individual plan

which dealt with their life, needs and preferences as a whole. For the majority of residents in this study, there was no formal individual planning process in which they could participate to make choices about goals. Contrary findings were reported by Shaddock and Bramston (1991), who found that 50 of 52 (96%) randomly selected government-run residences had individual plans for the consumers. However, only 26 per cent of the individual plans they reviewed referred to the previous plan, suggesting that individual planning may have been a very recently introduced practice in these houses. Shaddock and Bramston noted that, while an average of 6.2 people were in attendance at an Individual Program Plan meeting, the person most important in the process, the client about whom the plan was being formulated, was present at only 53 per cent of the individual planning meetings. The presence of a relative or advocate to assist the consumer was even less frequent. Even when individual planning is under way, it seems that the most basic form of consumer participation (physical presence at the meeting) is often absent.

If the consumer is present at the individual planning meeting, what degree of participation and control does he or she experience? Stancliffe (1992) asked staff and residents of community living services about individual plans. Staff responses indicated that only 13 per cent of consumers did not have an individual plan, whereas about half of the consumers stated that they did not know anything about their plan or did not have one. This suggests a low level of awareness by consumers of their individual plan. In the light of Shaddock and Bramston's findings, it could well indicate a lack of consumer involvement in the

individual planning processes. Amongst the consumers in Stancliffe's study who were aware of their plan, over two thirds felt that they had limited or no say about the individual plan goals. They mostly saw staff and family members as the ones who decided about these goals.

Some people with an intellectual disability are dubious of the individual planning process itself and its impact on their lives. Shaddock, Guggenheimer, Bennett and Bugel (in preparation) found that many self-advocates thought that such plans were ineffective ways of giving choice and that they were "unnatural," because only people with disabilities have them. Others were more positive, but stressed the importance of collaborative and sensitive implementation, and the need for the plan to target the *individual's* opinions, needs and best interests. Although the individual planning process is meant to involve and empower consumers, these research findings suggest that it may have little effect on the person's quality of life.

Self-Reported Choice versus Third Party Report

Quantitative research requires that technical factors such as reliability and validity be addressed. One issue which has occupied the attention of some Australian researchers has been the relative merits of self-report and third party informants in providing information about choice and quality of life. Burnett (1989) compared responses to the *Residential Satisfaction Inventory* from staff and people with moderate or mild intellectual disability who lived in community residential units or hostels and found a correlation of .11. Interpretation of this very low level of agreement was confounded by substantial problems of acquiescence

(the instrument has a yes/no response format) and unreliability for the consumer responses. Kent (1990) reported very poor inter-rater agreement between residential staff members in response to questions about responsibility, autonomy and choice available to clients. She suggested that "*staff are not as reliable a source of information as the residents themselves*" (Kent, 1990, p.230).³

Parmenter et al., (1991) reported discrepancies between staff statements that most residents are involved in decision-making and the results of assessment of choices available to residents. Jenkinson et al. (in press) reported a marked divergence of opinion between residents and staff in relation to three items — choice of living companions, choice of workplace and work performed, and choice of activities in one's free time. Substantially more residents reported that they had a choice about the first two of these matters. Resident autonomy on these items was indicated by a "yes" response, but Jenkinson et al. did not include any specific safeguards against acquiescence, so the interpretation of these resident-staff differences is open to question. Stancliffe (1993) identified and eliminated all acquiescent responses by administering oppositely worded versions of the Kishi et al., (1988) checklist. As already noted, Stancliffe's subjects had very high levels of choice on many items. A "ceiling effect" may have been partly responsible for the fairly high level of consumer-staff agreement on many items (average agreement was 77% for the six items mentioned earlier). There was a significant difference between consumer self-ratings and staff ratings of these consumers on two items — choosing whom to live with and choosing what job to have or what work to do (average agreement 41%). Consumers rated them-

selves as having a greater degree of choice than did staff.

It seems that consumers and staff often differ in their perception of the availability of choice in certain areas. This reinforces the fundamentally *subjective* nature of individual perceptions of choice and the importance of obtaining information about choice *directly from the person* whenever possible. If the person does not feel that he/she has a choice, then it is reasonable to assert that no choice is really available regardless of opinions to the contrary.

These findings have obvious implications for further research on choice. The validity of third party data is questionable, and where self report is possible, it should be used. Also, more work is needed on the development of ways of gaining valid and reliable information from consumers, particularly those with severe intellectual disability and communication impairment. For example, Shaddock, Dowse, Zilber and Bennett (1992) are currently researching a "communication profile" designed to help carers and staff who may not know a person well to promote the expression of choices.

Summary and Conclusions on Choice

Significant Australian research attention has only recently been given to the topic of choice and people with an intellectual disability. The importance of choice as a component of quality of life is widely agreed upon, but the high levels of choice and autonomy heralded by recent legislation such as the *Disability Services Act* (1986) appear not to have become widely accessible. Whilst greater choice is available in integrated and community settings, living in the community by no means guarantees

a high level of choice. Research has shown the availability of choice to be quite variable in community accommodation and in work settings, with disturbingly low levels being reported in some cases. Data about the degree of choice available to non-disabled Australians would be helpful in interpreting such research findings more fully. There is evidence to suggest that people with an intellectual disability are less likely to have a free choice about certain major life decisions, including major decisions about service delivery. Although group homes are the predominant form of community living service in Australia, significant difficulties were perceived in providing real choice and catering to individual preferences in such settings. Individual planning processes are by no means universal in Australia. Research indicates that there is limited involvement by consumers in their own individual planning meetings, with an even lower level of choice about one's individual plan goals. Australian research suggests that a distinction should be drawn between self-reports of choice versus third party reports. In conclusion, although Australian legislation has given prominence to the values of choice, autonomy and involvement for Australian citizens with an intellectual disability, there is an alarming gap between policy and practice.

Personal Competence and Self-Reliance

Competence and self-reliance are amongst the key "positive consumer outcomes" which have been a focus of recent Australian legislation, such as the *Disability Services Act*, 1986. Major deinstitutionalization initiatives have taken place in a

number of Australian states. Australian research has examined the effects of these initiatives on aspects of the quality of life of the people with intellectual disabilities, including changes in competence and self-reliance resulting from the move to the community.

Deinstitutionalization

The most extensive study of deinstitutionalization in Australia has been conducted by Cummins et al., (Cummins & Dunt, 1990; Cummins, Polzin & Theobald, 1990a; 1990b; Dunt & Cummins, 1990). This series of reports describe the relocation of about 100 adolescents from St. Nicholas hospital in Melbourne, Victoria, to small group homes and charts their progress over a four year period.

St. Nicholas Hospital was the epitome of Dickensian institutional architecture. Located in the inner-city, it comprised four wards with high ceilings and bare walls. The accommodation offered no privacy, primitive ablution facilities, and a need for daytime artificial lighting due to small windows. All meals were cooked in a central kitchen and the elevators were old and unreliable. This facility housed some of the most disabled children and adolescents in the state of Victoria.

Well before the institution's closure, a study was commissioned to record the progress of clients and staff as they moved into their new homes. Two baseline measures were made on a wide variety of variables before the move, and then at 1.0, 1.4 and 4.1 years following relocation.

Despite a history of similar research in North America, this study has special significance due to the extreme level of client disability. All had been diagnosed as being

severely/profoundly intellectually disabled, almost all had additional multiple disabilities and were nonverbal. Because of this, the move was undertaken with some trepidation in fear that it might increase mortality and have no long-term benefits.

In fact, none of these fears was supported by follow-up data. Briefly stated, there was no increase in mortality and life-quality was substantially improved. Life-routines became more normalized, living conditions were vastly improved, interaction with parents and the community increased, and life-skill development was substantial.

Of all the results to come from this study, the latter are of most interest. At the time of leaving the hospital the clients had a mean age of 16 years. The Progress Assessment Chart (Gunzberg, 1973) was used to determine their level of life-skill development at each of the intervals previously described. What was expected, on the basis of previous literature was, at best, a short-burst of development following relocation, after which the rate of development would decrease or even revert to institutional levels. In fact, the data showed an initial burst of development, as predicted, but this was followed by sustained skill acquisition. Over the period 1.4 to 4.1 years following relocation, six of the nine skill domains showed a significant level of development. Moreover a retrospective analysis of the overall skills acquisition rate indicated a total gain of 1.6 developmental years over that which would have been expected had these clients remained in the hospital.

An additional point of interest was the reaction to parents to the move. Consistent with previous North American studies, the families reported some initial concern with the idea that their son or daughter was to be

relocated (Cummins & Dunt, 1990). However, this was also tempered by a generally positive view of how their child would cope in their new group home environment. Ellis (1984) administered a questionnaire to 67 parents of the total 101 children. She found that they generally held positive expectations of their relative's ability to adapt to the new environment; 57 per cent felt that their son or daughter would easily adapt to the new physical environment, 50 per cent to new staff, and 70 per cent to the smaller group structure. Following the move these positive expectations were confirmed for most families. Cummins and Dunt (1990) reported that 18 months after the move many of the families initial concerns had dissipated; a trend which was even more marked after 4 years (Cummins, 1993).

Support for families

Deinstitutionalization and the closure of institutions has, as one consequence, an increased pressure on families to keep their disabled son or daughter at home. Moreover, there is no doubt that severe deficiencies in personal competence act as a stressor within the family environment. This is particularly the case when combined with overt behavior problems. Kupinski, Mackenzie, Meredith, and Stoller (1973) reported that the most common reason parents sought the institutionalization of their child was behavior problems and the consequential disruption to family life.

So, in order to ameliorate this burden, families have been surveyed in an attempt to establish the kinds of service support most useful to them. As an example, Baxter (1989) studied the kinds of needs expressed by parents caring for children with a moderate/severe level of disability in Victoria. She

found that foremost amongst these was the need to receive appropriate information about, and direct help with the child. This was so irrespective of social status, it was somewhat disconcerting to find, therefore, that a majority of parents of moderately/severely disabled teenagers had never received direct support from agencies (Baxter, 1986), even though such services were available. One reason for this may have been a simple lack of knowledge about such services. In a Queensland survey of parents and clients, Brown and Ringma (1989) found that 60 per cent had experienced difficulty in obtaining information on services. Moreover, the information had generally been acquired in haphazard ways, with few people realising they could seek relevant information from government departments.

Issues of Maladaptive Behavior

A detracting influence on personal competence and self-reliance is maladaptive behaviour. Tonge and Einfeld (1991) have confirmed that the incidence of serious emotional and behavioural disorders among children and adolescents with an intellectual disability is two to three times the rate of non-disabled children.

Various forms of treatment have been proposed to eliminate such behaviours. For example, King, Ollendick, Gullone, Cummins, and Josephs (1990) have concluded that maladaptive fears and phobias in such children can be successfully treated by exposure-based interventions and, in Victoria, Behavioral Intervention Support Teams currently provide behavioral training for parents and clients in the home environment with considerable success. A similar program was initiated in the state of New South Wales (Parmenter, Gray & Martin, 1990).

A more serious issue is raised by people involved in crime, either as the perpetrator or the victim. In the case of the former, some conflicting reports are available with Hayes (1991) reporting that 12-13 per cent of the NSW prisoner population have an intellectual disability, while Jones and Coombes (1990) claimed an incidence of 1.2 per cent in Western Australia. The difference may, in part, reflect different committal procedures. Jones and Coombes claim that 'up to one third' of charges made in Western Australia against people with intellectual disabilities are withdrawn because the people are clients of the Authority for Intellectually Handicapped Persons.

These two reports are also notable for their differences in the reported incidence of violent crime. Jones and Coombes (1990) reported that 47 per cent of the prisoner population considered either to have an intellectual disability or to be "borderline" were serving a sentence for a violent crime against a person and, of these, 78 per cent were sexual offenders. Overall, 37 per cent of prisoners who could be classified as intellectually disabled or borderline were serving terms for sexual offences; about three times the incidence of the rest of the prisoner population (13%). Hayes (1991), on the other hand, concluded that in New South Wales there was no evidence that people with intellectual disabilities were over-represented in the sex offender population.

There are several reasons to suspect that the Jones and Coombes (1990) data are inflated. In the first place their sample size was small; only 6 people diagnosed as having an intellectual disability and 13 people designated "borderline". Secondly, their definition of the 'borderline classification was very loose. Finally, the differen-

tial committal procedures referred to above may well have resulted in the selective retention of those people charged with more serious crimes.

These data do not provide compelling evidence that people with intellectual disabilities are more likely to commit sex-related offences. They are, however, certainly more likely to be the victims of crime. Carmody (1991) detailed figures from the Sexual Assault Service (NSW) which record that in the first six months of operation in 1989, of the 855 referred adults, 6.4 per cent were intellectually disabled. In support of this high incidence she cited the Office of the Public Advocate (1988) which concluded that sexual offences and sexual assault are the most frequently recorded crimes against this population. This issue is especially important as feelings of security and safety have been shown to be a key factor in the quality of life of this population (Halpern, Nave, Close, & Nelson, 1986).

These concerns are highly relevant to the issue of sex education. As Carmody (1991) noted, a lack of sex education and opportunities to develop a sexual identity results in confusion and uncertainty about what is acceptable behaviour from other people. This, coupled with the persistent experience of powerlessness in the face of authority, may allow these people to be unaware that they have been the victim of a crime, or that they are entitled to seek police assistance.

Summary and Conclusions on Personal Competence and Self-Reliance

Efforts to enhance personal competence and self-reliance have focused especially upon deinstitutionalization and com-

munity-based training. The former has resulted in a substantially improved life quality for those people who have returned to the community. This has been found to apply particularly for people with a severe/profound level of disability in terms of their skill development, normalization of routines and personal interaction. Community-based support and training, on the other hand, is undergoing a phase of rapid development where much of the focus is related to issues of maladaptive behavior. Of particular concern in the area of community living are people who are the victims of sex-related crime or exploitation; a situation which is certainly related to the overall inadequacy of sex education programs in this country for people with intellectual disabilities.

Community Participation

The extent to which people participate in community-based activities is a component of quality of life (see Figure 5-1) and another of the "positive consumer outcomes" targeted by the *Disability Services Act* 1986. Australian research has provided insight into the forces influencing levels of community participation in areas such as community living, education, health care and employment.

Opportunity for Community Participation

One force which operates on many people with intellectual disabilities is the attitude held toward their community participation by parents or care-givers. These attitudes tend to be conservative. For example, Ellis (1984) asked the parents of St. Nicholas Hospital children how they antic-

ipated the level of community acceptance of their children once they had moved to a group home. While the overall level of anticipation was generally positive, 21 % expected that the neighbours would have trouble accepting the group home, while a further 33 % anticipated no more than partial acceptance.

More recently, Grbich and Sykes (1990) interviewed Victorian parents of children aged 13-18 years with a severe level of intellectual disability. While most parents (83%) agreed in principle with the ideals of normalization, in practice they were concerned that the lack of community service resources might have unfortunate consequences for their offspring. Moreover, when asked to nominate the expected future living placement for their children, a relatively high proportion nominated an institution (8% for males; 21% for females), with the other options being family care (35% M; 44% F), group home (53% M; 28% F), and independent living (4% M; 7% F). In terms of their perceived future work environment, the majority nominated a segregated setting (60% M; 83% F).

There is, however, some evidence for changing parental attitudes towards higher levels of community participation. Foreman and Neilands (1991), in a survey of retrospective data, found that whereas only 8 per cent of parents whose children were born in the 1970s regarded a regular class as the ideal placement for their child, for the parents of children born in the 1980s this had risen to 21 per cent.

Another critical factor affecting community participation is care-giver and professional attitudes. In a survey of New South Wales group homes, Parmenter et al. (1991) found that the majority of staff

(65%) were definitely positive in their views of people with disabilities living in the community. However, some concerns were also expressed and 23 per cent felt that the residents were gaining few benefits from community living. This attitude was related to the low level of community interaction achieved by some of the residents and their continued high levels of dependency.

A Victorian survey of staff in Special Development Schools for children with a severe/profound level of disability produced similarly cautious attitudes concerning the value of integration for their students (Grbich & Sykes, 1990). These staff viewed social benefits as the only positive feature of integration, an attitude probably influenced by poor support services and inadequate teacher education.

Other professional groups hold more substantial conservative attitudes. Beran (1990) conducted a survey amongst medical staff involved in the area of developmental disabilities and concluded that they felt devalued, were experiencing declining morale, and that their authority was being undermined by the nursing staff. The author also expressed dismay that 'patients' were being integrated into environments in which they could not cope and that there was "an evolving ineptitude in dealing with this sector of health delivery for which no one appeared to show much concern" (p.277).

In terms of community understanding about intellectual disability, surveys conducted during the 1980s have generally indicated a high level of knowledge concerning the characteristics of this disorder (Ellis, 1984; Foreman & Andrews, 1988). Unfortunately, however, community attitudes are characterized by the same stereo-

types as are found in other Western cultures. Gething (1990), for example, has reported the general perception of people with disabilities to be that they are less well adjusted and less capable in terms of personal characteristics which have no necessary link with their actual disability.

The level of community concern with deinstitutionalization, however, seems to be low, with little overt opposition to the establishment of group homes. Foreman and Andrews (1988) conducted a survey using retrospective data on neighbor attitudes after at least one year of group home occupancy. They reported before vs. after attitudes to have changed towards positive (41% to 93%) and away from negative (17% to 2%).

An important aspect of enhanced community participation should be consumer consultation on the nature of support services required. Unfortunately, however, the extent of client consultation has been found to be low. In their Queensland survey of parents and clients, Brown and Ringma (1989) found that they had generally not been consulted by the service delivery agencies, and had not participated in making decisions regarding the agency. However, a persistent finding in this area is that parents and clients usually regard such lack of consultation as appropriate. Brown and Ringma (1989) reported that consumers expressed a personal reluctance and a sense of inadequacy regarding such participation. In many ways this finding is not surprising given the substantial and sustained power-differential which dominates the parent/client-professional interaction. However, it is highly undesirable if the aim of understanding consumer needs is to be achieved.

Employment

Of all areas of community participation, none is so coveted as paid employment. Not only do people with disabilities prefer open employment (Parmenter, 1988), but those who actually gain open employment seem to evidence a higher level of job satisfaction to those in sheltered employment (Jiranek & Kirby, 1990). Compared with people who are unemployed, however, both employment groups provide evidence of enhanced psychological well-being.

Despite this, the manner of integrating and supporting people in open industry is a poorly researched area. One recent study has reported on the success of an "enclave model" at the Australian Mint (Warth, 1990). In this situation a small group of workers worked as a unit within the industry, with payment linked to productivity. It will be interesting to see whether this model survives, with its overtones of sheltered employment in a community setting.

The preponderance of research in vocational areas has been driven by economic imperatives, rather than a conscious effort to determine the effects the various competitive and supported employment programs are having upon the person's life quality. Undoubtedly, there are good economic reasons for having people with disabilities as part of the paid workforce. For instance, Jeltet (1991) found that there were substantial financial benefits for people with an intellectual disability who are in a supported employment program as well as for the taxpayer. In a sample of 38 job placements over a four-year period it was found that for every public dollar spent a consumer earned 84 cents compared to 21 cents for persons employed in sheltered workshops. Two comprehensive economic analyses of one

of Australia's leading supported employment services, *Jobsupport*, have revealed that over time supporting people with significant intellectual disabilities in the open workforce compares favorably in both cost and employment outcomes with other models of support, especially with payments of a pension alone (Tuckerman, Morgan, Smith & Delahunt, 1992). Jeltet (1991), and Clear and Mank (1990) have highlighted the need of many people in supported or competitive employment programs for support, particularly in the area of social integration, as well as job skills training. Parmenter (1992b) suggested that one of the major reasons for the slow growth of innovative employment programs worldwide was the lack of adequately trained personnel to implement comprehensive training programs that addressed both the vocational and personal needs of people with disabilities. The push for economic and social independence of people with disabilities espoused by government legislation presents somewhat of a paradox when viewed from a social welfare perspective.

This situation is especially evident for people with severe and multiple disabilities, for whom significant periods of employment may not be feasible or may not be their preferred option. In a survey of post school options for people with disabilities, Parmenter and Knox (1989) found the group most underserved in the provision of day options was this population, a situation that still obtains in 1993.

In an attempt to address the wider social and personal issues of community-based employment, some promising insights are being revealed in studies that are utilizing a qualitative methodology. In a study of the social networks and support

mechanisms for people with mild intellectual disability in competitive employment, Knox and Parmenter (1993) found that the major sources of social support came from the person's family and/or from social organizations catering for people with disabilities. Support obtained in the workplace generally did not extend beyond it, nor was it integrated with the wider support networks. This in-depth study of nine people suggested that a more detailed analysis needs to be made of the social support construct. In particular, the roles that friendship networks play need to be examined, as it appears that community-based employment is not providing the same opportunities for friendship development as it does for people without disabilities.

A similar study of ten people with a severe intellectual disability employed in a supported work program operating as a small business, which also employed non-disabled workers, showed that most of the observed interactions between the ten targeted employees and others were initiated by the work supervisors and most were work related (Ford, Parmenter & Koop 1992). Nevertheless thirty-two percent of the interactions were between the ten targeted employees and other disabled employees. Overall the targeted employees were, for the most part, passive interactors in that they initiated far fewer interactions than they received. Not surprisingly, the majority of interactions were work-related but during periods of arrival, departure and break times the incidences of teasing and joking between supported employees and their non-disabled co-workers significantly increased. The results of this study high-

tween workers in community-based employment programs.

Actual Levels of Community Participation

In Australian institutions, as the world over, the extent of client participation in community activities is very low, even when measured against contact with their own families. In Victoria, Krupinski et al. (1973) reported on family contact with people in institutions. They reported that of those with parents still living, only about half were visited at the institution, and less than half had been home during the past twelve months. Moreover, 53 per cent had no visitors other than parents and 51 per cent had not left the institution at all during the preceding year. More recently, Suttie and Ashman (1989) have also reported very limited levels of community contact in people with a mild/moderate level of disability living either in institutions or large group homes. They found that less than 30 per cent participated in general community leisure activities on a regular basis, about two-thirds never received visits from family members, and none reported friendships outside their residential setting.

Cummins et al. (1990) found even lower levels of community participation among the ex-St. Nicholas residents. While a substantial increase in the proportion of clients who engaged in community activities was recorded following deinstitutionalization, from 13 % - 33 % in absolute terms the degree of participation remained low. After four years living in the community the average resident engaged in two community-based activities per week. This

also remained low, at about once per two months for relatives, and three times per month for friends. It was hypothesized that these low levels reflect a legacy of the almost total community isolation while in the hospital. The severity of their disability is also likely to have been a contributing factor.

In terms of the kinds of leisure activities engaged in by people living in the community, Barlow and Kirby (1991) found them to be quite similar to the general population. Of the top ten leisure pursuits, six were in the top ten of the general community.

Community Involvement and Life Quality

While it is very clear that the objective life quality of people has improved following their return to the community, the data on subjective well-being are scarce and ambiguous. Barlow and Kirby (1991) compared two groups of people with mild intellectual disability employed full-time in a sheltered work environment, one group was living in an institution and the other in the community. Comparisons revealed essentially the same level of life satisfaction, self-esteem, and locus of control between the two groups. The only significant difference was that those in the institution were more satisfied with their social life, and those in the community with their autonomy.

More recently, Cummins (1992a) has developed the Comprehensive Quality of Life Scale (ComQol) which measures both objective and subjective life quality across life "domains" of material things, health, productivity, intimacy, place in community, safety, and emotional well-being. For

non-disabled adults the scale is self-administered. However, for people with an intellectual disability it is more difficult to administer since the subjective scales require quite a high level of cognitive functioning in order to be completed validly. They require the conceptualization of the abstract terms "importance" and "satisfaction" and the ability to rate these onto a Likert scale.

Therefore the version for people with intellectual disabilities (ComQol-ID) incorporates a pre-testing protocol to determine whether the person being tested can validly use the scales. This involves a three-step process.

- Arranging wooden blocks in order of large to small
- Matching the blocks to a 'ladder' scale of size on paper
- Using an Importance Scale with objects known to be important to the persons being tested

If the person is able to succeed with this pre-testing, then they can use a version of ComQol that adjusts the complexity of the Likert scale to match the person's level of competence. At a minimal level of usage this involves a binary choice for each item.

The ComQol-ID Scale has recently been tested on 60 clients and their carers; the clients responded for themselves and the carers provided additional third-party responses for their clients (Cummins, 1992b). In summary, the clients' subjective responses indicated a life quality within the normal range. However, major discrepancies were found between the individual carer-estimations of client life quality and the estimations obtained directly from the clients. These

results emphasise the danger of relying on third-party estimations of subjective QOL.

Summary and conclusions on community participation

Opportunities for Community participation appear to be governed substantially by the attitudes of families, service providers, and members of the general community. In general, such attitudes have been found to be mainly positive, with the level of acceptance increasing over time. Such attitudes can also tend to be conservative, especially relating to such issues as integrating children with severe to profound levels of disability into regular schools, and in relation to providing effective medical care to group homes. There is an increased level of community participation among people who were previously institutionalized, albeit at quite a low level of absolute terms. Moreover, employment confers a heightened state of well-being among these people just as it does for members of the broader community. However, a closer analysis needs to be made of the broader dimensions of working in the community, especially a study of support networks. The development of the Comprehensive Quality of Life Scale has enabled people with an intellectual disability to rate the importance of items according to their perceived importance.

The Future

There is little doubt that the last decade has witnessed a major revolution in the way services are provided for people with disabilities in Australia. One of the major catalysts in the paradigm shift has obviously been the federal government's leadership in enacting its 1986 legislation that will

possibly be judged as Australia's most significant contribution to disability services in this century.

Despite the great promise held by rhetorical statements such as those contained in the Principles and Objectives of the *Disability Services Act* (1986), research detailed in this chapter reveals that much has yet to be realized in people with disabilities achieving those aspects of life quality that are very personal and subjective. Many would argue that while structural changes to a person's lifestyle are necessary prerequisites for the achievement of a desired quality of life, they are not alone sufficient. Thus it is not the environments alone that should be emphasised, but the way in which people interact within those environments, and in so doing develop a self-identity with which they are comfortable and from which they derive satisfaction.

Therefore, while we have established a better infrastructure upon which to base our disability services, with emphasis upon community-based living and working, much remains to be accomplished before the essential elements of desired quality of life can be achieved. A significant impediment to the realisation of this goal lies in the ever present danger that we may, in Burton Blatt's (1979) term "bureaucratize" the very values on which services rest.

The roles that governments play in shaping social policies need to be critically examined. In Australia, at present, there is an uneasy relationship between government, disability advocacy groups and major service organizations. Much of the debate centers naturally upon financial resources and mechanisms to implement and monitor services. As this review has revealed, too little of the debate has focused upon those outcomes