

Community participation 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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June 2003



ISBN (Document): 0-478-25321-4
ISBN (Internet): 0-478-25322-2

HP: 3667

National Advisory Committee on Health and Disability
(National Health Committee)

Wellington
June 2003

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PLAIN LANGUAGE SUMMARY

Introduction

People with disabilities and the Government agree that they should be supported to participate fully in the community. But what does “community participation” mean? What is “the community”?

There are many different ideas about what “community” means, and it is often seen as the opposite of living in an institution. The three important points to think about are that “the community” involves

- a **place** where other people do things
- other **people** to do things with and get to know
- a feeling of **belonging**.

For adults with an intellectual disability, community participation usually means doing things with non-disabled people, not only with other people who have an intellectual disability. It can involve lots of different areas of our lives – school, work, leisure, sports, getting “out and about”, friendships, helping other people.

The community itself is not always welcoming, however, and sometimes adults with disabilities are lonely or teased or do not know what to do in some situations. To make community participation work for everyone, the community may need to change too.

What has happened in the past?

When white people first came to New Zealand there was no help for families with disabled children. There were no support services for adults with an intellectual disability.

Later on some institutions were set up for all sorts of people that needed extra help or were seen as “problems”. Some of these places were actually gaols.

Special institutions for people with an intellectual disability were set up from the 1920s onward. So instead of living in the community with everyone else, people with an intellectual disability were often sent away to institutions. Segregation can also be seen in the setting up of separate special schools and workshops for people with an intellectual disability.

Almost all the institutions have now closed and the people living there have moved to live in houses in ordinary communities. Even then, they can sometimes still be isolated and not spend much time in the community.

The experience of community participation

Studies have been done to find out:

- **where** adults with an intellectual disability spend their time

- **who** they spend time with
- **what** they do and what is it like for them.

What have these studies found about adults with an intellectual disability?

- Some people who live with their families often have only a few friends and do not get out into the community very much.
- People who live independently or with just a few other people tend to get out more and have more friends, than those who live in homes with five or more other people.
- Some people are more able to join in community activities than other people, but parents or staff may still not encourage them to do this.
- Even when people are involved in community activities they still may not meet other people much and find new friends.
- Older people are likely to be more lonely and have fewer opportunities to get out and join in community activities.
- Many of the activities people are involved in, happen in **groups** of adults with an intellectual disability.
- Many adults are not given choices about where they would like to go and what they would like to do in the community.
- Adults who are given more choices and responsibility in their lives, are more likely to be involved in the community.
- It is important for parents and staff to encourage and support adults to be involved in community activities.

Friendships

Having friends and belonging is a very important part of being in the community. People feel cared for and valued, and feel they have something to give to other people too.

Studies have found that many adults with an intellectual disability have very few friends – apart from family, staff, and other adults they live with or spend the day with. They are likely to have more other friends if they live in smaller homes. Younger people often have more friends. If people have severe disabilities or difficult behaviour they often have fewer friends.

Adults with an intellectual disability are often **in** the community, but not really **a part of** the community, but out on the “fringes”. They often need staff support to help them to join in and make friends in the community. Friendships may also need help to last.

Practical things can be a problem too – like not being able to use a telephone; not enough money; and no transport.

Other people in the community can sometimes be unkind to adults with an intellectual disability.

Sometimes friendships with people who used to be staff can last a long time and be very enjoyable.

Adults with severe disabilities will need support to meet with friends and learn about how to enjoy doing things together.

Everyone needs social activities and opportunities to make new friends and enjoy time with old ones.

How can staff support community participation?

Staff may need special training on how to best support adults with an intellectual disability to become part of their community. The studies show that staff can learn to support people with severe disabilities too.

Sometimes staff can actually “get in the way” of adults getting out and making new friends, because they are worried about them getting into trouble of some sort, or being hurt.

Part of becoming a community member can be taking more responsibility in services. For example, an adult might get elected on to the Committee of the service they use. Services should encourage this sort of participation too.

What is community participation like for adults with an intellectual disability?

How much and what sort of participation each person is involved in should be their own individual choice. We are all different in how we want to spend our time.

Community participation can be experienced as good or bad. Some of the things that make it more enjoyable are:

- knowing the places and people; knowing how to find your way around
- choosing yourself whether you want to be involved
- knowing you will have support when you need it
- not being made to go to places where you have had a bad experience in the past
- knowing that the people there accept you and like you
- being involved in social activities with other people
- knowing what to do in that place or activity.

Many adults with an intellectual disability say they would like to have more involvement in community activities and would like to have more friends. Other adults are happy with their lives as they are.

What often stops more community participation are the attitudes of parents and staff. There may also not be enough money or staff to provide the support.

Leisure and recreation for adults with an intellectual disability

What do adults with an intellectual disability do in their spare time? Like lots of other people, most of them spend a lot of time sitting around – watching TV or videos, and listening to music.

Sometimes lack of transport means people cannot go out much. Also, some community clubs and groups are not welcoming to adults with an intellectual disability.

Leisure time should take account of what people are interested in and what they are good at. People also need lots of chances to find out what they like doing, by trying different activities.

Adults with severe disabilities may need help to learn how to make choices and make sure other people understand what they like doing. Sometimes support is needed to teach people the skills they need to join in an activity – like what the rules are; how to actually do the activity, for example, how to play soccer, or how to order your own drinks in the pub.

Adults with an intellectual disability can also be helped to develop their own “plan” of how to enjoy their spare time, and how to become more independent. Sometimes they get too used to other people doing it all for them.

How can we promote more community participation for adults with an intellectual disability?

This review has provided lots of useful ideas. These have included:

- using more volunteers, instead of always paid staff, to support adults in the community
- providing special support to people with severe disabilities
- letting people choose what they want to do
- planning more carefully on how to support community participation
- making sure people get to know places and how to get around
- making sure they get to know people in the community, like neighbours
- helping them to be accepted and valued by people in the community
- making sure they have the support they need in the community
- giving people lots of different experiences so they can find out what they like and have more choices
- helping people to learn to be more independent.

Getting involved in sports or physical activities

Keeping physically fit is very important for our health, as well as good fun. Many adults with an intellectual disability are unfit and too fat because they do not do enough exercise.

Special Olympics provides opportunities for adults with an intellectual disability to get fit, learn different sports, compete, and make new friends. Some people do not like the fact that Special Olympics is **only** for people with an intellectual disability. They think it should focus more on helping people to join in with non-disabled people in other sports activities. Some people also think that Special Olympics can treat adults as children, and make them look **more** different to the rest of the community.

It is clear that Special Olympics is very important to people with an intellectual disability. They learn to be athletes and feel proud at how well they do. They get to travel and make new friends. We should listen more to what adults with an intellectual disability tell us about their own experiences and feelings.

Special Olympics is also changing. It is doing more now to help adults with an intellectual disability join in with other community sports and physical activities.

As well as supporting adults with an intellectual disability to be part of their community, we need to teach the community about accepting people with disabilities. The community needs to change too.

What does all this mean?

People with an intellectual disability have often been kept out of many community activities. They have not had many chances to get out and about, join in, and make new friends. Community participation is about changing all this.

This review has told us what it is like now and ways we can make it better. But there were not many studies about how to make the community, and people in the community, more welcoming to adults with an intellectual disability.

Community participation is about all parts of a person's life, not just leisure and sports. It means being included in education, work, where and how we live – everything that is part of being a part of the community.

We need to look at:

- what support services can do to provide better support for each person
- making it clear to staff what their responsibilities are, and providing training for them
- providing more money for transport, and teaching people how to use public transport when they can
- giving people more choices and making sure they can tell other people what they prefer
- working out how to change the negative attitudes of other people.

COMMUNITY PARTICIPATION AND LEISURE FOR ADULTS WITH AN INTELLECTUAL DISABILITY

Introduction

Community participation is a major goal for all disabled people, but one which can be particularly difficult to achieve for adults with an intellectual disability. The vision underpinning the New Zealand Disability Strategy (2001) is:

A society that highly values our lives and continually enhances our full participation (p 1).

The importance of community participation has also been endorsed in the Government's recent strategy and specific goals for "vocational" services in New Zealand (Pathways to Inclusion, September 2001). The second of the two broad aims of the strategy is "to increase the participation of people with disabilities in communities" (p 6).

Community participation is not only a goal, but also a "process by which other goals are achieved" (Emerson 1985, cited in Myers et al 1998). But what exactly is "community participation" and how can it be promoted and measured?

This review will begin by outlining recent conceptual analyses of "community participation" and models of its assumed components. Following this, a brief historical context will be provided, which outlines the movement towards community participation by adults with an intellectual disability.

The review will then examine research on promoting community participation and on the experiences and understandings of adults with an intellectual disability themselves about community participation. The next part of the review will address issues of participation in leisure activities, as one specific component of community participation. Following this, the review will explore how barriers to community participation in general and in leisure activities may be addressed. Finally, general conclusions and implications will be provided as to how the vision of the New Zealand Disability Strategy can be achieved for adults with an intellectual disability.

It is important to note that this review should be considered alongside other reviews, particularly Review Three, which covers the areas of social relationships. The area of friendship is particularly critical to considerations of community participation.

What is "community participation"?

The concept of "community" itself is highly debated and the focus of a considerable body of theoretical discussion. For the purposes of this review, it is sensible to use a "commonsense", general concept which views "community" as a geographical place which includes the ordinary and varied activities of other citizens. It may also be seen as including sub-communities and "communities of interest", such as "community groups".

In the field of disability research, “community” is typically presented as the opposite of segregation or isolation in “special” facilities or services which only include disabled people and those who are paid to support them.

A number of definitions of “community” include the three inter-related components of **“Place, people, and a sense of belonging”** (Bell and Newby 1974; Wellman and Leighton 1979 both cited in Walker 1999). This multifaceted concept is helpful in the context of this review, as it avoids a narrow view of community as simply a location which is **not** an institution (Walker 1999). From the point of view of adults with an intellectual disability, therefore, simply conceiving of “community” as a place or location, cannot address the issue of “community participation”. However, this three-part model of community provides a useful framework. Do adults with an intellectual disability have “a sense of place” in the community? Are they involved in a variety of social networks? Do **they** feel a “sense of membership” or belonging to a community or communities?

The concept of “place” can also be examined in more detail. Relph (1976, cited in Walker 1999) pointed out that “place is just not the ‘where’ of something; it is the location plus everything that occupies that location seen as an integrated and meaningful phenomenon.” In considering “place”, we can consider to what extent adults with an intellectual disability occupy places designated for that group, rather than places which are used by the general public.

A further useful distinction is between public versus private places. For example, there is an increasing tendency for people to spend more leisure time in private rather than public spheres. It has been suggested that we derive our sense of community through private connections more than through broad community-based connections and involvement.

“Community participation” is conceived to involve more than mere “community presence.” It would also be unrealistic to expect all individuals to participate comfortably in every conceivable community context. No person, non-disabled or disabled, experiences universal acceptance or rejection in community places or contexts. Everyone feels accepted and welcome in some places and rejected and unwelcome in others.

Taylor, Bogdan and Lutfiyya (1995, cited in Walker 1999) note that the actual **experience** of “community” is complex and dynamic, and is composed of both negative and positive experiences. They also described a continuum of community participation, ranging from mere “community presence” to a “sense of place”, involving a positive attachment or identification with a place (Agnew and Duncan 1989; Cloke, Philo and Sadler 1991; Eyles 1985; all cited in Walker 1999).

A further dimension of community is the notion of a political entity, as well as a geographic and psychological sense of place and belonging (Abraham 1989; Baron and Haldene 1992; Wilmot and Thomas 1984; all cited in Myers et al 1998). Past conceptions of “community” have tended to be based on monocultural and traditional values, and failed to reflect the variety of communities to which we actually belong. People move between a number of different communities to reflect different aspects of their lives and this enhances their choices and experiences.

There is a general agreement that an essential component of the **experience** of community is a personal feeling of belonging. A sense of belonging also includes experiencing support and greater control over one's life (Biklen 1983). It is clear, therefore, that "community participation" must involve participation in the **social** life of the community through a growing network of personal relationships" (O'Brien 1987). For a positive experience of community participation, adults with an intellectual disability need to be able to be involved in various community places and activities free from discrimination and abuse from other community members (Menard 1997).

Community participation also requires a consideration of the various valued roles that individual community members fill eg, tenant, citizen, volunteer, employee, parent (Broderick 1996). Adults with an intellectual disability may play few roles, and these may be roles which imply dependency and lack of community contribution. For example, the roles of "client" or "resident" (of a particular facility) are not usually perceived as valued roles of community members. The roles available may be significantly created and maintained by the type of support services provided for adults with an intellectual disability.

Ryan (1997) relates community participation to citizenship which she describes as "about" a person's capacity to fully participate in all dimensions of social, political and community life" (p 19). She goes on to note that such participation must include participating in decisions which affect our lives. Thus community participation is an **active** process, not a passive one. When adults with an intellectual disability are placed in the role of mere service consumers, they will not be seen as "citizens actively engaged in community life" (p 20).

Support services have also been charged with the responsibility for enabling people with an intellectual disability to enjoy a 'quality of life', characterised by "community participation". O'Brien (1987) identified five core service accomplishments or outcomes, in services for people with an intellectual disability:

- having a community presence in the 'ordinary places that define community life'
- having the opportunity to make choices both at the level of day to day decision making and more fundamental life choices
- having the opportunity to develop the competencies and skills to be able to undertake functional and meaningful activities
- being accorded respect
- participating in the social life of the community through a growing network of personal relationships (O'Brien 1987).

There have also been concerns raised that the concept of community participation and the values implied within it, have not paid sufficient attention to a social model of disability, which identifies and challenges the community's role in the construction of disability. An uncritical notion, for example, that "the community" does not need to change, (to address the goal and process of community participation), should be strongly challenged. Simply trying to "fit" adults with an intellectual disability into existing structures and community activities, without addressing issues of discrimination, devaluation, and rejection – is bound to fail.

Some of the assumptions inherent in some concepts and empirical research also deserve serious reflection. For example, why are relationships and friendships between adults with an intellectual disability seen as somehow less desirable or less valuable than relationships with non-disabled people? Surely an “inclusive community” also **includes** all adults with an intellectual disability? Are the issues of personal choice in danger of becoming subsumed uncritically to an overly simplistic ideology?

In summary, a consideration of the community participation of adults with an intellectual disability will need to examine the following components of community participation:

- **where** do adults with an intellectual disability spend their time?
- **what** do they do in these places?
- **who** do they do things with?
- **what social relationships** and networks do they have?
- do they feel they **belong** – in various places, activities, and social groups?
- are they perceived by others as **community members**?
- what roles do they fill in the community?
- what are the barriers to their participation in community(ies)?

Before the research literature is reviewed to examine these questions, it is helpful to remind ourselves of the history which has led us to the current situation.

Community participation of adults with an intellectual disability: A historical context

In the early days of New Zealand’s settlement by Europeans there were no supports or services for disabled people outside of family. Thomson (1995) provides a critical account of the development of social policy in New Zealand for people with an intellectual disability. There were few provisions, by government or voluntary agencies, to support people with disabilities in the 19th century. There appeared to be little collective sense of responsibility for those who needed assistance of any sort. It has been suggested (Fairburn 1989, cited in Thomson 1995) that Maori families, with whanau and hapu support networks, probably were better able to support their disabled members than pakeha, during this period.

We have very little evidence to draw on, but it appears that those adults with an intellectual disability who could contribute through work, in the family, or in other work, may have experienced a sense of community participation and been seen as community members by others. However, for those who could not work, the family was the location for all or most community and life activities.

In 1846, the colonial government took the first steps towards providing welfare support. Four state hospitals were established to meet the needs of the Maori, and sick or destitute Europeans (Thomson 1995). A few private charities were also established. People with an intellectual disability were often “lumped in” with other people with a range of “mental impairments”, taken out of the community, and cared for in “Asylums”, some of which were actually gaols.

There followed a long period in which removal from the community to institutional care was perceived as the most appropriate response to both the support needs of those with an intellectual disability **and** the fears or inability of the community itself to provide support.

The early institutions, based on perceptions of disabled people as dangerous and disruptive (Rioux 1993) included a very diverse group of people. Institutions specifically for people with an intellectual disability were not developed until the 1920s. Institutional care has been seen as the complete opposite of community participation. Institutions were typically built in isolated areas. They involved the segregation and congregation of people with disabilities in large groups. Some proponents of institutional care have argued that an institution is a “community” in its own right, albeit a “special” one. A continuation of this perception is seen today in models such as “sheltered villages” or “special communities”. However the benefits of such service models are argued, the usual understanding of ordinary community and communities does not encompass segregated “communities” as a **total** way of life except by personal choice, such as a religious community. Being limited to participation in one isolated “community” is not what disabled people, nor the general public, conceive of as “community participation.”

Lack of community participation, or segregation, was also characteristic of other societal provisions during the 20th century, and still exists today. Separate special schools and classes were seen as necessary and appropriate for children with an intellectual disability. Sheltered workshops and day services were seen as the appropriate site for work and daily activities. These segregated educational and vocational services are still a feature of New Zealand society, although more and more children and adults are participating in ordinary classes and ordinary work.

The closure of institutions for people with an intellectual disability has been a long and fraught process in New Zealand, with the closure of the last large institution (Kimberley Centre) only recently announced. But it would be naïve to assume that alternative living provisions (group homes) have achieved full community participation for adults with an intellectual disability. The features of institutions can be replicated on a smaller scale. People with an intellectual disability often still live on the edges of society (Moore 2001). They may still experience lack of control over care arrangements and a general state of dependency and powerlessness (Northway 1997; Waxman 1991; both cited in Moore 2001). The review of research on “support for living” examines these issues in more detail.

The history of provisions for children and adults with an intellectual disability shows a long and gradual transition from families to segregation to a move back to community **location**. While community participation is increasing in education, work, and leisure, most living options (apart from family) involve segregated, group living. Many segregated provisions in education and work still exist, and are viewed by some as exemplifying “community”. But research clearly documents the continued separation of people with an intellectual disability from non-disabled members of the community. Adults with an intellectual disability can still spend large amounts of time in “special places”, which are designated for people with an intellectual disability. Level of community participation cannot be inferred from a mere physical presence in a geographical place.

The experience of community participation

Where people spend their time, who they spend time with, and how they experience these activities is what community participation is all about. Most of the research on community participation has focussed on the number and type of activities and social relationships of adults with an intellectual disability, with relatively little effort to examine the issues from the disabled person's perspective.

Methodological issues

A brief consideration of conceptual and definitional issues illustrates some of the difficulties inherent in reviewing research relevant to community participation. Research varies in its conception, labelling, and measurement of "community participation." As previously outlined in the review of definitions of intellectual disability, adults with an intellectual disability are a heterogeneous group of people but empirical research does not always reflect this fact. As Myers et al (1998) point out:

The significance of the differences in the terms used or in the different meanings attached to the same terms, is that they potentially disguise conceptual and, hence, technological divergences. In effect, the goals to be achieved, the indices felt to reflect the realisation of these goals and the measures employed are all potentially contestable (p 393).

Myers et al note the wide variation and problems within studies of community participation, in terms of:

- the scope of studies, in terms of their focus and breadth
- the range of sample characteristics, and the relative lack of attention to demographic variables, such as age, sex, and ethnicity
- the relatively limited focus of comparisons of experiences, particularly the lack of comparisons with the "normal" experiences of other members of the community, of the same age, gender, and ethnicity
- the frequent limitation of the research to adults with an intellectual disability who can communicate verbally (often dictated by the measures used)
- the research method used to identify, measure, and judge the "success" of community participation, or "integration"
- the uncritical use of "proxy" informants, such as care staff or family members for provision of information, whichever method is employed eg, diaries, postal questionnaires, interviewing
- the relative lack of research which collects information directly from people with an intellectual disability themselves, either through interviews or participant observation (Myers et al 1998: p 393-8).

What is surprising, therefore, given the variations in methodology among studies, are the common themes and findings emerging from the research.

Opportunities for community participation

The actual number and type of opportunities for community participation that are available to adults with an intellectual disability are related to their living situation. While there is limited research on adults living with their families, it appears that these adults may experience smaller social networks than adults living in other settings (eg, McConley, Walsh and Mulcahy 1982, cited in Todd, Evans and Beyer 1990).

The type of residential setting also affects the range and quality of social interactions with community members. In a study of 24 adults living in one hospital and in 10 urban, community-based hostels, Markova, Jahoda, Cattermole and Woodward (1992) found that **both** groups had virtually no involvement with people outside the residential setting. Thus, mere location of a residential service in the community does not necessarily increase community participation. However, **within** the community-based service, the adults experienced more positive interactions than those in the hospital. The authors concluded that “the routine nature of institutional life actually fosters impersonal functional interactions between people”.

Chen, Bruininks, Lakin and Hayden (1993) also found the degree of community participation and related variables differed according to the type of living situation. They compared people with an intellectual disability living in small group homes (six or fewer residents) with those living in foster homes. Unlike other purely descriptive studies, Chen et al used multivariate discriminant analysis procedures to determine factors that discriminated between the two living situations. The measures covered eight dimensions of personal competence, leisure activity/community participation, family contacts and social relationships; and community assimilation and positive acceptance in the community.

The study included 181 residences and 336 people with an intellectual disability in 37 states of the United States of America selected using systematic stratified random sampling to ensure a representative sample of these types of services. Within the services, random sampling was used to obtain the sample of residents. The analyses were based on a subsample of 169 individuals for whom complete data sets were available. The evidence indicated that this subsample adequately represented the original sample on most relevant characteristics. Data were gathered from key informants.

The results showed that:

- in most aspects of personal competence and community integration, people living in foster homes showed significantly lower ratings
- personal self-care skills and community-oriented adaptive behaviours were least important in distinguishing between foster home and group home residents
- foster homes were higher in community assimilation/acceptance in the neighbourhood and lower in degree of perceived problem behaviours
- group homes were higher in home living skills, family contacts/relationships, recreation/leisure integration, and community living training goals.

The researchers concluded that patterns of relationships and activities are the key differentiating factors between group homes and foster homes, not the personal characteristics of residents. In other words, the living settings of people with an

intellectual disability are more important influences on their lifestyles than their own individual skills. They conclude:

...if social and community integration are primary goals of community living, ongoing efforts are needed to promote them (p 398).

But do staff working in residential services actually understand these philosophies and do agencies adhere to them in their practice? Balcazar, MacKay-Murphy, Keys, Henry and Bryant (1998) measured staff knowledge of the values of community inclusion, agency adherence, and staff satisfaction. The study involved 518 staff members in 130 agencies providing individualised community living support. This type of support represents an increasing trend away from group homes as the predominant service model.

This study developed a “community inclusion” measure, the responses to which yielded a three-factor model from a factor analysis:

- opportunities to engage in daily community activities
- opportunities to make choices
- service rights of persons with disabilities.

The finding of most concern is that staff were **least** knowledgeable about encouraging the adults they supported to make choices. If adults are participating in community activities simply on a basis of other people’s views or programme directives, rather than making personal choices, then “community participation” becomes yet another disempowering service goal.

Other findings included the following:

- the more knowledge staff had about the philosophy of community inclusion, the more likely they were to report adherence by the agency to this philosophy
- job satisfaction of staff was positively related to staff perceptions of agency adherence.

Even when participation in community activities occurs, opportunities for wider interactions with community members may still be minimal. Todd et al (1990), as part of a longitudinal evaluation of service changes in Wales, examined the community activities and social networks of 318 people with an intellectual disability living in the community. (Sixty-eight of this sample were children under 16 years). The majority of people lived with their immediate families. Most of the information gathered was from primary carers rather than adults with an intellectual disability themselves.

Todd et al found participants were involved in a range of community activities, with the most frequent being shopping, going to the pub, and swimming. Those people classified as “able” were likely to experience more activities. Younger people (below 24 years) were involved in more activities than people over 45 years. The researchers conclude that these people with an intellectual disability had a degree of “community visibility” or “presence”. An analysis of the activities, however, showed that many of the more “social activities” were largely “specialist” activities involving groups of people with disabilities. Only a small number of people were involved at all, and rarely on a frequent basis, in activities which had the potential for wider social contact. Family members and staff

played a major role in arranging and providing these activities. Almost half of the study group had no identifiable friends (apart from family or paid staff). These researchers conclude that:

... people with developmental disabilities were not intimate members of the wider community but could, in some fashion, be identified as living and operating within it (p 215).

This state of affairs is likened to that of the “stranger” (Simmel 1964, cited in Todd et al 1990), one who is “culturally distant from the group and yet is a part of group life” (p 215).

The contribution of the disabled person’s own abilities and skills to the level of community participation is not clear. As noted, Todd et al did find that more “able” adults with an intellectual disability experienced more community activities. Heller, Miller and Factor (1999) studied 58 adults with an intellectual disability living in 20 different community settings over a period of three years. They investigated the relationships among degree of resident autonomy, levels of adaptive behaviour, and community “integration.” The issue of autonomy was seen as a critical part of community participation. Heller et al cite a study by Lakin, Burwell, Hayden and Jackson (1992) which found that a majority of adults with an intellectual disability had no choices regarding when they went out with friends or how they could spend discretionary money.

Heller et al (1999) collected data using measures including demographic, health, and service information and assessments of adaptive behaviour, community integration, and environment. The Community Integration Scale used measured the frequency of participation in 12 types of activities eg, visiting family, shopping, church. The environmental measure included choice-making opportunities, among other measures of the residential environment. The data were subjected to two hierarchical regressions to examine the relationship of environmental variables to outcome variables. These analyses yielded the following results:

- adults with higher initial levels of adaptive behaviour had greater levels of community integration at follow-up
- a higher level of community integration at follow-up was associated with living in smaller settings
- a greater resident involvement in policy-making (within the residence) was significantly related to greater levels of community integration at follow-up
- beyond size of facility, opportunities for choice and involvement in policy making, were related to outcomes of adaptive behaviour **and** community integration.

Heller et al conclude:

It seems that individuals are more likely to be involved in community activities when they have a voice in making decisions in the facility where they live (p 454).

Choice and autonomy are important as a basic right, whether they influence other outcomes or not. Autonomy is also linked to the dignity and respect accorded to adults with an intellectual disability. These issues are reflected in the burgeoning empirical

research and philosophical disability literature on “self-determination”. Unfortunately a review of this literature is beyond the scope of this review. However, the following conception of self-determination (Wehmeyer 1998), applying to all adults with an intellectual disability, illustrates its relevance to community participation. The emphasis is **not** on “independent performance, absolute control, and success” but is instead on:

- providing individuals with adequate opportunities to be the causal agent in their lives, make choices, and learn self-determination skills
- enabling them to maximally participate in their lives and communities
- ensuring that supports and accommodations are in place (Wehmeyer 1998: p 14).

Kennedy, Horner and Newton (1989) also found patterns of very little social contact between adults with an intellectual disability and typical members of their local communities. As they point out, “without repeated social contacts an individual has little chance of gaining acceptance by members of a community” (p 190). Across the 23 people directly observed over 30 months, Kennedy et al found great variability but, on average, social contacts only occurred once every two days, and relationships seldom continued for more than 12 months, except for family or “best friends”. One problem in interpreting these results, of course, is that we do not have comparable information about the social contact patterns of non-disabled people or people with other disabilities. The authors also note that these participants were living in relatively “enriched” services. Thus these data may **overestimate** the contact patterns of other adults with an intellectual disability.

Summary

Where and how adults with an intellectual disability live has a significant influence on their opportunities for community participation, particularly if they need some support to avail themselves of those opportunities. At one end of the continuum, adults may live in a house in “the community” but have no interactions with community members. What family and support workers do to encourage greater self-determination and support community participation may be the most critical influence for many adults, rather than their own abilities per se.

Also, a critical characteristic of community participation appears to be individual choice. There is a danger of deciding what is “good for” adults with an intellectual disability, whether they have chosen to participate or not.

Getting “out and about” may still not result in social inclusion or membership in the community, particularly if it always involves being in groups of other people with an intellectual disability.

Given that one of the assumed goals of community participation is “community belonging”, the issue of social relationships and networks is of critical importance.

Social relationships and social networks

The centrality of social relationships and social networks in community participation has been highlighted in a number of studies. Newton, Horner, Ard, LeBaron and Sappington

(1994) noted that concepts of “social network” usually include two aspects: the people described as important to the individual and the people with whom activities are undertaken. The most important characteristic for the individual concerned is the **quality** of these various relationships.

Newton et al argue that an ignored aspect of promoting quality lives for adults with an intellectual disability is the provision of “**social support**”. They note an earlier model of social support as **information** (Cobb 1976 cited in Newton et al 1994) which involved three types of information, which “led individuals to believe they:

- were cared for and loved
- were valued and esteemed, and
- belonged to a network of communication and mutual obligation” (p 394).

This model of social support illustrates a trend in this literature to recognise social support “as being good in and of itself, even in the absence of any direct evidence of its beneficial effect on mental or physical help” (p 395).

As noted in the previous review on “adult relationships”, many adults with an intellectual disability rely primarily on paid staff, or other adults with disabilities as sources of social support. This reliance reinforces the likelihood of limited opportunities for community participation and the development of other sources of social support, as social support presupposes social interaction (Newton et al 1994).

Restricted social networks of adults with an intellectual disability are described in a study by Robertson, Emerson, Gregory, Hatton, Kessissoglou, Hallam and Lineham (2001). This research included 500 adults living in varied types of residential settings, identified as examples of “good practice”. Earlier publications by this research group had shown that:

- people living in either “village communities” or community-based residences had larger social networks than did people living in residential state campuses
- people living in community-based residences had more people with an intellectual disability in their social networks than did people living in residential state campuses
- people living in community-based residences had more people without disabilities, who were not family members, and who were not staff in their social networks than did people in either village communities or state campuses
- people living in **smaller** community-based services had larger social networks and more non-disabled, non-staff, and non-family members in their social networks than did people living in larger residences
- people with an intellectual disability expressed greater satisfaction with their friendships and relationships if they had a greater number and proportion of people with an intellectual disability in their social networks.

This latest research report provided more detailed information on factors associated with the size and composition of the adults’ social networks. Power analyses were undertaken and reported regarding sample sizes and calculations – an aspect seldom reported in most research in this area.

Data collection included: questionnaires for staff who knew the participant; structured interviews with participants (wherever appropriate); interviews with key informant members of care staff; and cost information from agency accounts. In addition information was collected using a range of structured measures of residential services. The researchers note that participants living in village communities had more adaptive skills than those living in community residences, who, in turn, had more adaptive skills than those living in residential campuses.

In terms of social networks, information was obtained on the individual's currently active social network, its composition, type of relationships, type of support, degree of reciprocity, and closeness of the relationship

The main findings of this large study were:

- when staff members were excluded, the median size of participants' networks was two people
- one quarter of participants had one or fewer people in their social networks
- eighty-three percent of all participants reported a staff member in their social networks
- staff and family members provided the main sources of informational, practical and emotional support to participants; people with an intellectual disability were rarely seen as **providing** support to others.

Four personal characteristics were associated with variation in the size and composition of their social networks. As reported by Robertson et al, these were:

- younger participants had larger networks, and these networks were more likely to contain a relative, a non-staff member, and a non-disabled person
- people with autism had smaller social networks
- higher functioning participants were more likely to have networks which included non-staff members, relatives, and non-disabled people
- participants with **less** severe challenging behaviour were more likely to include other people with an intellectual disability in their networks.

The history of people's living arrangements was also influential. For example, people who had moved to their current setting from their family home had larger social networks. People living in small group homes (3 or fewer people) also had larger social networks. Other variables, such as staffing resources and organisation of the care environment, were also associated with variation in the size and composition of social networks.

The authors conclude that their results confirm previous findings and also highlight additional issues (p 210-11). They conclude that:

- people with an intellectual disability are marginalised and socially excluded in western countries
- once family and staff are excluded, social networks are dominated by other people with an intellectual disability; these relationships are important, as they are often

long-lasting, reciprocal, and associated with satisfaction with friendships and relationships

- there is an increased risk of social exclusion faced by older adults with an intellectual disability
- some individuals need targeted support to reduce challenging behaviours and increase pro-social behaviours
- smaller community-based living settings ie, no more than three people are associated with larger and more inclusive social networks
- people in services which take an active-support approach rather than an institutional approach generally had larger and more inclusive social networks.

A recent review of research on studies of “community integration” supports the contention of marginalisation of people with an intellectual disability, as being **within** but **not a part of** the community (Myers, Ager, Kerr and Myles 1998). “Community integration” is a term commonly used from the 1980s to refer to what is now usually called “inclusion” or “community participation”. The studies reviewed were concerned with both physical presence **and** social participation in the “ordinary world.” The following findings were supported from a number and variety of studies since the 1970s:

- individuals with an intellectual disability may use a variety of facilities and resources within a geographically defined community but they have limited social engagement in such use; this finding also applies to people who have always lived in the community
- actual opportunities for expanding social networks are usually limited by circumstances
- activities tend to be undertaken with other service users, and are often held in segregated settings, or at “special times”
- the more severely disabled the person, the fewer opportunities they have to participate in community places and activities
- smaller homes have greater potential for enabling community participation, but this depends on organisational factors that shape what staff actually do
- staff or support workers are significant in both facilitating social participation **and** often playing a key role **within** someone’s social network
- practical barriers, such as lack of access to a telephone, lack of autonomy or reliance on transport, are significant factors in trying to **sustain** relationships
- there are significant financial barriers to community participation for most adults with an intellectual disability
- community responsiveness to adults with an intellectual disability significantly affects how the community is actually experienced, with rejection and victimisation not uncommon.

In order to understand the implications of research on social networks, it is helpful to look at the issue of social relationships in more depth. In addition to the previous review of research on friendships, some additional studies are pertinent here.

An important characteristic of social relationships which are likely to provide social support and enhance a feeling of belonging is the **stability** or maintenance of those relationships.

A study by Kennedy et al (1989) analysed the social relationships of adults with a severe intellectual disability living in community settings. This study found very few ongoing interactions with community members. Over a period of 30 months, they studied the patterns of social contact between 23 adults and members of their local communities. On average, there were only 2.6 community members who interacted at least once with a participant in as many as 12 of the 30 months, and only 1.2 community members who interacted at least once in 20 of the 30 months of the study. The most significant finding in this study was the limited number of community members who were part of the person's social sphere for more than a few months.

Newton et al (1994) point out that:

Social relationships may well be the most essential elements of, and indicators of, societal inclusion. Thus, our ability to foster and support social relationships may be an essential indicator of our effectiveness as support personnel and researchers.

Newton, Olson and Horner (1995) identified and studied **stable** relationships between 14 community members and 11 adults with an intellectual disability, living in community services. Both quantitative and qualitative data on the relationships were obtained. They found four factors which influenced the stability of these relationships (while acknowledging the uniqueness of each relationship):

- the community members having previously been staff members
- their willingness to overcome practical barriers (eg, transportation, finances)
- their perception of reciprocity in the relationship
- other idiosyncratic variables, such as mutual effort and need; personal characteristics and needs of the adult with an intellectual disability.

Other factors in developing social relationships are the difficulties experienced by some adults in the areas of communication and social interaction. The assumption that these deficits are the **major** reason for the social isolation of adults with an intellectual disability needs to be challenged as too simplistic although it may be of particular relevance to some adults with disabilities such as autism. While the previous review of "Effective Communication" outlined the range of effective interventions available, intervention which is **only** focussed on the disabled person is inadequate to remove the barriers to greater social participation.

Whitehouse, Chamberlain and O'Brien (2001) evaluated an intervention to facilitate friendships among four men with a severe intellectual disability, through a "social contact" group. All four men could speak but did have difficulties in social interaction skills and had few meaningful friendships.

Within the group sessions, social skills were not directly taught but members were "guided" into more positive social behaviours. Measures were taken of the verbal interactions of each group member during group sessions.

The four men attended the group regularly and expressed a desire for it to continue. Activities that were highly structured around the group, eg, charades, were most successful. Also, interactions slowly increased over time. Unfortunately once the support

of the researchers ceased, the group was not maintained by support staff whom the men relied on to make the necessary arrangements for them to meet. The authors deduce some useful conclusions from this study, which were:

- when offered the appropriate support, adults with a severe intellectual disability and social skill difficulties can enjoy spending time together
- developing and maintaining relationships is impossible without an adequate level of support, both logistical and “on-hand”
- adults with an intellectual disability do not have to learn particular social skills **before** they can interact socially with other people
- greater value should be accorded to relationships between adults with an intellectual disability.

An extensive study by White and Dodder (2000) of people with an intellectual disability refuted another common assumption – that frequency and severity of challenging behaviour are significantly associated with social interaction opportunities. The data for this study were obtained from personal interviews with 3,781 individuals and their caregivers. The correlational data from this study showed some statistically significant relationships, but most of these were relatively weak. The strongest finding was that people with more adaptive skills (eg, self-care skills, mobility) participated in community outings more often, and, as a result experienced more opportunities for social interaction in community settings. This finding needs to be interpreted with care, as the authors point out. The actual causal path may be mediated through the actions of staff and how organisational and attitudinal factors affect staff ability or willingness to support clients in community activities. Caregivers are often necessary and clients who need less practical support are more likely to receive it. A further relevant finding from this study is that people with higher adaptive skills reported liking and making more choices in their daily lives.

Summary

A “sense of belonging” in the community can only be achieved through social relationships, networks, and acceptance. For many adults with an intellectual disability, the literature suggests, their social lives are limited in numbers and scope of relationships. Thus, their opportunities for and experiences of “community” are also limited. In particular, many adults may have few experiences in the “private” spheres of social community life – for example, socialising with friends and extended family in their own homes and settings. In addition to practical support, family members and staff typically constitute the social supports of adults with an intellectual disability. Older people with an intellectual disability appear particularly at risk for a very restricted social and community life. Physical presence in the community often does not include social participation and belonging for adults with an intellectual disability.

Practical barriers to greater participation exist, eg, money, transport, but the role played by other people in facilitating and supporting social participation may be more important, particularly for adults with greater support needs.

Community members' welcoming and accepting of social contact with adults with an intellectual disability is variable, with previous close experience with people with an intellectual disability often an important variable.

Friendships among adults with an intellectual disability are an important part of their lives, but may also require prompting, practical help, and ongoing support, particularly for those with more severe disabilities.

The role of support staff in enabling community participation for adults with an intellectual disability is clearly important.

Can staff members be trained to provide more effective supports for adults with an intellectual disability to participate in community activities and settings?

The role of staff in supporting community participation

Newton and Horner (1993) evaluated a "social guide model" used to train residential staff to use a set of "community network strategies." This was a small study involving only three adults with an intellectual disability and the staff members involved in their residential support. Two of the adults had spent many years in institutions. Measures included social network size and composition and instances of engagement in an activity with a social network member. A multiple baseline design across participants was used to evaluate the effects of the staff training. The staff training clearly resulted in an increase in both size of clients' social networks **and** experiences of social interactions with network members, and these increases were generally maintained during the follow-up condition. The researchers note the need for more qualitative information on the quality and stability of these new relationships. Furthermore, in any intervention to increase social participation, the preferences and opinions of the person should be the primary guide, not some assumed "norm" or "programme goal".

Sometimes the support services provided to adults with an intellectual disability can actually act as barriers to community participation. For example, Lutfiyya (1991), (outlined in the previous review of Adult Friendships), concluded that the biggest barriers to friendships were the practices of the human service system.

Werner, Horner, and Newton (1997) undertook a study to identify and reduce the social and structural barriers to social participation experienced by three adults with a severe intellectual disability. One of the problems identified by previous researchers is the fact that staff support can supplant socially supportive roles normally filled by peers (Nisbet and Hagner 1988, cited in Werner et al 1997). As Werner et al explain, the presence of paid staff can have a variety of unintended consequences, including:

- removing the need for simple instances of support
- engaging an individual in a "social bubble" of ongoing interactions that others find hard to penetrate
- limiting the opportunities for an individual to contribute socially
- stigmatising or isolating a person with disabilities (p 138).

The three male participants in the study had a long history of institutionalisation, problem behaviours, and isolation, and had recently moved to the community. None of them could speak. Also included as participants were the 19 staff who provided supervision or support for these three men, who each lived in a different residence.

The three dependent variables monitored were: weekly frequency of social activities (with someone who was not paid staff or a housemate); the number of different people the person did activities with; and the stability of these social relationships. The intervention involved a “package” of component strategies to reduce “social barriers”. These strategies were developed during interviews with support staff. These strategies included:

- a personal scheduling book and weekly scheduling of social activities – to reduce the barrier of difficulties in scheduling social activities
- a personal information sheet – to reduce difficulties in making social introductions to new people
- a friendship form – to enable staff to identify available social companions
- a photo address file and photo activity file – to help the three adults to express their preferences for people and activities
- weekly feedback – to enable staff to get feedback and “keep track” of the adults’ social lives.

The study design involved a multiple baseline across participants. Staff were given initial training and support for two weeks by the principal researcher. Monitoring of staff use of the strategies confirmed the use of almost all of the strategies for the three men over the six months’ duration of the study.

Although there were individual differences in the extent of changes, the strategies were responsible for:

- increases in the number of social companions
- increases in the number of social activities
- positive changes in the stability of some relationships for two individuals.

The authors conclude that an important implication from this research was to show that factors other than the person’s social skills can affect social participation. As they explain,

social life is more than a set of skills and opportunities to engage in greetings. The structure within which support is provided can also affect social life. Support staff may face, and even contribute to, social barriers. Support staff may also minimize social barriers (p 147).

Secondly, the success of staff training, in reducing barriers, was demonstrated and its association was established with positive changes in social participation for the three men with a severe intellectual disability.

Some researchers have pointed out that there is also a danger of conceiving the community participation of adults with an intellectual disability as a process which entails **individuals** doing things with “**non-disabled**” people. Ryan (1997) describes a project aimed at supporting adults with an intellectual disability to improve their “participation in

community life” (p 21). Their work built upon an existing forum for service users to influence service provision. They then sought to redevelop the forum to foster greater sharing of each others’ experiences, and to foster a sense of “shared identity and consciousness”.

What has such an approach to do with community participation? Ryan argues that such opportunities for talking together and developing shared understandings about life experiences can provide a basis from which adults with an intellectual disability might “begin to see themselves as members of the community with rights and obligations as citizens, rather than customers in the narrower field of service provision” (p 22). It can also help people to develop concerns about others, leading to possibilities for collective action. There are numerous examples of the “self-advocacy movement”, since the 1980s, providing valuable opportunities for the development of a positive identity and an active, collective role in community action and participation. Other social movements play similar roles for other community members. Ryan argues strongly for promoting this more active participation which enhances the citizenship of adults with an intellectual disability.

A consideration of adults with an intellectual disability as citizens also raises the issue of their participation in the actual agencies which provide their community support. There is a growing trend to include adults with an intellectual disability in advisory and governance roles in disability services. Drake (1994) describes the exclusion of disabled people from positions of power in such organisations in Britain. He argues that disabled people experience the same sorts of barriers to participation in these settings as they confront in the wider community. Drake surveyed 149 disability organisations in one Welsh county. These agencies provided services for a range of people with disabilities and disadvantages, including 14 agencies for people with an intellectual disability. In addition, 20 respondents were interviewed. Unfortunately, there is no detailed breakdown of the situation in these 14 agencies.

The attitudes of agency spokespersons to active consumer participation in such organisations was generally very positive. Also, of the 149 agencies, 33 had governing bodies on which disabled people were in the majority. The respondents from these 33 agencies were also significantly more positive about the role of consumers than were other agencies.

However, the overall reality was very different. Two-thirds of the agencies had little or no consumer presence at all. There was a marked lack of involvement of people with an intellectual disability. In other words, there was a marked disparity between what agencies said and what they did. If participation by adults with an intellectual disability is not a reality in their own support services which espouse community participation, this seriously weakens the exhortations by these agencies to other communities to welcome and include adults with an intellectual disability. It is known that at least some service agencies in New Zealand do include adults with an intellectual disability on the governing bodies.

This form of participation by disabled people in relevant community organisations has also been criticised on the grounds that the consumers involved are “unrepresentative”. As Beresford and Campbell (1994) point out, however, what this usually translates to means that “they don’t fit the stereotypes of lack of capability and passivity”. The actual

experience of such participation, in itself, can lead to the growth of skills and confidence. Also, the mere fact of involvement can be seen as leading to these people with disabilities being seen as “unrepresentative”. Beresford and Campbell claim that “representativeness” only assumes importance “if what they say threatens or challenges the status quo” (p 318). They also point out that while service providers interpret “representativeness” in terms of “typicality”, people with disabilities mean “having their perspective, views, interests, demands and rights **fully represented** in discussion, forums, and decision-making” (p 320).

Summary

There is evidence that deliberate strategies may be needed to train staff in how to assist adults with an intellectual disability to have positive experiences of community participation. Many staff may not see this as part of their role, or may not know how to do it, or the service system in which they work may include barriers to this role.

Even adults with severe disabilities and a long history of isolation can be supported effectively towards greater community participation and an increase in positive social experiences.

How adults are treated as citizens **within** the support services they use is also worthy of consideration, and moves towards responsible roles and collective self-advocacy can be seen as part of community participation as a valued citizen.

While the research reviewed provides many useful findings and implications for support services, there is very little research exploring the perspectives of adults with an intellectual disability themselves.

How do adults with an intellectual disability experience community participation?

The goal of community participation is perceived as a shared goal among people with disabilities and “the community”. In reality this is clearly not the case, particularly when community attitudes towards adults with an intellectual disability are considered. Furthermore, at the individual level, we all differ in our personal preferences for different degrees and types of community involvement. As Myers et al (1998) point out, “there is a risk of imposing goals which may be at odds with the goals an individual would themselves seek to achieve and the choices they would seek to make” (p 405). The majority of the measures used in the research reviewed do not include consideration of the subjective experiences of “community participation” of adults with an intellectual disability. A recent study redresses this imbalance and provides valuable insights relating to community participation.

Walker (1999) provides an in-depth examination of the experiences of seven adults with an intellectual disability, ranging in age from 24 to 60, with a range of disabilities and living situations. Walker spent 15 to 35 hours with each participant in their homes and other community settings. The data included participation observations and repeated interviews with the individuals and others who knew them well.

Walker found that these adults with an intellectual disability spent significant amounts of time in places designated for people with disabilities. These places included separate locations and separate spaces **within** larger settings that included other people. These separate places spanned most dimensions of daily life: educational, residential, work/day, and leisure time. These adults also all participated in **some** community settings with others without disabilities.

Unlike other community members, these adults spent very little time in the **private** social worlds of other people, outside of their immediate family. They had very limited social networks, as outlined in the review of “Relationships for adults with an intellectual disability.” Most of their time (outside of when they were at home or work) was spent in **public** places eg, city streets, shopping malls, **if** they had independent access to these places. Walker (1999) concludes that their “lack of access to private social worlds is related to their very limited social networks outside of family or group homes and the lack of transportation” (p 26).

Most of the community places visited by these adults were contexts involving business transactions. These contexts typically provided few opportunities for social interaction with other members of the community, unless they involved regular contact with the same people eg, a small, local shop.

What were the important components of these adults’ actual experiences of community? Walker (1999) identified six broad themes which constitute six continuums of negative to positive types of experience. First, the participants experienced a sense of greatest vulnerability in unfamiliar places, in places where they were sent against their will, where they witnessed frightening behaviour, or experienced a lack of support or rejection. They felt safest in familiar places of their own choosing and where they knew they could access support.

Second, being known is contrasted with being anonymous and socially isolated. She found that these adults with an intellectual disability felt more isolated in large public places, even if they went there regularly. There were also places where they felt left out or limited in their social interactions. In contrast, their sense of being known was experienced in small groupings of people where they went by choice on a regular basis.

Third, people did not want to go to places where they had had negative experiences, or where they were sent against their will. They positively identified with places associated with personal choice, interest, and positive social interactions.

The fourth theme – from rejection to acceptance – was illustrated by experiences of negative versus positive social interactions. The feeling that other people at that place liked them was contrasted with feeling unwelcome and rejected. Positive interactions were more likely in places where they chose to go that included people of their own choosing, that focussed on social rather than business transactions, and where they felt supported.

Familiarity was also a factor in community participation, with some adults avoiding going to any unfamiliar places. Experiences or fears of being lost or disoriented were described.

Familiarity also included knowing the routines or rituals associated with various places or contexts – “knowing what to do”.

Finally, these adults with an intellectual disability were very aware of places where support or accommodations to their needs could be expected. When they went along to some community places they never knew whether support would be available.

This research has been outlined in detail because it provides an understanding of the realities of community participation experiences of adults with an intellectual disability. These findings also imply that simply increasing the frequency and variety of community activities will not necessarily increase positive experiences and could have negative outcomes for the people themselves.

Another study which did explore the views of people with an intellectual disability is reported by Ramcharan, McGrath and Grant (1997). Family carers and service providers provided information for those people who could not speak for themselves. The activities undertaken by these 54 adults were varied, with the two most common activities involving public places eg, shopping (28%) and leisure activities such as sporting events, films (24%). Sporting activities constituted 16 percent, and segregated leisure programmes were 15 percent (p 52). About 25 percent of leisure activities were undertaken with other people with an intellectual disability. Only 20 percent of friendships were with non-staff, non-disabled people. Independent living did **not** appear to lead to a greater number of independent friendships.

Those people with an intellectual disability who stated that they wanted more friends were also likely to say they wanted more contact with the community and vice versa. Of those living with family, 40 percent wanted more contact with community and more friends. Ramcharan et al found that:

the entitlement to ordinary friends and community resources is severely constrained by the attitudes and values of family carers. Such carers are highly unlikely to encourage their relative into ordinary friendships and community contacts... (p 60).

Service providers were also constrained by the often overprotective views of families. Huge amounts of staff time went into dealing with the family so that community participation and extending friendships could become possible. In 42 percent of cases, staff saw a need for more services or support to promote community participation but such services were not provided due to factors such as budgetary and other constraints. As Ramcharan et al point out:

*... even for those who were able to express a preference – the degree of substitute decision-making and advocacy by service providers and parents effectively makes the power over decision-making theirs **despite the person’s wishes** (p 62).*

Of those people living independently of the family home 48 percent wanted to extend their community networks and friendships. Service providers saw a need for supports to do this but did not provide them (55%). Once again, structural constraints prevented this happening. Ramcharan et al stress the need for a re-evaluation of service directions and practices.

The imbalance in favour of formal service solutions, economy and managerialism needs to be redressed in considering ways of setting the economic prerequisites for a sufficient equality of wellbeing for all citizens (p 64).

This report includes a number of direct quotations from interviews with adults with an intellectual disability. The following segment illustrates some of the loneliness and constraints experienced by people with an intellectual disability. Jack (48 years old) lives in a flat with a few hours' support a week.

'...like to go to the sports centre. I can't afford it... The problem is the neighbours aren't very friendly. I had egg thrown at my window... I would like to see more people drop in. I speak to the bird sometimes. Other people think I'm talking to myself but I'm speaking my problems to the bird (p 65).

This study confirms that more community participation is often, but not always, also a goal or hope of adults with an intellectual disability themselves. Unfortunately other key people in their lives may not share that vision or may be unable to help them to achieve it, due to systems constraints.

Summary

While community participation is espoused widely as a positive process and goal for adults with an intellectual disability, there is surprisingly little research evidence presenting their own experiences of "the community". Given the long history of isolation and rejection from "the community", this lack of direct "voice" is disturbing.

The study by Walker (1999) is a critical exception, providing an important counterpoint to a simplistic and uncritical approach to the community participation of adults with an intellectual disability. "The community" is not one big, welcoming, exciting shopping mall – experiences can be positive, neutral, or negative, and are also experienced individually. Unfamiliarity, social isolation, lack of personal choice, rejection, not knowing what to do, and lack of support – can all be the reality for adults with an intellectual disability of what others may sentimentally applaud as "community participation".

Leisure for adults with an intellectual disability

Leisure can be conceptualised as a particular type of community participation, but leisure also includes individual pursuits. In western societies it has come to mean "recreation" or "free time" spent away from work or other obligations. In earlier history and in other cultures today, "leisure" as we know it, does not exist for many members of society. Leisure has also been **valued** differently at different times and in different cultures, with its highest value probably accorded by ancient Greek culture (Gattuso and Neumayer 1997).

The societal values accorded to leisure activities also change. Gattuso and Neumayer claim that sports, tourism, and high technology stimulation are currently valued more highly than activities such as meditation, or socialising with friends. For adults with an intellectual disability, involvement in leisure activities can be an important source of empowerment, self-expression, and community participation. Is this the picture shown by research?

Participation in leisure activities

How do adults with an intellectual disability spend their leisure time? Henderson (1991) studied the recreational patterns of 33 adults with an intellectual disability in New Zealand and found a similar overall profile to the general population with a predominance of “spectator” activities; such as watching TV and listening to music. His study also found that community clubs and societies may be unwelcoming to people with an intellectual disability. Out of 33 groups approached, only three gave a positive response to the possibility of involving people with an intellectual disability. One barrier to engagement in activities outside the home was the lack of any form of private transport (63%). Gender differences were only apparent in two traditionally female activities. The only sports or physical activities mentioned were: walking, bowls, cycling, and billiards.

Another New Zealand study (Neale 1995) also explored the participation of people with disabilities in recreation and leisure activities. Neale’s study, however, only included 17 people with physical disabilities living in supported accommodation. The most frequently mentioned activities were again “spectator” activities – reading, watching TV, and listening to the radio and music. The telephone played a significant part in leisure, both in arranging activities and as a way of keeping in contact with others. Other activities mentioned were: visiting friends or relatives, shopping, going to the pub, clubs and organisations, eating out, sporting events, concerts, plays and films. These activities are very similar to those found in the general New Zealand population (Cushman et al 1991). Some people felt they had “too much spare time” while others would have liked more time for recreation. Participation in physical activity varied, but some had no physical activity involvement at all, due to lack of time or motivation, or the individual’s physical circumstances. Barriers to participation were: transport, need for support, lack of energy, the extra time used up for ordinary daily living due to the effects of the disability.

Jahoda and Cattermole (1995) compared the activities of adults with an intellectual disability in an institution and another group living in community-based hostels. The researchers used intensive ethnographic observations of people in their daily activities covering different times of the day and week.

Institutional life offered little scope for activity and there was no integration with the local community. Initiating activities and socialising with the residents were not seen as central to the staff’s role and work. Even though hostel life provided a more flexible and enriched environment, there was still a marked level of inactivity among the residents, particularly those with the greatest difficulty in communicating their wishes. The percentage of time in home-based leisure activities was approximately three times higher in the hostel group than the institutional group. Also, the institutional group showed the same pattern of activity in the ward and in the hospital “work-based” setting. Jahoda and

Cattermole emphasised the importance of exploring people's interests and capitalising on their abilities, to ensure that their activities have meaning to them.

Cipriano (1998) endorsed the importance of leisure focussing on the **individual's** abilities, not disabilities, and ensuring that barriers to inclusion are removed. "Abilities" are conceptualised as including: strengths, capacities, interests, and experiences. He promotes the use of generic, community facilities and the need for planning and coordination between the community organisation and the agency providing support to the person with an intellectual disability.

Cipriano's "person-centred" model for recreation services involved the following five steps:

- assess – abilities and interests
- explore – research the opportunities in the community in areas of interests
- plan – identify the barriers to involvement (eg, transport, modifications, attitudes)
- implement – support the person to take part
- evaluate – revise and improve, based on the person's experience.

With the emphasis in leisure/recreation on individual choice and voluntary participation, it is critical that inability to express choices clearly does not deny an individual the chance to enjoy leisure activities. Browder, Cooper, and Lim (1998) demonstrated how adults with a severe intellectual disability can be taught to express their choice of settings for leisure activities. Research across a wide variety of individuals has shown the importance of personal choice, in that people, when given choices:

- show a preference for tasks in which they have a choice
- participate more in activities
- perform better on tasks
- exhibit fewer problem behaviours and more cooperation
- report less discomfort with unpleasant stimuli (Browder et al 1998: p 228).

Providing choice and enabling people to express preferences is particularly important to enhance participation by adults with a severe intellectual disability.

Browder et al used a systematic, three-part intervention that:

- compared behaviour across community settings (eg, duration of participation) to determine preferences
- taught communication object "labels" for each setting
- evaluated how participants used these communicative labels to make choices.

Two of the individuals had spent over 50 years in institutions and the other had lived with his family for 65 years.

The comparison of segregated versus community settings showed clear preferences for community settings, in terms of levels of participation. In the second phase, all participants learned to express their preferences by selecting the object representing that

choice. In the third phase, all three participants continued to choose which activity setting they wished to go to.

The authors stress the importance of providing a range of activities for adults with severe disabilities to experience, in order to be able to assess their individual preferences for different settings and activities. Also, preferences may change over time, so ongoing experiences of new activities are needed.

In addition to the need to teach some adults how to express leisure choices, some adults with an intellectual disability may need to learn particular skills to enable them to participate in leisure activities. O'Reilly, Lancioni and Kierans (2000) note that while it has been generally accepted that adults with an intellectual disability often need structured support to learn skills in work, educational, and living settings, the area of skills for leisure participation has received a lot less attention.

This study used a social skills, problem-solving intervention to teach specific skills to four adults with an intellectual disability to increase independence and social inclusion in their local bar, which they visited twice a week. Before the intervention, they did not interact with bar staff or other patrons. The focus of training was on ordering and paying for their drinks, and associated interactions with bar staff. This choice of training focus came from the adults themselves when talking about how they felt about interacting in community settings.

A multiple baseline design across pairs of participants was used to demonstrate the effectiveness of the social skills training. The training involved a structured, problem-solving approach and practising of skills in role-plays.

The three adults learned all of the skills successfully and retained these skills at a three-year follow up. They also generalised the skills to other bars, and showed increased interactions with other bar patrons. The participants themselves noted that they were now more "at ease" when they visited the bar, and were happy to interact with bar staff and other patrons.

This study illustrates the type of targeted training and support in leisure skills that adults with an intellectual disability can benefit from in order to be more independent and included in ordinary community activities. This type of carefully designed strategy is likely to be necessary for adults with a severe intellectual disability.

Sigafoos, Tucker, Bushell, and Webber (1997) describe an intervention with two adults with a severe intellectual disability and challenging behaviours in a leisure programme. The rationale for this study was based on previous research that had shown that the provision of structured leisure activities can reduce challenging behaviours in adults with an intellectual disability.

The two adults involved in the Sigafoos et al study both required pervasive support in all areas and had no expressive speech. They rarely participated in available leisure activities. Their challenging behaviours usually occurred when they were alone or unoccupied. A reversal replication design was used to establish the effects of intervention on both participation in leisure activities and on challenging behaviours (spitting, aggression, and stereotypic behaviours).

The intervention involved prompting and assisted the adults to engage with the leisure materials. It was successful in increasing participation and decreasing the challenging behaviours to zero on most occasions.

This study shows that some adults with a severe intellectual disability may require specific strategies initially to enable them to participate in leisure activities. Without some positive experiences of a range of leisure activities, adults who fail to initiate participation themselves may be denied leisure options and the chance to develop further skills and demonstrate choice.

Hamre-Nietupski, Nietupski, Sandvig, Sandvig and Ayres (1984) also reinforce the need for training in leisure skills for adults with severe multiple disabilities, in this case adults who are also deaf/blind. They provide useful considerations for selecting leisure targets for this particular group of adults:

- the leisure skills should be chronologically age appropriate
- they should provide enhanced sensory input, as the majority of deaf/blind individuals have some residual sight and/or hearing
- select materials that require minimal motor skills to activate them (ie, that are easy to operate and do not require rapid reaction time)
- adapt the materials for ease of use, if required (eg, tactile prompts; stabilizing materials, enhancing the visual or auditory input, task simplifications).

A rather different approach may be more appropriate for people with a less severe intellectual disability. Fullagar and Oowler (1998) describe a leisure programme for people with a “mild” intellectual disability in Sydney, based on the premise that “the quality of a person’s ‘leisure life’ is an important indicator of that person’s overall quality of life (p 442). The programme (“Live It Up”) provides group activities and individualised services which promote independence and community connections. They criticise the tendency for leisure for people with an intellectual disability being constructed as therapy, or as “filling-in” time. People with an intellectual disability are not usually assisted to develop leisure planning skills or to initiate their own plans. Leisure activities usually follow a routine, and people are discouraged from “taking risks to do things for themselves” (p 444). Reliance on spectator leisure activities, or “being entertained” is then justified by service providers as personal choice.

Fullagar and Oowler stress the opportunities that can arise through leisure of developing “stories” with people of what they can do and become, not what they lack, helping people with an intellectual disability to “imagine themselves differently” (p 447), so they can overcome their fears and take risks. Community participation, for adults with an intellectual disability, can be over-ridden by fears of rejection, shyness, and not knowing what to say or do. People can be helped to overcome these fears by drawing on alternate stories of themselves in which they did try and were successful. The “Live It Up” leisure programme is based on the principles that it is good planning and building self-confidence that is more likely to result in pleasurable leisure experiences.

Summary

Adults with an intellectual disability may show a similar pattern of leisure activities to the general population, with a preponderance of “spectator” pursuits, largely sedentary. However, their leisure activities outside the home may be more restricted and less variable.

The amount and variety of leisure activities is also related to the person’s living situation, and the practical barriers to leisure participation. Once again, the role of support staff can be crucial for some adults with an intellectual disability.

Personal choice is a critical component in leisure, and without a way of expressing choice or preference, “leisure” appears to be a very inaccurate way to describe how people spend their “free time”. This basic aspect of leisure participation can also be promoted and supported using careful, evidence-based strategies. Actual skills needed to participate in various leisure activities can also be developed, even when adults have severe disabilities. Different strategies are needed for different people – adults with an intellectual disability vary widely in their skills, learning styles, and personal preferences.

One important type of leisure activity is the area of physical activity and individual and team sports.

Leisure involving physical activity

The area of physical activity has received attention both from the viewpoint of recreation and due to its importance in general health. A number of studies have found a higher prevalence in obesity among adults with an intellectual disability, with overall prevalence estimates ranging from 29.5 percent to 50.5 percent (Horwitz, Kerker, Owens and Zigler 2000). Individuals living at home have the highest prevalence (55.3%), followed by those living in group homes (40.9%). Studies also suggest that adults with an intellectual disability lead more sedentary lifestyles than the general population.

Special Olympics is a special sports programme which recognised the need for people with an intellectual disability to have more opportunities to participate in individual and team sporting activities. The goals of Special Olympics are as follows:

The mission of the Special Olympics is to provide sports training and athletic competition in a variety of Olympic-type sports for all children and adults with mental retardation, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in the sharing of gifts, skills, and friendship with their families, other Special Olympics athletes, and the community (Songster 1984, cited in Klein, Gilman and Zigler 1993).

Within the general Special Olympics framework, four specific programmes have been developed to encourage those at increased risk of inactivity to participate in physical activities. These include:

- a motor activities training programme for people with a severe intellectual disability

- a sports programme integrating people with a mild intellectual disability with their non-disabled peers (Unified Sports)
- a play activities programme for young children
- an athlete leadership training programme (Sharkey and Hunt 1999, cited in Horwitz et al 2000).

Special Olympics has been operating for approximately 30 years and now caters for over 400,000 individuals worldwide. However, Special Olympics continues to be the focus of considerable criticism and controversy, due to its “segregation” of people with an intellectual disability rather than including them in “non-disabled” sports programmes. The debate illustrates the difficulties encountered when a particular goal or philosophy eg, of community inclusion, when interpreted in a narrow, ideological way, can actually be devaluing of people with an intellectual disability. Why is it essential that people with an intellectual disability do everything with “non-disabled” people, even in their recreation and leisure pursuits? Are people with an intellectual disability of “lesser value” as friends or leisure partners? Why do the standards for sporting success have to be set by non-disabled athletes only?

One suggestion by critics is that Special Olympics perpetuates stereotypes of people with an intellectual disability. Roper (1990) examined the perceptions of people with an intellectual disability held by volunteers involved in Special Olympics. The types of stereotypes which have been said to be reinforced by practices at Special Olympics are those of: childlike, incompetent, requiring assistance, or different (Roper 1990). The study examined volunteers’ perceptions and their relationship to the number of Special Olympics state games attended, amount of experience within Special Olympics, and general contact with people with an intellectual disability. Questionnaires were completed by 369 volunteers. The results suggested that opportunities for contact with people with an intellectual disability at Special Olympics did **not** enable positive changes in the perceptions held by community volunteers. Also, volunteers with sustained levels of contact had more negative perceptions. Roper suggests that when contact situations create dependency of a person with an intellectual disability, a reduction in positive perceptions may result (p 173). In particular, those volunteers with more extended contact had higher scores on items reflecting notions of incompetence in people with an intellectual disability. This picture appears to be the opposite to the proposed goal of Special Olympics. It appears that although positive feelings may be experienced by volunteers, the impact on their perceptions of people with an intellectual disability is less positive. As Roper concludes, “acts of charity, while commendable, may substitute for more substantial changes necessary in attitudes and perceptions” (p 174).

Klein et al (1993) examined the attitudes towards Special Olympics of a group of 40 parents (of participants) and 41 “experts” in the field of intellectual disability. A telephone questionnaire explored participants’ views of the strengths, weaknesses, and goals of Special Olympics, whether these goals were achieved, and the programme’s role, if any, in “normalization”.

Among the “experts”, 85 percent agreed that Special Olympics is a beneficial programme, particularly citing the benefits to self-esteem, physical benefits, and social opportunities. Among the remainder, 15 percent disagreed and felt it should be abolished. Others, while acknowledging its past contributions, criticised Special Olympics for its failure to become more integrated.

Parents were generally positive, and none said they wished to withdraw their child. The few criticisms mentioned were: lack of communication with coaches; poor programme information; too much competition; and not enough individualised attention. Benefits cited included: family support (43%); building independence; belonging to a group; physical development; and general skill development.

Many of the benefits cited related to self-esteem, happiness, a sense of comfort and belonging, and opportunities for friendship and making a contribution to others – all characteristics often noted as exemplifying a sense of citizenship and community. Parents perceived these social benefits as more important goals for the programme than did the “experts”. Far fewer parents than experts cited “segregation” as a weakness of Special Olympics. One criticism from some experts was that the programme does not develop life-long leisure skills or encourage people with an intellectual disability to participate in other community activities. However, 95 percent of parents said that their son/daughter was involved in athletic activities other than the Special Olympics games, although over half of this was actually in training for the Special Olympics.

Unfortunately this study failed to explore the views of the people with an intellectual disability themselves. From both the parents and experts, however, the observed enjoyment and benefits to the participants were stressed. Klein et al conclude:

*Special Olympics occupies the terrain between the two meanings of the term **normalization**. On one hand, it promotes a normalized lifestyle by giving people with mental retardation access to sports experiences generally available in the society. On the other, it serves a special population and attempts to adapt its services to meet their needs. Considering that its services are sports, however, this practice may be more normal than is generally realized (p 22).*

A survey of service agencies in the United States about their perceptions of Special Olympics also adds further information on these issues. Porretta, Gillespie, and Jansma (1996) note that Special Olympics has recently attempted to address some of the criticisms by:

- the development of Unified Sports
- sports partnerships
- partners club programmes
- the introduction of lifetime leisure sports
- encouraging and assisting community-based recreation facilities and programmes to open their services to people with an intellectual disability.

Porretta et al (1996) surveyed 232 agencies to provide information about current service philosophies, terminology, strategies to attract clients, and perceptions of the Special Olympics mission. Responses were received from 117 agencies (50.4%). On the basis of these responses, the authors concluded that Special Olympics needs to examine its current programmes and events. The recommendations for change included:

- providing even more opportunities for participation with non-disabled peers in inclusionary-type programmes
- examining a shift in terminology away from “mental retardation”

- providing opportunities for people with a wider variety of disabilities and age groups
- examining its mission statement to better reflect contemporary philosophies and goals.

The continuing debate about Special Olympics is characterised by the lack of contributions from people with an intellectual disability themselves. Hingsburger (1997), who had been strongly opposed to Special Olympics ideologically, changed his views drastically after experiencing (for the first time) a day at the Special Olympics World Games. He wrote:

I wonder if the ideologues who would determine the lives that people with disabilities live, went to the games. I wonder if those who are philosophically pure would have the courage to tell Martin Fudge (a Special Olympian) that he is perpetuating oppression. I wonder if those who think that people with disabilities should be disallowed from sport, social contacts, and media coverage would think the same if they stood in an arena filled to the brim with pride.

... To me, it is only a short run from pride in sport to pride in self. From pride in self, it is only a jog to pride in purpose. But it is we in human services who have dropped the torch. SO shows that pride is possible. We haven't yet understood the possibilities of pride (p 10).

Involvement in physical activity can also contribute to greater self-determination. Reid and Hermo (1998) stress the importance of moving beyond a focus on skills, in efforts to promote physical activity. The important goals of choice, freedom, and initiative are probably more important to long term involvement in and enjoyment of physical activities. They suggest a number of strategies to pursue in the area of physical activities as leisure:

- providing personal choice
- personal goal-setting
- increasing people's perceptions of competence
- helping people to attribute their successes to their own efforts and abilities
- promoting decision-making and problem-solving
- presenting competition as a fun event to test one's skills and improve oneself
- providing a balance of cooperative and competitive activities.

Summary

Contemporary society has a heightened awareness of the importance of physical activity throughout life as a contributor to health and general wellbeing. There is evidence that adults with an intellectual disability are at greater risk for a sedentary life, obesity, and the morbidity and mortality outcomes of such a lifestyle.

A primary contributor to redressing this has been Special Olympics, but this programme has also been the subject of considerable criticism. It is probably time to pay far greater attention to the participants' views and experiences, and less attention to simplistic ideology in this debate. At the same time, greater participation in community sports and

physical activities could be promoted by support services **and** general community organisations, with a wider focus than physical skills alone.

Strategies for promoting community participation

The previous literature reviewed has outlined some specific strategies for promoting individual community participation and identified some of the barriers and constraints faced by adults with an intellectual disability.

Werner et al (1997), in their own research report, provide a list of positive strategies which prior research had supported (p 139). These include:

- natural (unpaid) support, or different approaches to paid support, may be more successful and may also avoid some of the negative effects sometimes seen with paid staff support
- some sort of formal support is likely to be needed for adults with severe disabilities, probably for extended periods, but we need to examine how to minimize the barriers this may pose to other social relationships
- focussing on the choices and preferences of each individual
- using daily schedule books to build a social calendar
- planning integrated activities
- incorporating formal feedback systems for those providing support.

There are also general guidelines which can be drawn from the study of Walker (1999), to help to increase **positive** experiences of community participation.

- ***Promote safety, familiarity, and identification***, by enabling people to do things in homes, neighbourhoods, and communities of their choice. Make sure they have regular experiences in the same places to develop familiarity, attachments, and long term connections to places **and** people.
- ***Promote a sense of being known and accepted***. Support to develop and maintain social relationships with people of their own choosing needs to be available as long as it is needed.
- ***Promote accommodation/adaptations***. People with an intellectual disability have more constraints on where they can go and what they can do. The common issues are cost, convenience, and compatibility. Disability support services need to be resourced and operate in ways which **reduce** these constraints, rather than maintaining them as insurmountable barriers. Also, community activities themselves need to be willing to adapt to include **all** community members.

This section will also briefly describe some illustrative published descriptions of programmes or agencies which place a strong emphasis on community participation.

Developmental Services of Strafford Co. Inc (DSSC) is an agency in New Hampshire which, in its individualised support for living, “strives to expand the network of community places and relationships in the lives of the people it supports” (Racino 1994: p 9). The various strategies include:

- getting to know neighbours
- maintaining and re-establishing ties with family members
- meeting and knowing community people, such as store owners, café proprietors
- striving for individuality, rather than group strategies or stereotypes
- getting to know people with disabilities and listening to what they want, through building trust and rapport
- being flexible and changing the nature of support, as people's lives change
- providing more experiences so people can make 'real' choices
- challenging staff to think about issues from the point of view of people with an intellectual disability
- respecting and supporting the decisions of those who work most closely with the people with an intellectual disability
- fostering personal commitment between support staff and people with an intellectual disability, and encouraging staff to use their own personal networks to find others who might become involved in people's lives.

Carlos (1994) describes a small Australian agency called "Maps West". The service developed for a small group of young people leaving school, who had both a physical and intellectual disability. "MAPS" stood for "making a positive start". For individuals using the service the primary areas to improve the quality of life of these young people with multiple disabilities were:

- greater range of choice in all areas of life
- development of relationships outside of family and paid staff
- independence and personal development
- use of community environments
- improvement of status and reputation and greater respect by the community.

The conclusions about how well these goals were achieved, from an evaluation of two years of operation, were:

- physical limitations limited **participation** in many activities
- parents were often reluctant to support more flexible hours of operation
- looking for opportunities in the **local** community, where a person could be involved as a regular member of a group where all had a common interest, helped to develop a wider range of social relationships
- the use of 1:1 support for individuals and better communication with parents enabled the service to respond more quickly to needs as they arose
- the adults with disabilities showed improvements in physical wellbeing, probably from being involved in more activities
- parents reported positive changes in behaviour, alertness, and happiness in their sons and daughters
- the service tried to use community, generic services (non-disability), but this was not always possible
- expanding the community participation of adults with disabilities requires skills in solving logistical problems **and** in community development approaches.

Other approaches to community participation have been described in the literature. A well-established model called “citizen advocacy” (eg, Widrick, Hasazi, and Hasazi 1990) provides 1:1 volunteer friendship/advocacy support for adults with an intellectual disability. This type of relationship can promote community participation and extend the adult’s social network. “Circles of Friends” (eg, Gold 1994) is another approach to friendship and social network building. While such deliberately established groups can contribute towards the process of community participation, there is a danger of over-formalising friendship development. As Gold points out, the primary question is, “How can we facilitate and support friendships in typical places and typical ways?” (p 451). The earlier review on “Relationships for adults with an intellectual disability” addresses these issues in much more detail.

Finally, the responsibility for developing more community participation for adults with an intellectual disability cannot rest solely on the adults and their support persons. “The community” and its members also have a critical role. As Amado and Victorian-Blaney (2000) point out, it is absolutely essential to **ask** the community. These authors describe community projects which promote inclusion of people with an intellectual disability. Unfortunately, disability support services staff are seldom trained in a community development approach, with a long history of individualised approaches based on addressing skill deficits.

In Seattle, a project called “Involving ALL Neighbours” has a staff position dedicated to the neighbourhood inclusion of people with an intellectual disability. Strategies pursued include:

- pursuing personal interests in the neighbourhood
- nurturing neighbourhood hospitality
- getting involved in existing neighbourhood organisations
- developing inclusive neighbourhood organisations
- organising neighbourhood projects and efforts.

Other agencies have used “Community Members’ Forums” to work in partnership **with** the community to promote inclusion and participation. People need to be asked to be able to respond. As one disability agency explained:

The concept of the community as an equal and active partner in achieving relationship and membership turned out to be just the shift in thinking that we needed to get unstuck... we had never seen the community as experts in building community... we still implicitly saw ourselves as the experts (p 17).

Summary

Research evidence and a variety of models and options exist to enhance the community participation of adults with an intellectual disability. In addition, the community itself may be a large untapped resource. There are no doubt excellent examples of “good practice” in New Zealand, but few published reports.

What are the implications of this review for New Zealand communities, community groups, and disability support services?

Conclusions and implications for New Zealand communities and disability support services

This review has provided an overview of some of the recent research and publications on the community participation of adults with an intellectual disability. In addition, the area of leisure/recreation was examined as an important part of life which typically involves community participation, at least some of the time.

Why do we need to consider community participation for this particular group of people? Because unlike the majority of other citizens they have traditionally been isolated and segregated from community life. Furthermore, it was society itself, or sections of it, which sanctioned and carried out the segregation and congregation of people with an intellectual disability, against the strong desire of families to care for their own members (Mirfin-Veitch, Bray and Ross 2001).

Who has the responsibility to redress these past denials of community belonging? The research itself provides a range of strategies focussed on people with an intellectual disability themselves, their families, and disability support workers. Very little research or discussion appears to focus on the community itself, or on the importance of a community development approach. The issue is still largely conceptualised as one of “fitting” adults with an intellectual disability into existing communities – which may or may not be welcoming – rather than considering changing the communities themselves to become less prejudiced and more inclusive. In New Zealand, the importance of changing community attitudes towards people with **psychiatric** disabilities has been recognised at national level, but a similar strategy has not yet been embraced regarding adults with an intellectual disability. Public and media reactions to the resettlement of people from institutions illustrates the significant degree of prejudice and stereotyping still present in New Zealand.

The goal of community participation for people with disabilities has been set out in the new Government “vocational service” strategy, “Pathways to Inclusion.” This location of an explicit goal of community participation could cause confusion for some people, as community participation is clearly a concept which embraces a person’s whole lifestyle/wellbeing, and **applies to all areas of life** – education, family, work, leisure, citizenship. Like “mainstreaming”, there is a danger that it will be perceived and pursued as a particular activity – “now we’re going to do community participation” – a sure recipe for limited progress.

Another area for considerable reflection is the implied assumption in some philosophies, research, and services, that it is to be preferred that individuals with an intellectual disability have non-disabled friends rather than friends with an intellectual disability. Such an implication devalues people with an intellectual disability and confuses what community inclusion and participation means – “finding ways of ensuring that everyone is a participating citizen without being penalised because of a difference in race, sex, ethnicity, religion, or physical or mental ability (Rioux 1993: p 21).

At the practical level of what the research suggests we **can** do now, the following implications and questions can be considered for New Zealand.

1. Do our current support services, particularly residential support, provide the individualisation and flexibility necessary to increase the positive community participation of adults with an intellectual disability?

With the preponderance of traditional group homes of about five or more people in New Zealand, the research suggests that we face major barriers to moving forward. Smaller and more individualised living options are generally associated with greater community participation and belonging for adults with an intellectual disability.

2. **Which** disability support services or staff have **responsibility** for planning and supporting community participation for individuals with an intellectual disability? Is “community participation” simply going to be the alternative day service to real work?
3. Do all support staff **understand their role** in this area and are they adequately trained?

The research demonstrated that supporting adults with an intellectual disability to become accepted community members is **not** a simple task. Although the research provides us with a range of evidence-based strategies, the majority of staff working in the field will never have heard of them. Moreover, approaches need to be tailored to individual differences, rather than “group” approaches, but systems and resources may pose barriers to this, in addition to lack of training and professional development.

4. The issue of **personal choice** for adults with an intellectual disability is likely to be significantly limited by:
 - practical barriers of resources, logistics, and transport
 - lack of effective communication to express choices and preferences, for some adults with an intellectual disability (see previous review also)
 - the need for specific “teaching”/intervention strategies based on thorough assessment and up-to-date knowledge, for some individuals.
5. Finally, how do we begin to face the broader issues of “the community” itself. People’s experiences of trying to participate in “the community” can be frightening and unpleasant.

Marcia Rioux (1993) should have the last word here:

*In the end, people **without** mental handicaps will have to change who they are and what they do. Recognizing the contribution of people with mental handicaps is not a matter of making everyone the same. It is a matter of changing the way we do things to accommodate uniqueness and difference – and doing so in a way that ensures that, in every aspect of life, all people have the opportunity to participate (p 21).*

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