COMMUNITY PARTICIPATION AND QUALITY OF LIFE FOR EX-TEMPLETON CENTRE RESIDENTS: POLICY, THEORY AND PRACTICE: AN OPPORTUNITY FOR NGO COLLABORATION

John R. Grant
General Manager, SkillWise[1]
Christchurch

Abstract

The quality of life for adults deinstitutionalised from the Templeton Centre in Christchurch is surveyed through the eyes of their mothers. Results are compared to those of other studies that followed up people discharged from similar institutions. These results are looked at in the context of contemporary disability policy and the challenges faced by community-based support providers to implement these policies. In particular, the paper will focus on the issues faced by day service providers of vocational training, leisure and recreation services, business enterprises, community participation and supported employment. It argues that in order to increase the quality of life for their clients, day services and residential providers (organisations providing "residential care" where housing is a part of a person's disability support package) need to work in a more collaborative way. The challenges of inclusion and social role valorisation for non-government organisations (NGOs) providing support services is also discussed.

INTRODUCTION

The deinstitutionalisation process in New Zealand and overseas has been underpinned by the notion of community inclusion and participation. Residential and day services were intended to facilitate the inclusion and participation of adults with intellectual disability in the wider community.

This paper examines the quality of life for adults with intellectual disability living in the wider community. Quality of life is looked at in terms of a person's social relationships and interaction, leisure and recreation activities together with autonomy, personal choice and independent living skills. The principles of normalisation and social role valorisation are discussed briefly as a means of providing an overview of the theoretical framework that has underpinned deinstitutionalisation. The results of this study are discussed relative to similar studies both in New Zealand and overseas.

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1 Skillwise is a community organisation supporting adults with intellectual disability in community participation as a part of *Pathways to Inclusion* (Ministry of Social Development 2001).

Also, contemporary government disability policy is looked at, including *Pathways to Inclusion* (Ministry of Social Development 2001) and the *New Zealand Disability Strategy* (Minister for Disability Issues 2001). The focus of this relates to the challenges faced by providers in the process of implementing these policies. It will be argued that a collaborative approach is required in order to realise the ideals set out in these policies. In other words, day services will need to work alongside residential providers in order to increase the quality of life of the people they support.

BACKGROUND

Theory Underpinning the Deinstitutionalisation Process

In the mid-1960s Bengt Nirje, the executive director of the Swedish Association for Retarded Children, developed the theory of normalisation. He argued that people with intellectual disability should be able to experience the conditions of everyday life as closely as possible to the patterns and norms of mainstream society (Biklen 1979).

However, it was Dr Wolf Wolfensberger who developed the theory further and incorporated the theory of social role valorisation (Biklen 1979, Wolfensberger 1983). Wolfensberger (1987) argued that people with intellectual disability were at risk of developing "social devaluation" as patients in institutional environments. For example, institutions that modelled prison or hospital conditions created a physical setting that encouraged staff to label people with disabilities as subhuman or deviant, or as objects of fear, pity, ridicule or sickness (Wolfensberger 1987). The theory of social role valorisation argues that to enable people to be relabelled as "valued" they needed to live and work in a "valued setting" such as the wider community (Wolfensberger 1983, O'Brien et al. 2001)

Underlying this belief is the idea that every person, regardless of the extent of their impairment, is entitled to develop and to enjoy the maximum level of independence. This principle recognises the right of the individual to live in the environment that is the most supportive and the least restrictive of his or her freedom.

Being included as part of the community means having ties and connections with others. People build up these ties and connections that give their lives meaning through friendships and acquaintances, making a home, keeping up interests, and active involvement with family and the neighbourhood. Accordingly, the "valued social roles" Wolfensberger refers to include friend, neighbour, worker, student, relative, club member and so on (O'Brien et al. 2001:78). Social role valorisation, it is argued, leads to wider community acceptance and greater inclusion of people with disabilities. If people are seen to be adding to society – living in a local area, making it a better place, being employed – they are seen as being valued members of that society.

The principles of normalisation and social role valorisation can provide valuable guidelines for the design and implementation of support services, together with standards against which such services can be monitored and reviewed (McVily and Rawlinson 1998).

Quality of Life

As far as quality of life is concerned this has shifted from being primarily a topic of academic discourse to playing an essential role in decisions that have a major impact on people's lives (Borthwick-Duffy 1996, Schwartz and Rabinovitz 2003). This is clearly evident with a social policy such as deinstitutionalisation, as quality of life represents a key aspect of this policy. However, there are two fundamental questions regarding the measurement of quality of life. First, what aspects of a person's life should be considered and, second, what procedures or approaches should be used in measurement (Schalock 1996:46)?

Efforts to measure quality of life tend to focus on either objective or subjective indicators (Schalock 1996:46, McIntyre et al. 2004:132, O'Brien et al. 2001:68). Objective indicators refer to external, environmentally based conditions such as health, social welfare, friendships, standard of living, education, public safety, housing, neighbourhood and leisure activities (Schalock 1996:46). Such indicators are useful for measuring the collective quality of community life, but are insufficient for measuring a person's perceived or subjective quality of life. Subjective indicators focus on the person's evaluation of psychological wellbeing or personal satisfaction, including physical and material wellbeing, interpersonal relationships, social and community activities, and personal development (Schalock 1996: 46).

The composition of "quality of life" remains controversial, with little agreement concerning its definition (McVily and Rawlinson 1998). Most studies assessing quality of life include more objective indicators that are more likely to be common to many people (McIntyre et al. 2004:132). However, proponents of quality-of-life models for people with intellectual disability have increasingly stressed the importance of subjective indicators (McIntyre et al. 2004:132). Whether using subjective or objective measures, the evaluation of social reforms such as deinstitutionalisation has inherent methodological problems (for a discussion of these issues, see Jenssen 1995).

New Zealand Government Policy

Recent government disability policy in New Zealand has demonstrated a commitment to inclusion and the empowerment of people with disabilities. *Pathways to Inclusion* (Ministry of Social Development 2001), which builds on aspects of the *New Zealand Disability Strategy* (Minister for Disability Issues 2001), sets out a framework

for improving the quality of services that assist people to participate in their communities.

The *New Zealand Disability Strategy* represents a long-term strategy for changing New Zealand from a disabling to an inclusive society. The strategy has the vision of a society that highly values the lives and continually enhances full participation of disabled people. This document sets out some very clear objectives designed to facilitate increased participation in the wider community. Central to this is supporting lifestyle choices, recreation and culture for people with disabilities. This objective is designed to create and support the lifestyle choices of disabled people within the community and promote access to recreation and cultural opportunities. The *New Zealand Disability Strategy* is also concerned with providing some direction in the creation of opportunities in employment and economic development for people with disabilities, as well as supporting quality living in the community. These policies must provide the cornerstone upon which disability support services are provided.

METHOD

The participants in this study were the mothers of 10 people relocated from the Templeton Centre (on the outskirts of Christchurch) into the wider community. Clearly, the ideal methodology in this area of social research would be to interview the people directly involved. However, there were a number of reasons why this ideal was not met in this case. Firstly, there were challenges in terms of the ability to communicate verbally with a number of the people in this study. While this does not and should not preclude the participation of non-verbal people in this area of research, it was a determining factor for this study. This was primarily due to the constraints of time and the nature of the information required to inform the study. Also, it was of some interest to gain an insight from a parent's (in this case mother's) perspective in relation to an emotionally charged issue such as deinstitutionalisation and its impact on quality of life.

It should be acknowledged there are inherent methodological issues with mothers as participants in this type of research (for a discussion of these issues see Munford 1992). The use of just mothers as participants was not initially by design. The first person contacted was the mother of an ex-Templeton Centre resident and she provided the names of other mothers willing to take part. As the interviewing process unfolded it became apparent that these mothers were willing to talk about an emotional and somewhat sensitive area.

In order to gain access to participants the snowball sampling technique was utilised. This approach is often used to obtain a sample when there is no adequate list that could be used as a sampling frame (Arber 1993:73). Snowball sampling involves contacting

a member of the population of interest and asking whether they know anyone else with the required characteristics, and so on (Arber 1993:74).

Of the 10 former Templeton Centre residents, eight were male and two were female. The average length of time spent in an institution was 29.2 years, with a range of 22 to 40 years. They had been in a community setting between two and four years and all were living in a community residence. They were relocated from the Templeton Centre between February 1997 and October 1998. The interviews were conducted in late 2000 and early 2001.

Access to most disability support services is via an assessment of an individual's needs, followed by a process to coordinate access to available services to meet the assessed needs. This service, which is contracted out by the Ministry of Health, is known as Needs Assessment and Service Coordination (NASC). The three categories of need are minimal needs (A), moderate needs (B) and intensive needs (C), and each attracts a different level of funding. In terms of the needs assessment categories, seven people in the present study are category C and three category B.

The present study utilised qualitative research methods by way of semi-structured interviews. The cornerstone of qualitative research is studying people's understanding of a phenomenon; that is, understanding the meaning they ascribe to an event, occurrence or process (McIntyre et al. 2004:132). An assessment of people's quality of life post-deinstitutionalisation formed the basis on which the study was constructed.

RESULTS

Meaningful social relationships and social interaction contribute significantly to the quality of life for people with intellectual disability living in the community (Cambridge et al. 1994, McIntyre et al. 2004, O'Brien et al. 2001). Social relationships can be nourished through the establishment of community roles (Harlon-Simmons et al. 2001). Of particular interest is the extent to which people with intellectual disability interact and have social relationships with others in the wider community.

The mothers of the former Templeton Centre residents in this study reported somewhat limited social relationships and social interaction. These were almost exclusively confined to family, residential and day service support staff and other clients. This would appear to result from support processes that lack a focus on creating opportunities for interaction with people in the wider community – such interaction being minimal to the point of insignificance. It seems that both residential and day service environments (which for the most part consisted of sheltered workshops and leisure and recreation services) operated in a segregated fashion and thus isolated people from the wider community.

The issue of neighbour contact in the present study is a rather interesting one. While there appeared to be tacit acceptance of people with an intellectual disability living nearby, the situation did not seem to extend much beyond this. In other words, we found little or no evidence that supports any meaningful social interaction between neighbours and residents.

The findings are supported by some other studies. Horner (1994) also found that contact between residents and the wider community was minimal. She suggests that many people with an intellectual disability living in the community are lonely, and have fragile or non-existent support networks (p.171). Cambridge et al. (1994) reported similar findings to the present study in relation to the nature of social interaction and social relationships. Most of the participants in their study had some friends, but relatively few. Most friends had been met through clubs, day services and when they moved into their homes in the community, or they were long-standing friends from hospital. Satisfaction with social contacts varied. In terms of contact with friends who were not co-residents (that is, friends living elsewhere) only 50% of participants were satisfied with the frequency of contact.

However, O'Brien and Thesing (1999) in their study of former residents of Kingseat Hospital living in the community found that over half of residents had some contact with neighbours, according to staff that were interviewed. Also, just over 20% of staff reported reciprocal visits of some sort or other (p.53).

To summarise, there were a number of issues to emerge in relation to social relationships and social interaction. Some mothers felt that social interaction between residents had been reduced by the virtue of the fact that they were dispersed throughout the community. It would appear that almost all social interaction took place between staff, other residents (both at the community residence and day services) and family members. Social interaction with the wider community appeared to be minimal, to the point of being insignificant. This is particularly true of contact with neighbours.

There is no question that leisure activities are part of an "ordinary" and valued lifestyle. Broadly speaking, leisure and recreation activities are significant on two levels. Firstly, there is the personal enjoyment gained from participating in such activities, which undoubtedly contributes to an individual's quality of life. Secondly, such activities can provide a platform for social interaction, thus establishing social relationships.

Mothers varied in their assessment of the recreation and leisure activities their children were involved in subsequent to the move from the Templeton Centre. Some felt their children were busier in this regard than when they were in the Templeton Centre, others disagreed. There appeared to be some degree of disparity in terms of the frequency, quality and nature of leisure and recreation activities. This depended on factors such

as resources and the philosophy of both residential and day providers (whether they structured activities "in house" or accessed wider community-based activities) and the quality and commitment of staff. It would appear most of the day service activities occurred "in house". However, several mothers reported infrequent "outings" that involved picnics and trips to shopping malls and cafes.

It would appear some services have more of a focus on community participation and integration. In her thesis looking at the experiences of former Mangere Hospital residents living in the community, Levien (1996) discovered that many residents were able to take advantage of a variety of community-based services and organisations, including the library, video library, recreation and community centre, and Disability Resource Centre. At one house, three and a half days per week were spent mainly as a group attending various community activities or going out for lunch together. Residents were also able to access other community resources, such as parks and a beach where they could enjoy long walks. Similarly, another house reported a variety of individual and group activities, with both fellow residents and others (p.349).

O'Brien and Thesing (1999) found that most of the residents in their study – all of whom were high functioning – were able to access and participate in three levels of recreation and leisure activities. Firstly, residents participated in a number of different leisure activities within their residential placement, such as listening to music, watching television, baking and gardening. Next there were the activities undertaken at day services, including socialising, craft, music and reading. Lastly, many residents took part in community activities such as shopping, sports, eating out, visiting friends and travel, which tended to be integrated rather than segregated. O'Brien and Thesing found a higher level of activities in an integrated setting than was found among the ex-Templeton residents in the present study.

Overseas studies have found that in many cases people with intellectual disability living in the community have opportunities to engage in new leisure activities. For example, Booth et al. (1989) found that a quarter of participants in their study talked about the opportunities for new leisure pursuits, including gardening and going hiking. Cambridge et al. (1994) found that many residents of community placements simply enjoyed being able to watch television, or listen to the radio in their rooms without restrictions. They also concluded that while living in the community provided the opportunity to participate in leisure activities such as going to pubs, cafes and clubs, this did not necessarily ensure community participation, integration or access to wider social networks (Cambridge et al. 1994:68). In other words, people with intellectual disability living in the community could experience social isolation and segregation.

It would appear that for some ex-Templeton residents in the present study, the quality and frequency of leisure and recreational activities improved and in other cases they

declined according to their mothers' assessments of their situations after leaving Templeton. A major determinant in this regard relates to the resource levels and philosophy of service providers.

Autonomy, personal choice and independent living skills represent a significant component of community living. These are pivotal factors in people achieving community membership and taking on socially valued roles. The degree to which this can be achieved depends on a number of factors. Firstly, an individual's level of functionality can be a factor influencing the degree to which autonomy, personal choice and independent living skills can be achieved. Indeed, research indicates a correlation between an individual's level of functioning and their quality of life (McIntyre et al. 2004:132). Another important factor relates to the staff within community organisations. In order to achieve certain elements relating to autonomy, personal choice and independent living skills, an individual may require quite a high degree of support and assistance from the staff. The philosophy that guides respective organisations may also have quite a strong influence on whether or not areas relating to autonomy, personal choice, and independent living skills receive much attention.

The location of the service may have an impact on the scale to which these things can be achieved. For example, the ability to access certain community resources such as parks, and shopping and entertainment facilities will be influenced by the physical location of a community placement (both residential and day) and the transport services available.

The present study revealed a variety of levels to which aspects of autonomy, personal choice and independent living skills were being achieved. It would appear the main emphasis was on the development of domestic independent living skills. Most of the mothers reported tidying rooms (dusting and vacuuming) and doing the dishes, but not cooking, washing or ironing.

The ex-Templeton residents in this study seemed to experience little autonomy and personal choice. In the residential environment it would appear life followed a somewhat structured pattern, with daily routines more or less replicated one day to the next. The extent to which people had (and were encouraged to exercise) choice in terms of their daily routine was unclear, but there seemed to be little opportunity for people to choose what they ate and when, the places they visited and the people they interacted with. Nevertheless, all the mothers in this study felt there was greater potential for the development of autonomy, personal choice, and independent living skills in a community setting in comparison to an institution.

This is supported by Levien (1996:350), who suggests that former Mangere residents in her study were more able to exercise autonomy and choice, and that this is due to a number of factors. Firstly, the demarcation between groups that had existed in the

institution was eliminated (Levien 1996:350). Also, the smaller number of residents per staff (an average of five residents and two staff per house) meant that residents were more able to exercise autonomy and choice. She found increased efforts by residents to be independent, often without staff prompting them. As a result, residents were able to take greater responsibility for themselves, thus reducing the control and restraint they had experienced in Mangere.

Overseas studies reflect a similar perspective. Stancliffe and Abery (1997) concluded that people with intellectual disability living in the community had a greater degree of choice in their lives than those living in an institution. However, the degree of choice varied according to the level of functionality, with those who had lower levels of functionality exercising less choice, particularly for those who were non-verbal and had limited skills with which to identify and communicate their preferences (Stancliffe and Abery 1997). Wing (1989:98) found that another variable was the type of accommodation they were in, with those living in private hostels experiencing less independence than tenants of small houses.

DISCUSSION

A total of five reports have been published by the Office for Disability Issues (2001, 2002, 2003, 2004, 2005) subsequent to the implementation of the *New Zealand Disability Strategy* (Minister for Disability Issues 2001). These reports provide an update of work being carried out by government departments in their implementation of the strategy. It would appear all government departments are developing a variety of programmes to bring the strategy to life, with more work being done in some areas than in others. In particular, there has been a focus on infrastructure issues such as human resources, physical access, communications, consultation, staff training and information. Also, a number of departments have demonstrated improved consultation processes by ensuring people with disabilities are included on various advisory and reference groups that give input into policy development. It was particularly pleasing to see three Crown entities (Accident Compensation Corporation, Sport and Recreation New Zealand and Housing New Zealand Corporation) reporting on their efforts in implementing the strategy. Now it is only government departments that are required (through a Cabinet directive) to report on the implementation of the strategy.

There is currently no such reporting requirement for NGOs either. Given the role NGOs play in facilitating community inclusion and participation for people with disabilities, it seems reasonable to expect some type of reporting process whereby NGOs provide an indication of outcomes achieved. This need not be an onerous task and could constitute a part of the contract reporting process. Such information would provide a clearer picture of progress being made.

In 2003 the National Advisory Committee on Health and Disability provided a report to both the Minister of Health and the Minister for Disability Issues entitled *To Have an "Ordinary" Life*. Its aim was to build a detailed picture of the lives of adults with intellectual disability who are supported by government-funded services in New Zealand. This report is the first comprehensive piece of research whereby much of the information collected has come from adults with an intellectual disability themselves. The areas of life examined included accommodation, communicating, work (paid and unpaid), being a part of the community, learning new things, relationships, having fun and moving around. There are a number of findings from this research that both residential and day service providers must embrace in the quest to support people to the "ordinary life" that many have historically been denied.

Firstly, residential providers must ensure their model of support is not based on "residential care". Support must be flexible, promote independence and recognise individual needs, goals and aspirations. Both residential and day service providers must make certain there are systems in place to ensure that people are encouraged to openly communicate their thoughts, ideas and feelings and that these provide the foundation for client planning processes. Furthermore, support organisations must ensure that people are encouraged to have a collective voice both within the organisation providing the support and within the wider community. A client representative group is one way of facilitating a collective voice, but such a group needs to have a clear interface with management and governing boards.

It is vitally important that support providers facilitate a process whereby people are supported and encouraged in socially valued roles that provide meaning for each and every person. This involves ensuring that people are supported in "ordinary activities in ordinary places", including leisure, recreation, training, education and employment. These activities provide not only a sense of fulfilment and meaning for people, but also facilitate a process whereby people can become more financially and socially independent.

Service provision must align more with the notion of community membership now that the era of deinstitutionalisation has come to an end. This involves ensuring support is tailored to individual goals and aspirations, is underpinned by a clear emphasis on self-determination and promotes social inclusion. This model of support facilitates a process whereby people are supported to be "of the community" not just "in the community". In other words, it leads to greater levels of social inclusion.

There are a number of challenges that both residential and day services face in their efforts to implement the ideals contained within the *New Zealand Disability Strategy*, *Pathways to Inclusion* and *To Have An "Ordinary" Life*. These challenges include resourcing issues (which mainly relate to funding levels), attitudes held in wider

society toward people with disabilities, and developing good working relationships with key organisations. Both residential and day services must ensure a paradigm shift whereby the era of community membership is fully embraced and constitutes the foundation upon which service provision is based.

Day services in particular must work from a model of support that is based on brokerage and not the traditional centre-based vocational models. A brokerage approach involves facilitating a process for people to access their communities and their resources. The notion of "bridging the gap" captures the essence of the concept of brokerage. "Bridging the gap" involves linking those people receiving support with people and opportunities in the wider community. This incorporates access to mainstream leisure and recreation activities, together with employment and employment-related opportunities. This helps people to greater levels of independence and self-determination through such things as gaining paid employment and forming new friendships, including those with non-disabled people – all of which facilitates greater levels of social inclusion.

As far as funding levels are concerned, it would appear that current levels are not adequate to deliver services in a way that realises the ideals set out in the *New Zealand Disability Strategy* and *Pathways to Inclusion*. According to Saucier (2002), it is largely due to resource constraints that many disability services can only help people maintain their current status, as opposed to actively promoting independence. Clearly this does not meet the expectations of the *New Zealand Disability Strategy* and *Pathways to Inclusion*. The disability sector needs to be infused with greater expectations of habilitation and rehabilitation. Clients need more opportunities to express their aspirations and participate in the development of flexible service packages that enable increasing participation in society (Saucier 2002).

In terms of the challenges relating to attitudes held in wider society, this is something that will take time to improve. The *New Zealand Disability Strategy* has as its first objective "Encourage and educate for a non-disabling society". This includes developing national and locally based anti-discrimination programmes. The Mental Health Commission's *Like Minds, Like Mine* campaign is a good example of a well-planned and implemented anti-discrimination initiative. However, further work is required in the area of educating for a non-disabling society, and NGOs can play an important role in this process.

In light of the challenges relating to resource levels and societal attitudes, it seems obvious that one way of attempting to begin to reduce the impact of these factors is for community support organisations to work more collaboratively. This will undoubtedly improve quality-of-life outcomes for clients. It would appear that for the most part social relationships and interaction occur between staff, other residents (both at

the community residence and day service) and family members. Day providers and residential providers could work more closely with clients to facilitate social relationships and interaction with members of the wider community.

Developing involvement with the wider community would require looking at a client's leisure and recreation goals, and their vocational, employment and personal development goals, and day services would need to provide less recreation and leisure services "in house". However, staffing levels would need to be looked at as part of this process. In order to access more community-based leisure and recreation activities, funding would need to increase in order to have the necessary staff-to-client ratio. There may need to be extended one-on-one support with clients in order to facilitate and sustain access and participation in mainstream leisure and recreation activities.

Funding increases may not need to be significant. As part of a collaborative approach residential and day services should be encouraged to share resources, including human and physical resources, together with information and ideas where appropriate. This could result in significant streamlining, with the added benefit of increased consistency and continuity in the services provided.

Supporting autonomy, personal choice and the development of independent living skills should be the responsibility of both residential and day providers. These ideals should provide the cornerstone of all community support organisations. Where streamlining services improves consistency and continuity, this can be particularly helpful in the area of autonomy and independent living skills. By adopting a joint planning and support approach, goals would be set and reviewed through a planning process involving clients, family and significant others, together with residential, day services and education providers where appropriate. In other words, a collaborative approach could extend beyond just residential and day services. This would provide an opportunity for a continuity of goals relating to a person's interests and aspirations in their home, education, day service and employment-related environments.

CONCLUSION

Both residential and day services must be driven by quality-of-life outcomes. Such outcomes need to incorporate social relationships and interaction, leisure and recreation activities and employment, together with autonomy, personal choice and independent living skills. There is evidence to suggest that residential and day services need to look at ways in which their clients' quality-of-life outcomes can be enhanced. Also, the government needs to look not only at funding levels but at the way in which funding services are structured.

The challenge is to ensure that both residential and day services operate in a way that facilitates meaningful community participation and promotes social inclusion. To be effective, such services need to embrace not only the ideals set out in the *New Zealand Disability Strategy, Pathways to Inclusion* and *To Have an "Ordinary" Life*, but also the principle of normalisation and social role valorisation. Increasing the quality of life for people with an intellectual disability requires, among other factors, residential and day services to work in a more collaborative way.

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