Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual disability.
Abstract

**Background:** Typically people with intellectual disability have small, highly restricted social networks characterised by interactions with other people with intellectual disabilities, family members, and paid workers. The goal of ‘inclusion’ has been central to policies that have shaped services over the past 30 years. It is an ill defined concept with disagreement about its meaning, the problems it seeks to overcome and how it should be realised. **Method:** Ethnographic and action research methods were used to support and collect data on the implementation of a program, known as the *Community Inclusion Framework*, in a group home for five adults with severe intellectual disabilities in Victoria, Australia. **Results and Conclusions:** A pattern of service delivery based on community presence rather than participation evolved and endured over 16 months. The findings show that most staff attached a different meaning to inclusion from that proposed in the *Community Inclusion Framework*, disagreed with the proposed meaning or felt these residents were too different for it to be meaningful. This suggests that priority will only be accorded to activities that lead to inclusion if staff are convinced of the veracity of this and given strong and consistent direction and support.
Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual disability.

Research on outcomes of institutional closure for people with intellectual disabilities has consistently concluded that it has led to their greater physical community presence rather than community participation in the form of new relationships with ordinary members of the community (Cambridge, et al, 2002; Robertson, et al., 2001; Cummins & Dunt, 1990; Barber, Cooper & Owen, 1994; Bigby, in press). People with intellectual disabilities, whether they have a history of institutionalisation or not, typically have small and highly restricted social networks characterised by interactions with co residents or co participants in day programs, immediate family members, and service workers who are paid to support them (Cambridge et al., 2002; Forrester- Jones et al., 2006; Robertson et al., 2001). For most, contact with non-disabled members of the public is likely to be mundane, impersonal and fleeting, characterised at best by casual acquaintances rather than friendships (Luckasson et al., 2002; Marquis & Jackson, 2000; McConkey, 2005; Myers et al., 1998; O’Brien, 1987, 2005; Ramcharan & Richardson, 2005). Todd, Evans and Beyer, characterise people with intellectual disabilities as occupying a “distinct social space” (1990, p.215).

Goals aiming to counter the occupation of a distinct social space by people with intellectual disability and achieve ‘inclusive communities’ have been at the core of deinstitutionalisation and disability policy for the past thirty years (Robertson et al., 2002). Policy has used terms such as community - ‘inclusion’ ‘integration’ ‘participation’ or ‘involvement’ interchangeably and they are subject to multiple conceptualisations. For example, one of the three goals of the Victorian State
Disability Plan is ‘Building inclusive communities’ (Department of Human Services (DHS), 2002b); one of Victorian Standards for Disability Services is ‘Participation and Integration’, where “Each client is supported and encouraged to participate and be involved in the life of the community” (DHS, 2002a, p.7) and the phrase ‘advancing the inclusion and participation in the community of persons with a disability’ is repeatedly found in the State’s Disability Act 2006.

The contested nature of inclusion is demonstrated in the academic and policy literature (Myers et al., 1998; Cummins & Lau, 2003) wherein after 30 years of debate, substantial disagreement remains as to its meaning, the problems it seeks to overcome and how it should be operationalised, realised and measured. Commonly, the various types of activity in which people take part and the frequency and type of social contacts they make are used as indicators of inclusion. Ordinary rather than specialist settings are generally seen as more desirable and higher frequencies in ordinary settings are usually taken as being indicative of greater ‘inclusion’ (Cummins & Lau, 2003). Relationships with non-disabled people may be privileged over relationships with people with intellectual disabilities. As a consequence activities in segregated day programs, specialist leisure programs, and other residential settings are not highly valued. The benefits of self-segregation are often ignored and whether people with intellectual disabilities prefer to mix with their ‘own kind’ is debated (Brown & Smith, 1992; Cummins & Lau, 2003; O'Brien et al., 2005).

However, an emphasis on frequency downplays the functionality and quality of relationships, ignoring a person’s own subjective perceptions (Tracy & Whittaker, 1990). Small networks for instance can be perceived as being more supportive than large ones. More subjective approaches and measures are particularly problematic when working with people with severe intellectual disabilities, whose preferences and
experiences may have to be interpreted by staff. Views such as that put forward by Cummins and Lau (2003) that whether people enjoy an experience or not should be the only criterion for judging the success of an activity ignores such issues and marginalises the impact of cognitive impairment.

O’Brien and O’Brien (1993) assert that, “People with developmental disabilities have just as much capacity for friendship as any other people do” (p.13), whereas Kennedy et al., (1989) suggest that individuals with severe intellectual disabilities may have more difficulty providing the reciprocity that is needed to maintain relationships. Rather than emphasise the characteristics of service-users, other writers have focused on the ‘handicapist’ or ‘disabling society’ and the role that services have had in the ‘exclusion’ of people with intellectual disabilities (Abbott & McConkey, 2006; Blatt et al., 1977/1981; Ramcharan et al., 1997). Here the emphasis is on non-disabled people changing their hostile or indifferent attitudes and challenging oppressive social, economic, political and legal structures. Somewhat perversely this focus on a hostile society is used to challenge the benefits of inclusion, emphasising its negative aspects. Taylor and Bogdan (1989) focus instead on trying to understand how people with intellectual disabilities come to be accepted by non-disabled people.

The goal of ‘building inclusive communities’ is likely to be influenced by a number of factors. For residents of group homes, the most important sources of variation in outcomes appear to be the level of adaptive behaviour of the residents and the care practices adopted by staff. The higher the support needs of residents the poorer are their outcomes (Felce & Emerson, 2001; Mansell, 2006), and better outcomes are associated with higher levels of staff contact and particularly of facilitative assistance (Felce et al., 2000; Jones et al., 1999; Mansell, 1995; Thompson...
et al., 1996). There is as yet little evidence of what predicts the adoption and maintenance of more facilitative practices. Mansell et al., (in press), suggest they are affected by four factors: service characteristics (type and size); staffing (the ratio of staff to residents, staff qualifications, experience, training, knowledge, attitudes and turnover); organisational hygiene (job satisfaction, stress, role clarity and conflict), and management (autonomy of managers and systems for organising care).

There are still significant gaps in what we know about how the formal culture of an organisation or informal work processes in a specific setting influence what staff do. This paper describes the implementation of a program, known as the Community Inclusion Framework, in a group home for five adults with severe intellectual disabilities in a metropolitan area in Victoria, Australia and reflects on why a pattern of service delivery based on community presence rather than community participation (J. O'Brien, 1987), evolved and endured, retaining people within ‘a distinct social space’ rather than perforating its boundaries.

**Method**

The data presented are taken from a large multi-method research project in Victoria, Australia, which examined the lives of people with intellectual disabilities after they had left an institutional setting. A detailed description is available in Clement et al., (2007). The study employed ethnographic and action research methods to work with staff teams in five new group homes. Change is central to action research and an aim was to help the staff teams improve their practices in these workplaces (Coghlan & Brannick, 2001; McNiff, Lomax, & Whitehead, 1996). In one of the five houses ‘inclusion’ for the five residents became the focus of the action research project.

**Participants**
The participants were five middle-aged men with intellectual disabilities and their support staff, who lived and worked in a purpose built group home, owned and managed by the Government, located in a mixed residential and commercial neighbourhood. The men’s ages ranged from 49-57 years with a mean of 52 years 5 months. Organisational files recorded four of the men as having severe and one as having a profound intellectual disability. Three residents had epilepsy; two were diagnosed with a ‘psychotic disorder’, and one had a visual impairment. Results of a Triple C communication assessment (Bloomberg & West, 1999) showed one resident as being at Level 2 (Pre-intentional reactive), three at Level 4 (Intentional informal) and one at Level 5 (Intentional formal). The degree of intellectual disability and related level of receptive and expressive communication are important factors in this project given that people with severe intellectual disabilities rely on other people to plan, organise, identify and coordinate resources to access the community (O'Brien, 1987). In addition it is important to recognise that non-disabled people experience difficulties when they first encounter somebody with significant impairments, a lack of expressive communication and /or socially disconcerting features (Clegg, 2006).

The house was staffed 24 hours a day with a minimum of two staff members, except at night-time, or when residents are at day programs. The house supervisor is an integral part of the roster, working shifts, and providing direct support to the residents. The supervisor reports to an external manager who has managerial responsibility for a number of houses. When the house opened, five of the seven staff had worked between 6 and 32 years in institutional settings. All the staff were qualified, having undertaken either a one or two year further education course in the field of intellectual disability.
Consent for the residents to participate in the research was obtained from a proxy, a named family member and consent for their own participation was given by the staff team and interested family members. Approval for the research was given by the Human Research Ethics committees of both LaTrobe University and the Victorian Department of Human Services.

Data collection and Procedures

In the first 9 months after the men had moved to their new home, one of the research team spent 46 hours over 9 days collecting data using participant-observation methods. The researcher was usually present for a full shift, which during the period included various times and days between 06.45 a.m. until 22.00. Interviews were also conducted with 5 family members and 13 hours of training was observed. At the end of this period the data were discussed with staff in a half-day meeting. Although it was intended that, at this stage, staff would collectively identify the focus of the action research project, ‘inclusion’ had already been earmarked as an area for action by the house supervisor and more senior managers. As the researchers and staff were planning the action research project, the Community Inclusion Officer (CIO) negotiated entry into the house. This post had been created to work across group homes in the region to support staff to enable people with intellectual disabilities to, “make the most of [community inclusion]….and establish themselves as members of their local community” (Warren, 2005, p.1). The post holder had helped to develop a program known as the Community Inclusion Framework (Leatherland & Warren, 2004) which had been used and refined in over 20 group homes. It was agreed the researcher would work alongside the CIO and implementing the Community Inclusion Framework became the action research agenda.
The overarching aim of the CIO was to get group home staff to behave in ways that were in line with the State Government’s goal of building inclusive communities (DHS, 2002). The Community Inclusion Framework was premised on a belief about the benefits of facilitating relationships with non-disabled people. It reflected a specific reading of O’Brien’s (1987) conceptualisation of Community Participation, and aimed to expand people’s social networks by facilitating relationships with people who are not staff members, relatives, or people with intellectual disabilities (Robertson et al., 2001). This aim should not be taken to devalue other readings of ‘inclusion’ that focus on community presence but rather sees participation as a different, parallel and equally valued goal.

Figure 1 gives a simplified version of the Community Inclusion Framework, outlining a series of steps to be followed. It provided staff with a number of planning tools, and training designed to improve their practice, which included a three-hour session on ‘community inclusion’ as part of a two-week ‘transition training’, and a one-day training, ‘Developing community connections at a local level’ four months later.

Insert figure 1 about here

Over a six-month period seven meetings were held with various members of the staff team and three reflective meetings were held between the CIO and one of the researchers. Discussions with staff proposed that if people with intellectual disabilities were to have the possibility of forming relationships with people without disabilities then it was important to examine the specific activities staff support residents to do. The researcher kept field notes of all meetings and time spent in the house. In addition house staff kept ‘Activity Logs’, a diary of the activities that residents had taken part
in. The process for compiling these logs is set out in Figure 2. Figure 3 summaries the process of data collection along side the implementation of the CIO


Analysis

O’Brien’s (1987) distinction between *Community Presence* and *Community Participation*, which had formed the basis for discussion with staff about facets of an inclusive community, was used as the analytic framework to categorise the types of activities the staff group were supporting outside the house. Initial analytic choices were therefore structured deductively in advance, but new sub-codes were developed inductively (LeCompte & Schensul, 1999). Qualitative data analysis software, *Atlas.ti* (Muhr, 2005), was used to facilitate data analysis. Speech extracts from the field notes, which are given later, are presented in single quotation marks. This reflects their genesis in field notes, rather than verbatim quotations that typically come from an interview (see Emerson et al., 1995).

**Strengths and Limitations**

Qualitative research of this kind should be evaluated on the basis of trustworthiness, which includes credibility, transferability, dependability and confirmability (Lincoln & Guba, 1998; Cresswell, 1998). Credibility was gained by an extended engagement with participants that spanned a period of 16 months, and the trust built with staff over this period enabled their frank and reflective discussion of the analysis and interpretation of the fieldwork data (Creswell, 1998). The action research nature of the research has also meant that themes were shared with a reference group and with other staff within the organisation responsible for managing the house, their feedback
about the resonance with their experiences provided further opportunities for the credibility of the study to be established. Transferability has been addressed by the rich thick description of the field notes. A process of peer debriefing has occurred on a frequent and regular basis within the research team. It should be noted however, that the reliability of the Activity Logs kept by staff during the action research phase can be questioned, as diary records kept by direct-care staff have been shown to have limitations with regard to accuracy (Joyce et al., 1989). Staff did not record all the activities that people took part in, the people they engaged with, or the functional nature of those interactions. Although participant observation produced better data, it was not possible to observe every external activity. However, the claim that the broad pattern of activities supports community presence and not community participation is entirely credible and dependable, given the verification processes that are part of the action research methodology.

Findings

Enduring Pattern of Activities that Supports Community Presence

As Table 1 shows a pattern evolved where staff supported activities that were more likely to foster the residents’ community presence than participation. Most of the activities prior to the commencement of the action research project were categorised as community presence (e.g. group outings accompanied by staff to the beach, supermarkets, the cinema, and cafés/restaurants). The figures in the first column of Table 1 represent the activities identified by the staff group at the half-day meeting, when the house had been open for seven months. They also reflected the pattern of activities recorded in participant observation field notes. Activities such as, going for a trip to the Healesville Sanctuary, a popular Victorian recreation site were categorised as community presence, whereas a visit to another group home for a
barbeque is an activity in part of the service system and was categorised as a segregated activity. The possibility of forming close friendships with non-disabled people was unlikely as a result of participating in any such activities. Three activities, visits to the GP, Dentist and hairdresser were categorised as community participation as it was possible that acquaintances can develop by repeated use of the same dentist or hairdresser.

Insert Table 1 about here

After the first seven months the staff group agreed that the pattern of activities supported in the house was similar to that established at the institution. Groups of people left the house with staff to undertake an activity, which resulted in community presence. The biggest perceived difference was the size of the group (a maximum of five service users and supporting staff); the greater frequency of these activities; the increased variety of activities; and the introduction of new opportunities. Activities were still primarily determined by staff, who inferred likes and dislikes from the residents’ behaviours.

The second column in Table 1 is a compilation of the data recorded in the Activity Logs for the last month of the first cycle of action research and is reflective of the trends discussed in reflective meetings with staff. As Table 1 shows the pattern of activities had changed little by the end of the following 8 months, despite the training on ‘inclusion’, external support from the CIO, the provision of reflective space about the goals and means of community participation, and technology in the form of planning tools.

Previous research such as Mansell et al., (in press) and Harrison’s (1994) model, suggest the range of potential factors that might influence this pattern of staff
practice. We discuss below some of the possible explanations that relate to staff culture, drawn from an analysis of the qualitative data.

**Staff Awareness, Interpretation and Agreement with the Goal of Inclusion**

Despite the publicity and attention given to the State Disability Plan the staff team were generally unaware of its specific content. They were only able to make broad comments about it, saying that it contained ‘Philosophies’, ‘Aims’ and that, ‘It keeps us in line, influences what we do, and where we are going’. The most specific comment was that it was about, ‘Lifestyles for individuals, new experiences, supporting a variety of lifestyles’. Whilst everyone publicly agreed that ‘building inclusive communities’ was a laudable over-arching goal, the reflective space provided for staff uncovered individual variations about its meaning, how it might be achieved, the implications for staff practice, and questioning whether it could be achieved at all. By the end of 16 months staff did not have an understanding of ‘inclusion’ that mirrored the one held by the CIO and that had been explicitly stated in the Framework and discussed in work with staff. Some of the staff group shared an understanding of ‘inclusion’, as community presence, whilst others still seemed to have their own meanings. Most of the staff found it hard to give a more abstract definition and illustrated the concept with concrete examples. One staff said that it was, ‘Involvement around shopping and dining out weekly or fortnightly [with staff and other housemates]’; another suggested that it was about using ‘Rec-line’, a recreation, leisure and holiday service for adults who have an intellectual disability (Oakleigh Centre, 2006). According to one staff member ‘inclusion’ also happened in the home, ‘It can be in-house. Slowing down the way they eat, then taking them out’. Only one member of the staff group articulated a view that reflected a notion of community participation, ‘Going down the pub, and having other friendships. Other
people besides the guys [a term used to refer to the men in the house]’. This member of staff worked the night shift and had little influence on what activities happened during the day and in the evenings.

When the house supervisor discussed ‘inclusion’ it typically reflected the goal of community presence.

‘It’s many things, being included, how you are included. When we first went to the supermarket people stared, now they don’t. When we first moved here the men were intimidated. Last week we wandered around Bunnings [a home improvement store]. Seven to eight months ago we couldn’t do that. The men have developed confidence. People like to go for a drive, to go for a walk along the beach. That’s what we did on ANZAC Day [a public holiday].’

For much of the time however, differences in interpretations of ‘inclusion’, attitudes and values, were obscured by the use of different words and phrases. Staff in this house did not share a common vocabulary nor an accepted definition of ‘inclusion’, which O’Brien (1987) and Kennedy et al. (1989) point out is critical if services and professionals are to describe, measure, intervene in, and evaluate this aspect of people’s lives. O’Brien’s notion of community participation was challenged by staff vociferously declaring that when they went out from the house the residents always ‘participated’. For example, one staff said, ‘Community presence is the guys following us around the supermarket. Participation is pushing the trolley’. Staff were also unhappy when visits to other group homes were categorised as being a segregated activity.

O’Brien’s (1987) definition of community participation was helpful in explicating to the staff team the meaning of ‘inclusion’ adopted by the CIO and the
research team, but served to uncover people’s ‘problems’ with the goal which led to
conflict between the staff team and the CIO/researchers, and became the pattern of
interactions in meetings. Most of the staff group had problems with the ten-year
period of the State Disability Plan. One said, ‘I do not believe that by 2012 that things
will be hunky dory’ and another remarked that, ‘The issues are bigger than the time-
frame’. The house supervisor had more of an issue with the goal itself. He said, ‘I
do not think that we will ever get to community participation’. Non-disabled members
of the community were perceived to be a barrier, ‘You can’t expect the guys to
participate with non-disabled people. It’s about educating the general community. We
still get comments from check-out chicks like, “You do such a wonderful job”’. Ano ther staff member said,

‘There needs to be more education. My experience is that the residents are
overlooked. People never speak to the residents. People can be quite ignorant.
A person brushed by [a resident] and nearly knocked him down. It can be
frustrating at times’.

Staff did not understand their role to be part of the education process, and generally
attributed this role to others, ‘People under 24 are more accepting. Younger people
are more receptive. They don’t have fear. They should be educated, throughout the
school system’.

Some staff held opinions of the men that attributed their lack of relationships
with non-disabled people to their functional limitations or psychological losses. One
perceived barrier was the length of time the residents had spent in an institution. One
person commented that, ‘We really cannot expect much from these men because of
the time they have spent in institutions. It will be easier to have inclusion with the
next generation’. Or skill deficits, especially the lack of verbal communication or
challenging behaviour that needed to be overcome before using community facilities, ‘In the house with [a resident] we try to get him to sit at the table, eat properly and not steal other people's food’. These men were ‘too different’ for community participation to be a realistic goal. Even though the staff group were given real examples of effective community participation, they did not believe it possible for the five residents.

Many of these problems mirror the assumptions that people hold about people with intellectual disabilities that contribute to their ‘exclusion’ identified by O’Brien et al. (2005). One consequence of the men being judged as being too different was staff seeing their role as getting them ‘ready’ for community participation in the distant future. Although this represents logical thinking, it is also a barrier to community participation. The ‘readiness model’ is particularly restrictive for people with more severe intellectual disabilities (Kinsella, 1993). Such thinking emphasises the teaching of new skills until the person is competent, a situation that may not arise and as Beadle-Brown et al. (2005) point out, such training may be ineffective if social impairment is chronic, as it is for many people with intellectual disabilities. This suggests that greater success may be had teaching people to interact with those individuals with severe intellectual disabilities, rather than pursue a potentially unsuccessful strategy of teaching individuals labelled as socially impaired. However, if the staff team think that their approach is better than that being advocated by the CIO, they are more likely to emphasise their way of doing things (Fournies, 1988).

A second consequence of seeing the residents as too different was the perception by staff that the goal of inclusive communities in the State Plan was not relevant to the men in the house. It was either dismissed as being unrealistic or seen to be so far away that it was not worth bothering with in the here-and-now. These views
were compounded by the generally held view that the attitude of the community was more hostile than welcoming to these men.

Staff Skills and Perceptions of Leisure Preferences

Personal views about when leisure happens and how it should happen affected the way staff approached community participation. For some staff, leisure varied with the seasons. During the winter, when nights were dark and the weather colder, people stayed at home. For others, leisure happened at the weekends, which means that people stayed at home during weekday evenings. Other people suggested that what happens at day programs is leisure, and since people had been out during the day, there was no need to go out again in the evening. As well as taking no account of the men’s preferences, a consequence of cramming everyone’s leisure activities into the weekend was that activities tended to be group-based because it was thought to be unfair to leave anyone at home. Group activities were also justified by claiming that the residents enjoyed each other’s company, which indeed they might, but group outings were not conducive to creating opportunities for new relationships. Such views are problematic for people with severe intellectual disabilities who are relying on other people to plan, organise, identify and coordinate resources to access the community (O'Brien, 1987).

Staff also expressed the view that they did not know how to build relationships for the men in the house. Although this can be a reason for why employees do not perform (Fournies, 1988), the staff expressed this view after they had received the training. Most of the staff had worked in an institutional setting for a significant number of years, and in its final years a goal had been community presence, rather than community participation. It is possible that the training did not equip the staff with the knowledge, skills, and abilities to undertake this task. The training observed
as part of the participant observation was not directive or prescriptive to staff about the meaning of community inclusion. Staff came away without a clear understanding that at least part of inclusion is facilitating relationships with people without disabilities. The training presented multiple conceptualisations of community and inclusion to staff, asserting that ‘individuals are in a position to construct a concept of community for themselves and develop their own social ties and identities that are meaningful for them’. In practice however this meant staff working with residents with severe impairments were left without much guidance to construct concepts of community and ties on behalf of residents. Many of the examples given in the training were of people with less significant intellectual disabilities, which were perceived by staff as not being relevant.

**Reflections and Next Steps**

Maher (1984) lists a number of issues that should be taken into account when implementing a program, such as the *Community Inclusion Framework*. With hindsight many of the factors that he lists as being necessary for organisational readiness were not achieved at the house. Initially the nature and scope of the program was not clear to the staff team, the need for it was not apparent, nor could they see any positive consequences for the residents.

Unlike some people with intellectual disability this group of residents could not articulate their own views, to counter the position taken by staff. It is much harder to discount the wishes of people with intellectual disabilities when they make them directly, as does self-advocate Robert Martin (2006):

“Our vision is for an *inclusive community*, a community with a place for all….We want to live in a community that will open its doors to us and
welcome us as equals….An Inclusive Community is the key to our future if we are to join you as equals. However we need your support and commitment if we are to build communities that are truly inclusive. We need you to believe in the justice of our cause” (p.127).

Family members had their own doubts about community inclusion and so did not challenge staff practices. For example one mother commenting on the possibilities of inclusion for her son, said,

‘I don’t really know. I can’t really see it…I think there is a positive push and people are more active in society. How much you can do? Someone with no communication skills, no verbal communication skills and things like that, that’s more…maybe voluntary people assisting? …We can have too high hopes’.

Her comments are a stark contrast to some parent activists who openly challenge staff attitudes and practices.

“We came to understand that it is friendship, not skills or competencies, or even quality services, that is most important in [our daughter’s] life….It is friendships that make life worth living…. It is her and our only hope for a desirable future and protection from victimization” (Strully & Strully, 1993, p. 213-214).

Perske (1993) makes the point that families and human service workers provide and do things that friends cannot, but friends help to stretch us beyond the limits of our families, and friends help people to move beyond the limits of human service goals. These arguments have to be won with front-line staff if they are to see the need for and understand the benefits of facilitating relationships with non-disabled people. Our
research suggests that front-line staff in this setting thought service-based, family, and peer support to be more important than other sources of support.

The *Community Inclusion Framework* was based on the assumption that all people with intellectual disabilities occupy the ‘distinct social space’ that was outlined earlier. A consequence of this is outlined by Perske (1993):

……it is not enough merely to place persons with disabilities in a neighbourhood – they must be connected to it socially. Their lives must interweave emotionally with the lives of others…. good inclusion takes more than caring parents, committed professionals, and carefully matched volunteers.

It also takes friendships – lots of friendships” (p.2).

The danger of assuming that all people with intellectual disabilities occupy this distinct social space and require lots of friendships, is that people can end up being treated as a homogenous group, rather than as individuals. Tracy and Whittaker (1990) argue that we should avoid making assumptions about people’s social networks and that network data should be evaluated in relation to the presenting problems and needs of the clients. The *Community Inclusion Framework* started from a focus on the interests of each resident, rather than an assessment of the structure and function of their social network. However, on their own, the structural features of networks do not tell us about the quality, amount, and experience of social support (Tracy & Whittaker, 1990).

Beginning with an assessment that can subsequently be used to enhance people’s social networks may assist in overcoming staff’s resistance to the goal of ‘building inclusive communities’. If the precise structural and functional features of a person’s social networks can be discussed it may be easier for staff to see why and
how this might be enhanced and in turn individualised interventions may be adopted rather than a universal solution. This is a proposition to be tested in the next action research cycle.

Emerson and Hatton (1994) claimed that leadership and management in relatively isolated, dispersed services is important in producing positive outcomes for people with intellectual disabilities. In supported community-based accommodation much of the work takes place between individual workers and ‘silent’ clients in unobserved settings, and the ‘isolation’ of these settings allows relatively autonomous work groups (Handy, 1990) to set norms and goals that are not congruent with those of the organisation. Hewitt et al., (2004) concluded that it is house supervisors in these settings that establish a well-functioning work environment and define the job for direct support staff. Handy’s (1993) conceptualisation of negative power allows the distinction to be made between positive and negative leadership, “negative power is the capacity to stop things happening, to delay them, to distort or disrupt them” (p.131). In relation to the goal of ‘building inclusive communities’ the leadership in the house was categorised as negative leadership because the house supervisor’s stated goal was to maintain the existing pattern of service provision (community presence) and not move the service in the direction set by senior managers. Four months after the CIO began work in the home, and thirteen months after the house had opened, the house supervisor wrote that they would focus on community presence and ‘the aim would be to assess at a later date the ‘participation’ aspect’. The leadership in the house was therefore not conducive to the successful implementation of the Community Inclusion Framework because the house supervisor had a different priority (Fournies, 1988; Maher, 1984). In this instance the day-to-day practice was kept insulated from the aspirations of the wider organisation. In such circumstances
the input from external change agents like the CIO or the researchers are little more than exhortations.

The focus on community presence has increased the number and variety of ordinary places that the residents know and access, but an emphasis on creating community presence alone is unlikely to achieve the goal of building inclusive communities unless greater attention is given to the type of activities people are doing. A key factor appears to be how willing and capable are support staff in identifying potential activities that support community participation. This is all about making considered choices. Perske (1993) argues that human service workers cannot create friendships for people with intellectual disabilities. What service-workers can do is to help people with intellectual disabilities go to places where friendships are more likely to happen. This will be in places where the same people can meet routinely so that they can make a judgment about whether they want to spend time with one another (O'Brien et al., 2005). Attending a coffee morning at the same church each week has greater possibilities for community participation than driving 35 kilometres to eat at McDonald’s, which was a trip recorded in an Activity Log. Once in these settings, service-workers must have the willingness, knowledge and skills to exploit available opportunities and strengthen any relationships when they see them happen, especially for more severely intellectually disabled people.

Organisations only have so much capacity to achieve their goals. ‘Building inclusive communities’ is only one goal of the State Plan, and ‘community participation’ is but one facet of the goal. Philosophers have debated the relationship between the realm of ‘necessity’ and the realm of ‘freedom’ (see Honderich, 1995). At the risk of misapplying these terms, the distinction between what needs to be done and where there is greater choice is useful in suggesting why little progress has been
made towards community participation both in this house and more generally. A significant proportion of staff time is taken up with tasks that need to be done. Food must be bought, cooked, eaten, and the dishes washed. People must be helped to wash, dress, and complete their laundry. There are a number of organisational tasks that are given importance, especially administrative tasks. People go to day programs and must be driven there and picked up. People have to get their hair cut, buy new shoes, and visit their GP. This reduces the amount of time available where people are truly free to decide how to spend it. Some might be spent relaxing at home, or at the cinema with a support worker, or visiting another group home. These are legitimate choices, but they reduce the time available to work at community participation. Days may be filled with so many other tasks to do that there is no time, or negligible time left for community participation. It should be noted however, that there are numerous studies which suggest that the opportunities for residents to participate in such everyday aspects of their lives are not being fully exploited in this way (see Emerson & Hatton, 1994).

If services have a large responsibility for planning people’s lives they are directly implicated in the processes that lead people with severe intellectual disabilities to inhabit this distinct social space. O’Brien (1987) makes the point that ‘inclusion’ requires focused effort. Community participation is unlikely to happen when leisure is planned either on the basis of what has happened before or spontaneously. In the former you end up going to the same parks, beaches, etc. With the latter, you ask, ‘What shall we do today?’ The more time people spend in group homes, at day programs, using segregated leisure facilities, in a minibus, engaging in activities that lead to community presence, participating in group trips, then the less chance there is to change the pattern of activities to include community participation.
Over 30 years ago Nirje (1969/1976), one of the earlier writers on normalisation wrote,

“[The] principle [of normalisation] applies to all retarded people, whatever their degree of handicap and wherever they live….But it is wrong to think that living in the community can in itself be equated with being ‘integrated’ into society. The question still remains of how closely the life of mentally retarded people approaches that of ‘normal’ members of that community” (p.232).

30 years later the question still remains. Unless more time and focused effort is put into discovering whether we can build inclusive communities on a large scale the question is likely to remain unanswered and people with intellectual disability will continue to occupy a distinct social space.
References


Figure 1. Simplified outline of the Community Inclusion Framework. Adapted from Warren (2005)

Ongoing monitoring and review

Transitional training: introduction to ‘inclusion’. 3-hours of a 10-day program,

One-day ‘Inclusion’ training. Team Manager also in attendance.

CIO meets the residents at the group home. 2-hour ‘meet and greet’.

CIO determines intensive or active involvement.

Development of ‘inclusion’ action plan.

Individual planning for each resident.

Review systems within the group home that facilitate the development of ‘inclusion’.

Data collection by completion of Activity Logs.

Clarification and development of staff roles in relation to ‘inclusion’.

Final review of action plan and handover to Team Manager. CIO withdraws.
Figure 2. Steps in using the Activity Logs. Adapted from Warren, 2004/2006

- Complete the log after each activity
- Send logs to CIO and/or team manager every month
- Feedback from CIO every 3 months
  - Discuss at house meeting
  - Discuss in supervision meeting
Figure 3. Outline of data collection and action research process

- 46 hours Participant Observation
- One-day ‘Inclusion’ training
- Half-day Reflective meeting
- Ongoing planning and discussion 7 meetings with staff
- Discussion of logs (52 entries)
- Community Inclusion Framework 3 reflective meetings between CIO and researcher

Time

- 9 months
- 7 months
Table 1. Type of external activities named by staff categorised as community inclusion

<table>
<thead>
<tr>
<th>Type of activity</th>
<th>Half day meeting. House open for 9 months</th>
<th>Last month of the 5 month action research cycle. House open for 16 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community presence</td>
<td>n=17</td>
<td>n=14</td>
</tr>
<tr>
<td>Bus trips (7) (Ocean grove, Tullamarine airport, Phillip Island, Healesville, Federation Square, Christmas lights, barbeques)</td>
<td>Eating out (3)</td>
<td></td>
</tr>
<tr>
<td>Walking around the neighbourhood, walking along Arthur’s creek (2).</td>
<td>House shopping (2)</td>
<td></td>
</tr>
<tr>
<td>Cinema (1)</td>
<td>Personal shopping (1)</td>
<td>Bus trips (5) (St. Kilda, Port Melbourne, Dandenong Ranges, Frankston, Doncaster Park)</td>
</tr>
<tr>
<td>Shopping (5) (Safeway, K-Mart, Christmas shopping, Clothes shopping, buying shoes at the mall)</td>
<td>Library (1)</td>
<td></td>
</tr>
<tr>
<td>Tram (1)</td>
<td>Bowling (1)</td>
<td>Buying take-away food (1)</td>
</tr>
<tr>
<td>Eating (1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community participation</td>
<td>n=3</td>
<td>n= nil</td>
</tr>
<tr>
<td>Dentist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hairdresser (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Segregated activities</td>
<td>n=4</td>
<td>n= nil</td>
</tr>
<tr>
<td>Community Residential Services Christmas party</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visits to DHS Area Office</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visits to other group homes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barbeques at other group homes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>