Making life good in the community

Building inclusive communities: Facilitating community participation for people with severe intellectual disabilities

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April 2008

State Government Victoria
Department of Human Services

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Foreword

In April 2008 the last residents of Kew Residential Services (KRS), formerly known as Kew Cottages, moved from the institution to smaller group homes. The redevelopment of services and the consequent closure of the institution has enabled over 460 people to move from KRS to group homes in the community.

The redevelopment was informed by a body of research, both in Victoria and overseas, on how best to support people with significant intellectual disabilities who have lived in institutions for long periods. This research demonstrated that they have a better quality of life in small supported settings than they do in large institutions.

A research study being undertaken by La Trobe University on behalf of the Department of Human Services is examining how best to support people with intellectual disabilities living in group homes to lead fulfilling lives. The study, called ‘Making life good in the community’, has both qualitative and quantitative elements and used ethnography, action research, interviews and surveys to collect data. The survey which is comparing quality of life measures for 100 ex-KRS residents before and after leaving the institution is not yet complete but early results for the first 50 residents who have moved off site show improvement in the areas of choice and community presence.

The qualitative study is complete, and publications to date include ‘The story so far’, which marked the mid-point of the study, ‘The importance of practice leadership and the role of the house supervisor’ published in November 2007, and ‘When is a house a home? (February 2008) focusing on homeliness. This latest report, ‘Building inclusive communities’ reflects on the issues and complexities inherent in achieving this goal, and the broader issues it raises.

A specific research goal was to understand how staff in this group home could be supported to expand the men’s social networks with non-disabled people. The report sets out the argument that facilitating relationships with non-disabled people is a prerequisite to realising the Victorian State Disability Plan goal of building inclusive communities, but points out that this is not explicit in Department of Human Services’ policy.

The researchers argue that the goal of building inclusive communities involves concepts that are often poorly understood, hard to define, and difficult to apply.

The report critically examines the premises and complexities, assumptions and practises that underpin efforts to realise this goal. It brings to the forefront the many arguments, disagreements, understandings and misunderstandings that surfaced during the research, and that are also extensively debated in the wider field.

This reflective and thought-provoking report will be particularly valuable for those supervisors and middle and senior managers responsible for managing quality support services to people with intellectual disabilities, as well as for policy analysts, and the many people who struggle with how to realise the vision of an inclusive community.

I commend this report for your consideration.

Alma Adams

Alma Adams
Manager KRS Redevelopment

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Making Life Good in the Community is funded by the Department of Human Services, Victoria. This research has been made possible by the willingness of the staff at 64 Penny Lane to allow us to work with them for an extended period of time. We thank them for being generous with their time.

Executive summary

The Victorian State Disability Plan 2002-2012 states that:

> By 2012, Victoria will be a stronger and more inclusive community – a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria. (Department of Human Services, 2002b, p.7).

This report considers issues raised by a two and a half year action research project (Making life good in the community) that attempted to realise the notion of an 'inclusive community' in a Department of Human Services' group home. The house, 64 Penny Lane, was a home for five men with severe intellectual disabilities who had previously lived at Kew Residential Services, a large congregate care facility which will be closed in April 2008 following a major redevelopment. The research project focused on one of the goals outlined in the State Disability Plan, that of building inclusive communities, a goal that is central to the government's espoused vision for the future, not only for people with disabilities, but for all Victorians.

Such a goal is thought to be necessary because although most people with intellectual disabilities are physically present in the community there is a general consensus that they are not part of it. Most people with intellectual disabilities typically have small and highly restricted social networks, and are often reported to be socially excluded and lonely. Their restricted social networks are characterised by interactions with other people with intellectual disabilities, service workers, and immediate family members. Contact with non-disabled members of the public is most likely to be mundane, impersonal and fleeting. The report uses the concept of a 'distinct social space', to refer to this generalised pattern of social relationships that is typical of many people with intellectual disabilities.

The analytical use of a 'distinct social space' focuses attention on the boundaries around a specific individual and posits these as being in a state of flux. This suggests that the actions of human service organisations and their employees can influence these boundaries. If they are fluctuating they can be strengthened or weakened, enlarged or contracted. If the boundaries are permeable then people can be helped to cross them.

Over the last 30 years people have promoted a variety of ideas about how to 'include' people with intellectual disabilities, most of which have been embraced by human service organisations. Yet the goal of building inclusive communities is a term that is often poorly understood, hard to define, and difficult to apply.

The Making life good research used John O'Brien's (1987) distinction between community presence and community participation as an orientating concept. The former refers to the sharing of ordinary places, rather than the use of segregated facilities. O'Brien argued that people should be supported to increase the number and variety of 'ordinary' places that a person with intellectual disabilities knows and can access. Yet even if this happens, people with intellectual disabilities can remain in this 'distinct social space', going to ordinary places solely in the company of other service-users, staff, or immediate family members and only having fleeting contact with non-disabled people. The goal of community participation is to expand these restricted social networks to include non-disabled people, so that people with intellectual disabilities experience being part of a growing network of personal relationships that include close friends.

The project's specific research goal was to understand how staff in this group home worked and could be supported to expand the men's social networks with non-disabled people The report sets out the argument that facilitating relationships with non-disabled people is a prerequisite to realising the goal of building inclusive communities, a crucial point that is neither explicit in government policy nor mentioned in the Department of Human Services' most recent practice manual that provides guidance for staff working in residential services.

This report critically examines the premises that underpin this goal and brings to the forefront arguments, disagreements, understandings and misunderstandings that surfaced during the research so that they can be cross-examined by a wider audience.

It is argued that such a research goal does not devalue people with intellectual disabilities, stop people with intellectual disabilities mixing together or being friends, or 'privilege' relationships with non-disabled people. It is not logically inconsistent to want to facilitate relationships with non-disabled people and to also support and encourage relationships between people with intellectual disabilities.

The research is put forward as a 'politically important case', because the men who live at 64 Penny Lane have severe intellectual disabilities. Both type of disability and level of intellectual disability have implications for the goal of building inclusive communities. Realising the goal is likely to be harder for people with severe intellectual disabilities, who generally have more limited social lives. The level of disability has implications for staff practice, family members' views, and the reaction of the general public.

Even though building inclusive communities is harder for people with severe intellectual disabilities, the argument is made that they should not be excluded from this goal. A useful focus however is to learn from the struggle to realise it. Highlighting that the level of intellectual disability is an important variable brings important issues to the foreground:

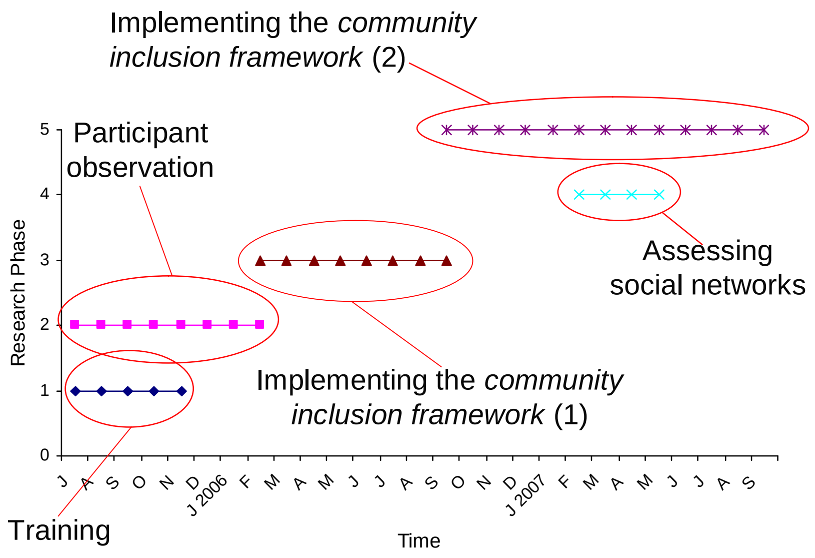
- People with severe intellectual disabilities are not likely to understand what the abstract goal of building inclusive communities means and are not able to express an opinion about it.
- The abstract ideas that underpin the goal of building inclusive communities may be seen by some individuals as being irrelevant or of less importance to people with severe intellectual disabilities.
- Some human service workers and families may believe in the importance of the goal but are struggling to realise it in the lives of the people they are supporting.

KEY FINDINGS

Enabling community presence

The research occurred in five overlapping phases, as shown in Figure 1. The seven-month participant observation phase showed that the focus of staff was on increasing the number and variety of ordinary places that the residents at 64 Penny Lane know and access. This led to a wide range of activities in the community, and gave the men greater community presence than had been the case when they lived at Kew Residential Services. (Early results from the quantitative study of the outcomes of the Kew redevelopment show that people who have left the institution are doing more activities.) Although this is an important part of building inclusive communities, it is argued that this focus alone is unlikely to result in community participation. This is because it is possible to go to activities that are in 'ordinary' settings, but which do not provide opportunities to establish relationships with people without disabilities. Community participation is an unlikely outcome.

Figure 1. Research phases at 64 Penny Lane



Neither the general accredited training, nor the specific transition training, received by the staff gave them much understanding that part of their role is to facilitate relationships with non-disabled people. It was therefore not surprising that they concentrated on supporting relationships with other people with intellectual disabilities, relatives, and staff members, and on increasing community presence.

As part of the Kew redevelopment, recurrent funding was provided to metropolitan regions to employ staff to support community inclusion and active support approaches. Over the next 22 months the researchers in conjunction with the 'Community Inclusion Officer' for the area, worked with staff about their understandings of inclusive communities, and supported them to think about planning individual activities where community participation was a more likely outcome. By the end of nine months, the pattern of supporting activities that led to community presence rather than community participation had not changed, and staff still held differing views about the feasibility of building inclusive communities for the men and the meaning of participation. The house supervisor changed and for several residents a new strategy of developing a detailed social network map was adopted to support staff to think about potential activities. At the conclusion of the project some 13 months later, individual activities for four residents had been trialled. However the final evaluation concluded that three of these four activities had little potential for facilitating community participation, but merely continued the pattern of community presence. The findings illustrate the enormity of the task of developing inclusive communities for people with severe intellectual disability. A key finding was that the types of activities that people did, and the way in which they were supported, are important factors in increasing the likelihood of community participation as an outcome.

Creating and unmaking of the 'distinct social space'

Given that people with severe intellectual disabilities rely on other people to plan and organise their access to community facilities, staff practice is an important variable that has been shown to be associated with variations in outcomes for service-users living in group homes. For this reason, the practice of human service employees is strongly implicated in creating the 'distinct social space', but also has an active role in breaking out of it.

The research found that both the organisation of services and staff practices at 64 Penny Lane were significant contributors to the creation and maintenance of the 'distinct social space', which ensured that the five men spent a lot of time with one another and other people with intellectual disabilities. This was bolstered by:

- service-centred thinking
- an emphasis on bonding rather than bridging relationships
- an 'inward-looking' tendency that resulted in group outings, the use of specialist facilities, and the privileging of staff-resident relationships
- and the failure to consider 'natural' supports.

Such practice enlarged and strengthened the boundaries of the 'distinct social space' surrounding these individuals and reduced the possibilities for weakening its boundaries.

Attitudes towards the goal of building inclusive communities and people with intellectual disabilities

The findings suggested that attitudes, both towards people with severe intellectual disabilities, and the goal of building inclusive communities are important influences on staff practice.

The term 'intellectual disability' or any of its derivatives (people with intellectual disabilities, intellectually disabled, disabled) are unlikely to have any personal meaning for the five residents at 64 Penny Lane. However, the label of 'severe intellectual disability' is strongly implicated in determining staff perceptions and the reactions of non-disabled people. This was an important factor in how the men's lives were organised at home as well as where they spent their weekdays and made use of their leisure time. It also had consequences for the non-disabled people they came into contact with, who may find some characteristics of severe disability disturbing.

The attitudes of non-disabled people

Staff expressed strong views about the attitudes of non-disabled people, which they saw as a barrier to the goal of building inclusive communities. Although the negative attitudes of non-disabled people are a significant problem, there are a number of important issues about the way in which staff frame and react to people's attitudes.

- First-hand experience of indifferent or negative interactions is likely to have an impact on direct support staff's perception, willingness and motivation to build inclusive communities. Unless staff possess a certain tenacity and resilience, or the work environment is designed to identify and work with the negative feelings that arise, then these negative experiences may make them less, rather than more likely to act as facilitators.
- It does seem to be important to state that people with severe intellectual disabilities are limited by the personal restrictions of their disability and they have features that non-disabled people with little or limited direct experiences of disability find disconcerting. Only by acknowledging this can we think about how to address the issues related to these factors.

The task of building inclusive communities should not be underestimated. This is because it will require an enhancement of the role played by the non-disabled public — a role that they have not, in general, actively asked for. At the moment, direct support staff have been given disproportionate responsibility for achieving the goal of building inclusive communities, a role for which they are inadequately trained and supported. The report makes a number of recommendations that may help in realising this complex and challenging goal.

An important prerequisite

A prerequisite for realising the goal of building inclusive communities is developing a common vocabulary for the concepts people use to discuss it and an accepted definition of what it means to build inclusive communities. This must include recognition of the multi faceted strategies that must be pursued, and explicit recognition that work at the micro level (with individuals to build social networks) is as important as strategies located at the more macro level (which seek to influence organisational behaviour). It seems probable that the absence of a common vocabulary and shared understanding of this Department of Human Services' goal is a major obstacle to achieving it. There is no guarantee that any employee will understand the multi layered strategies necessary to pursue the goal of building inclusive communities or possess the knowledge, skills and motivation to design or implement these. This may be the case whether they are new to the field, or have experience in either community-based or institutional settings, whether direct worker, manager or policy analyst. It is not an intuitive role and commonsense understandings of terms like 'inclusion' and 'participation' will not be enough to realise it.

Issues for policy makers

As building inclusive communities is a complex and multifaceted goal any working definition will need to be a nuanced concept that allows both bonding and bridging relationships. This will acknowledge that there is nothing wrong with people with intellectual disabilities choosing to spend time with one another together or being friends. However, any working definition or guidance must explicitly include the need to facilitate relationships between people with intellectual disabilities and non-disabled people.

Once a clear definition is available, a key task is to develop and instil a coherent planning framework that links strategic to operational plans, so that the principles that underpin strategy are congruent with the behaviours expected of direct support staff and the methods and techniques they employ.

Planning

Plans to realise building inclusive communities are unlikely to be successful if the people who are charged with meeting this goal are unaware of what it encompasses. Staff at 64 Penny Lane were making plans with a limited understanding of the implications for their practice of the goal of pursuing individual communities. They were given partial feedback about their progress towards this goal from more senior employees who had an equally limited understanding of the goal, frequently confusing community participation and community presence.

Progress towards achieving the goal of building inclusive communities will therefore require leadership and commitment at all levels of the Department of

Human Services. Since the focus of this research was at the house level, the findings reveal a number of implications that are related to the internal leadership of a group home.

- The house supervisor's post is central to realising the goal of building inclusive communities because the incumbent has a big influence on how direct support staff actually behave.
- House supervisors are practice leaders who have a key role in supporting the effective performance of the direct support staff they manage. They must provide support, direction and coaching to the staff they manage.
- House supervisors need specific knowledge, skills, and abilities in relation to the goal of building inclusive communities. They and the department more broadly must be clear about what the goal means for support workers.
- House supervisors need to anticipate people's 'objections' to the goal of building inclusive communities and have well-prepared counter arguments that may persuade direct support staff of the benefits of facilitating relationships with non-disabled people.
- House supervisors must be able to actively engage with the tensions within the complex ideas and perspectives that are addressed in the report, if they are to act in an informed way.
- House supervisors need greater flexibility in the deployment of staff to support community activities and to provide the necessary support to direct support staff.

Organisational stability

- Providing people with intellectual disabilities with a stable, skilled workforce is integral to providing quality services. Complex issues, such as building inclusive communities move in and out of focus when there is a high turnover. Community participation requires medium to long-term planning and continuity of support, neither of which are enhanced by an unstable staffing pattern at the team manager, house supervisor or direct support staff levels. Much of this instability is caused by staff 'acting up' rather than leaving the organisation and is potentially avoidable.
- Stability in the team manager and house supervisor positions improves the chances of giving better support to the staff team and developing strong working relationships with the residents and their families.

- Stability at the team manager level improves the chances of giving better support to the house supervisor. An enduring relationship increases the likelihood of good supervision, provides a platform for consistent messages, and means that both parties are aware of important issues, such as building inclusive communities, which are more likely to be followed through.

Enhancing organisational capacity

Organisations have a finite capacity for pursuing their goals, so overly focusing on community presence may leave limited or no time for facilitating community participation. It is important that the positive efforts currently undertaken by staff to enhance community presence are not discouraged nor stopped, but that staff supplement this aspect of their work with supporting community participation.

Given that community participation is not a day-to-day priority for many staff, ways need to be found of bringing it into focus and making sure that time is allocated to work at it.

- Direct support staff must understand that their role includes facilitating society’s responses to people with intellectual disabilities. Position descriptions need to emphasise that incumbents have an educational and facilitative role that makes use of ‘natural’ supports in supporting people with intellectual disabilities.
- The boundaries of the staff/service user relationship must be clarified. Staff relationships are inextricably related to service users’ quality of life and staff could act as conduits, linking people with severe intellectual disabilities to their own social networks.

Enhancing community participation

This report distinguishes between circumstances when acquaintances are likely to remain as acquaintances, and situations where it might be possible to move from acquaintance to friendship. Relationships are more likely to be made when people participate in recurring activities, over an extended period of time, and where social interaction is high.

- Direct support workers need to support people with intellectual disabilities to go to places where relationships 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.

- Direct support workers must learn to identify activities where the same people can meet routinely and where friendships are more likely to happen.
- A staff team in any group home must learn to adopt a highly critical attitude towards their own efforts to build inclusive communities. They will need to become good judges of ‘successful’ community activities, learn from others’ and their own ‘mistakes’, but try and avoid unproductive paths in the first place.
- As well as expecting direct support staff to put focused effort into community participation, the Department of Human Services should also consider other ways of doing this.
- Direct support staff suggested that they do not know how to facilitate relationships between people with severe intellectual disabilities and non-disabled people once introductions have been made. This is a training and coaching need that, at present, appears to be missing in current accredited training programs and the knowledge base of most house supervisors and more senior managers.

Useful concepts

There are a number of concepts in the report that may be useful in developing training materials. Ways need to be found of translating the goal of building inclusive communities and the values that underpin it into ‘practical guides for action’ for individuals supporting people with intellectual disabilities. This is even more pertinent when considering how to support people with severe intellectual disabilities. The concept of a ‘distinct social space’, the distinction between ‘universal’ and ‘particularist’ viewpoints, and outlooks based on ‘rights’ and ‘practicality’ all offer possibilities for developing theoretical ideas that can be used in practical ways in training and planning contexts.

Conclusion

The project’s findings reveal a great deal about a goal that is a key component of most industrialised countries’ social policy ‘vision’ for people with intellectual disabilities. The issues in this report help to illuminate why only modest progress has been made in enabling community participation in the last 30 years. Unless more time and focused effort is put into discovering whether we can build inclusive communities on a much larger scale, then to what extent this goal can be realised, is likely to remain unknown.

1. Introduction

‘As with the poor relation at the wedding party, so the reception given the handicapped person in many social situations: sufficient that he is here, he should not expect to dance with the bride’

(Davis, 1961, p.127)

‘Our ideas about institutionalizing the aged, psychotic, retarded and infirm are based on a pattern of thought that we might call The Toilet Assumption – the notion that unwanted matter, unwanted difficulties, unwanted complexities will disappear if they are removed from our immediate field of vision…Our approach to social problems is to decrease their visibility: out of sight, out of mind…The result of our social efforts has been to remove the underlying problems of our society farther and farther from daily experience and daily consciousness, and hence to decrease in the mass of the population, the knowledge, skill, resources, and motivation necessary to deal with them’.

(Slater, 1970, quoted in Zola, 1981, p.355)

‘What do you think of these grapefruit?’ I asked. The man jumped as though I had slapped him. He clutched his shopping cart, turned to me with his mouth open and blinked through his thick glasses. He was about 30 or so. He had Down syndrome. My 16-year-old stepson Jim has an extra chromosome, too.

I smiled and told him I couldn’t decide.

‘Which do you like, white or red grapefruit?’

He swallowed. ‘Yeah,’ he said, eyes wide.

At that moment, another man in a red ski jacket and neat beard hustled up to the shopping cart, dropped in a bag of potatoes and said, ‘Come on Bill, let’s go.’

Bill stood still and said proudly, with some difficulty, ‘I talk to lady.’

‘What? Okay, hurry Bill, we gotta go.’ But Bill didn’t budge.

‘We were talking about grapefruit’’ I offered, smiling again, still lingering and fingering the produce.

‘Oh.’ The man in the red jacket looked at me almost apologetically and said, ‘Come on Bill, we have to go.’ Before he finished speaking, the man in the red jacket had refocused his attention on the grocery list and jogged off. Bill, suddenly kick-started, steered the cart away. I ran into them a few more times in the store, purposely taking my time when I saw Bill maneuvering the cart down the aisle. The man in the red jacket would say, ‘Wait here,’ while he ran to select items, weigh bulk food and choose among the specials. Each time, Bill would stand silently at the cart, waiting. Each time he saw me, he almost seemed afraid I would ask him something again; that he would be expected to reply. He was used to just waiting quietly.

(Schwier, 1992, p.14)

‘And in the backs of our minds, we probably all carry a utopia, ‘a Jerusalem of up high’, and ideal kingdom, or republic, or dictatorship, or anarchy, or some sort of society which could exist some day, and in which only the better element of man would prevail, and in which needed helping forms would be provided automatically’.

(Wolfensberger and Zauha, 1973, p.1)

1. Introduction

This report considers issues raised by a two-year action research project investigating the Victorian government's goal of building inclusive communities for people with disabilities in a group home for five men with severe intellectual disabilities[1]. The specific focus for planning and taking action was a particular interpretation of O'Brien's (1987) conceptualisation of community participation. Our research goal was to expand the men's social networks, so that they would experience being part of a growing network of personal relationships that included the possibility of making close friends. We were particularly interested in attempting to expand their social networks with non-disabled people, rather than facilitating relationships with staff members, relatives, or people with intellectual disabilities (see Robertson et al., 2001).

It may be the case that as a reader you have already taken issue with the research goal. If you have, then we see this as a good thing. During the course of this research both the goal of building inclusive communities and the research goal came under intense scrutiny. An important part of the research process was examining these goals and our own roles in trying to implement them. As you will read, during the course of the research a great deal of energy has been spent addressing issues of conflict in relation to the research goal. Our approach to this conflict has been to see it as a creative force, because we believe that conflict that is faced and managed allows us to explore ideas, engage opinions, and generate change (Ford and Hargreaves, 1991).

The report draws on an earlier paper, 64 Penny Lane (Clement, 2007), which can be found in The Story So Far (Clement, Bigby, and Johnson, 2007). The paper described the interactions between the people who live and work at this house and the support that the residents received to participate in meaningful activities inside and outside the home. The paper summarises data that we had collected through participant-observation, which was used to describe and evaluate practice at 64 Penny Lane and provide feedback to the staff group about their practice.

We raised a number of issues in The Story So Far (Clement et al., 2007) that framed the research agenda at 64 Penny Lane and the writing of this report.

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[1] This is one of three overarching goals outlined in the Victorian State Disability Plan 2002-2012 (Department of Human Services, Victoria, 2002 b). The other two are pursuing individual lifestyles and leading the way.

- Providing high quality services to people with severe intellectual disabilities, who may have additional impairments and complex health needs is certainly a challenge, but it is not impossible[2].
- Many of the concepts embedded in the Department of Human Services' documents are complex terms, such as engagement, inclusion, involvement, and participation. This means that applying them with people with severe intellectual disabilities is not straightforward. As a consequence the concepts are often poorly understood and implemented by front-line staff.
- A fruitful area of investigation will be the assumptions that staff and family members hold about people with intellectual disabilities and the interplay between these assumptions and the Department of Human Services' espoused values.
- Ways need to be found of translating these espoused values into 'practical guides for action' for individuals supporting people with severe intellectual disabilities.
- The premises that underpin the espoused values should be subject to critical examination in order to ascertain whether they are the 'right' values.

All of these issues are relevant to our research goal at 64 Penny Lane. Building inclusive communities is a challenge for staff supporting people with severe intellectual disabilities. The term may be poorly understood and it is certainly hard to define and apply. It is linked to other terms, like 'choice' and 'control', which are also poorly understood and hard to apply. Good guidance may be necessary in order to realise the goal. People may hold different assumptions about whether the goal is relevant for people with severe intellectual disabilities and may believe that other goals are more important.

This report necessarily contains a lot about attitudes, beliefs and values[3]. We have deliberately gone out of our way to make our own beliefs transparent and provide a rationale for our actions. The story of undertaking the research is presented chronologically as a series of research phases where we explain 'why we did what we did' and 'what happened when we tried to do it'. We have deliberately brought to the forefront arguments, disagreements, and

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[2] In our earlier writing we have made the distinction between people with severe and profound intellectual disabilities. We have merged the two categories together in this report to simplify the writing.

[3] The terms attitudes, beliefs, and values are often used interchangeably, but can be distinguished from one another and used in distinctive ways (Rokeach, 1968). It is probably not so important for the reader to know the distinction between these terms, but we have tried to use them specifically.

misunderstandings that surfaced during the research in order that they can be cross-examined by a wider audience. We see this report as a continuation of the process of engaging with people's views about the goal of building inclusive communities and the ideas they may have about what the goal might mean and how it can be achieved. This seems to us to be essential if we are to add to the debate about quality of life and how this can be improved for all people with intellectual disabilities.

Beliefs and Practice

Peile and McCouat (1997) argue that the beliefs we hold have an impact on how we relate and act in relation to other people. They identify the following four areas of beliefs:

- How we think the world works
- How we understand human behaviour
- How we gain knowledge
- Our goals about what society and its people ought to be like.

In our introduction we stated the research goal in a clear way, but did not make clear the beliefs that underpinned it. In order to be transparent we believe that there are benefits of facilitating relationships with non-disabled people; that people want friends, not just acquaintances; and that good relationships are beneficial to people's quality of life.

It may be less obvious that the government's goal of building inclusive communities is also founded on beliefs. It reflects the creators' beliefs about what Victorian society should be like. We believe that expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people is a crucial part of the project to build inclusive communities (that is, a goal about what Victorian society ought to be like). In order to make it clear that beliefs impact on practice we want to present an extract form Cummings and Lau's (2003) article on 'community integration', which contains beliefs about human behaviour and how the world works. They write:

> The fact is, when people are given free choice they evidence a preference for integrating with their own kind, not with the community in general…Thus, people who are rich congregate in exclusive and expensive suburbs, new migrants live close to others who share their culture and language, people who are elderly congregate in retirement villages, and people with particular medical conditions seek social affiliation with others

> who share their diagnosis....So, how would such people define their 'community'? Would the rich banker regard the unskilled, newly arrived migrant as part of her community, and with whom she should 'integrate' to achieve an improved life quality? Would the elderly residents of a retirement village regard integration with the adolescent youth who surround their enclave as enhancing their sense of community? Perhaps not. Yet the philosophy of integration is so entrenched that writers on service policy simply assume that people with an intellectual disability are somehow different from other groups in society, such that integrated rather than segregated experience is necessarily of benefit to them (p.147).

You may be inclined to agree with these views, especially since some beliefs are derived from people in authority (Rokeach, 1968). This relates to how we gain knowledge. The authors are academics who work in a university and their article was published in a respected peer-refereed journal.

If you work in a group home and believe that a resident with an intellectual disability that you are paid to support is a 'certain kind' of person (that is, intellectually disabled), and that people of a 'certain kind' (that is, the intellectually disabled) like to stick together, you may well direct, encourage or support that person to make use of a day program for people with intellectual disabilities, attend a session at the local swimming pool that has been specifically established for people with intellectual disabilities, or attend a disco that has been arranged for people with intellectual disabilities. You may also believe that 'other kinds' of people may not want to spend any time with people with intellectual disabilities. If this is the case you probably think that your beliefs and related goals are more important than ours. The important fact is that beliefs have observable, behavioural consequences.

2. Issues in the literature

There is a vast body of literature related to the goal of building inclusive communities. Variations on this topic can be found in the rhetoric that has shaped services for people with intellectual disabilities over the past 30 years (Robertson et al., 2001). Our review of the literature identified three themes that we want to discuss here.

- An encounter with the literature is to enter a ‘terminological forest’ (Campbell, 1963, p.100) of related terms.
- Similar words are often substituted with little regard as to whether they have the same, similar or different intended meanings.
- Building inclusive communities and its variants is a contested term.

The terminological forest

Figure 1 lists a number of linked terms that are mentioned in the literature that we have cited in this report. The list contains various concepts, lenses, measures and tools that people have used to investigate or understand the social relationships of people with intellectual disabilities. It includes terms used to describe the patterns of social relationships that have been found and the strategies and tactics that have been used to try and change this pattern. It also lists goals and outcomes.

Figure 1. The terminological forest:
An A to Z of concepts, lenses, measures and tools

Accepting relationship…Accompanier…Being part of the community…[Community] Capacity building…Circles of friends…Circles of support…Communities of interest…Community…Community activity…Community capacity…Community care…Community connector…Community development model…Community exposure…Community integration…Community facilities…Community of people with intellectual disabilities…Community options…Community participation…Community presence…Community treatment approach…Distributive competence…Distinct social space…Elective communities…Emotional support…Exclusion…Friendship…Handicapped orientation…Inclusion…Inclusive communities…Informal resources…Instrumental support …Integration…Integration facilitator…Isolation…Formal resources…Functional measures…General community…Information support…Living in the community…Material support…Membership…Natural supports…Neighbour…Neighbourhood…Objective integration…Physical integration…Physical presence in the community…Primary community…Psychological sense of community…Purposive network…Relationship vacuums…Service-based supports…Social capital…Social connection…Social contacts…Social contact patterns…Social exchange theory…Social exclusion…Social impairment…Social integration…Socially integrated activities…Social interactions…Social isolation…Social network…Social network analysis…Social network map…Social relationships…Social participation in the community…Social Skills…Social stability…Social support…Social support network…Society…Structural measures…Supportive network…Supports

Both O'Brien (1987) and Kennedy, Horner and Newton (1989) make the point that we need a common vocabulary for the concepts we use and an accepted definition of what it means to build inclusive communities if we are to describe, evaluate, measure, and intervene in this aspect of people's lives.

Our aim in this report is not to bring order to this particular 'forest', although we think that this would be a useful task, but to be clear about the concepts that we have used to describe and intervene in people's lives.

Building inclusive communities: Disagreements

Not only is the absence of a common vocabulary evident, but there are significant disagreements about what the end goals should be, the means of reaching them, and the problems to be overcome (see the reviews by Cummins and Lau, 2003; and Myers, Ager, Kerr, and Myles, 1998).

End goals

The most common measures of 'inclusion' are frequencies of the type of activities that people with intellectual disabilities take part in and the sort of contacts made. Does this understanding mean that a person who goes shopping at the supermarket three times a week is more 'included' than someone who goes once? Or is a person who goes to a day program for people with intellectual disabilities less 'included' than a person who has a job at Hungry Jacks?

Older research studies in particular fail to make comparisons with the experiences of non-disabled people, in other words, provide normative data (Baker, 2000). How many times a week does a non-disabled person go shopping and how does this compare with a person with intellectual disabilities? If the former goes shopping on less occasions than a person with intellectual disabilities, does it means that he or she is less ‘included’?

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’. A consequence of this is that activities that involve day programs, specialist leisure programs, and other residential settings can be denigrated. This has resulted in arguments about whether relationships with non-disabled people are privileged over relationships with people with intellectual disabilities, the benefits of self-segregation, and whether people with intellectual disabilities prefer to mix with their ‘own kind’ (Brown and Smith, 1992a; Cummins and Lau, 2003; P. O'Brien, Thesing, and Capie, 2005).

A second consequence of emphasising frequency measures is that functional ones can be downplayed. As Tracy and Whittaker (1990) point out, questions about how people perceive their networks are important. Small networks can be perceived as supportive and larger ones the opposite.

The view 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 marginalises the impact of cognitive impairment. We would suggest that subjective measures can be problematic when working with people with severe intellectual disabilities as their behaviour has to be interpreted, which requires a high degree of inference (Ware, 2004).

Explanations

These discussions hint at a further area of debate; to what degree is a person’s ‘exclusion’ a function of their 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). Kennedy et al. (1989) on the other hand 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 and

McConkey, 2006; Blatt, Bogdan, Biklen, and Taylor, 1977/1981; Ramcharan, McGrath, and Grant, 1997). Here the emphasis is on non-disabled people changing their hostile or indifferent attitudes and challenging oppressive social, economic, political and legal structures.

A focus on a hostile society can lead to an emphasis on the negative aspects of ‘inclusion’ and perhaps result in the avoidance of places where people may be stared at or verbally abused. An alternative focus is put forward by Taylor and Bogdan (1989) who concentrate instead on trying to understand how people with intellectual disabilities come to be accepted by non-disabled people.

A reluctance to use specialist leisure programmes stems from the belief that ‘modern patterns of practice and belief segregate and isolate people with developmental disabilities as a matter of course’ (J. O'Brien and O'Brien, 1993, p.10). This view finds its most focused form in views about institutional services. Research by Robertson et al. (2001) suggests that people living in smaller community-based settings have larger and more inclusive social networks.

Building inclusive communities: Agreements

Although the literature is characterised by conceptual differences and some degree of conflict, there is a general consensus that people with intellectual disabilities occupy a ‘distinct social space’ (Todd, Evans, and Beyer, 1990). We use this term throughout our report to refer to a generalised pattern of social relationships typical of many people with intellectual disabilities. Most people with intellectual disabilities are physically present in ‘the community’ but typically have small and highly restricted social networks, which are organised around human services. People’s lives are often reported as being socially excluded and lonely. Their restricted social networks are characterised by interactions with other people with intellectual disabilities, service workers who are paid to support them, and immediate family members. Outside of this, any contact with non-disabled members of the public is likely to be mundane, impersonal and fleeting, with the possibility of some casual acquaintances. Any sustained meaningful relationships characterised by intimacy and friendship are lacking (Luckasson et al., 2002; Marquis and Jackson, 2000; McConkey, 2005; Myers et al., 1998; J. O'Brien, 1987; J. O'Brien and O'Brien, 1993; Ramcharan et al., 1997; Ramcharan and Richardson, 2005; Robertson et al., 2001).

As a generalised account, the ‘distinct social space’ that we have described in the previous paragraph will not be true for all people with intellectual disabilities all of the time. Hall (2005) makes the important point that ‘inclusion’ and ‘exclusion’ are not absolute positions, but that people's lives are a complex web of 'inclusionary' and 'exclusionary' situations and experiences. None the less, as a concept, it is useful in describing the marginalised position of most people with intellectual disabilities.

The pattern that has been found in the aforementioned international studies has also been replicated in the Victorian and Australian studies (Barber, Cooper, and Owen, 1994; Bigby, Frederico, and Cooper, 2004, 2006; Cummins and Dunt, 1990; Cummins, Polzin, and Theobald, 1990; Fyffe and McCubbery, 2002; Radler, 2004; Radler, Laurie, and Gavidia-Payne, 1999; Young, Sigafoos, Suttie, Ashman, and Grevell, 1998).

We disagree with the earlier view that contemporary human services segregate and isolate people with intellectual disabilities as a matter of course. The reality is more nuanced than that. As Perske (1993) points out, a large number of people have promoted a variety of ideas about how to 'include' people with intellectual disabilities, most of which have been embraced by human service organisations. We propose that the boundaries of this 'distinct social space' are typically in a state of flux and that the actions of human service organisations and employees influence its boundaries. The boundaries can be strengthened or weakened, enlarged or contracted. People can be helped or hindered to cross those boundaries in either direction. If a staff member decides to drive a group of people with severe intellectual disabilities to a new activity that is solely for other people with intellectual disabilities he or she has probably gone some way to enlarging that 'distinct social space' for those individuals. If on the other hand that same staff member decides to support one person to go to the local RSL every Thursday evening at the same time,, they might have gone some way to weakening the boundaries and could act in a way that invites other RSL members to step over the boundary.

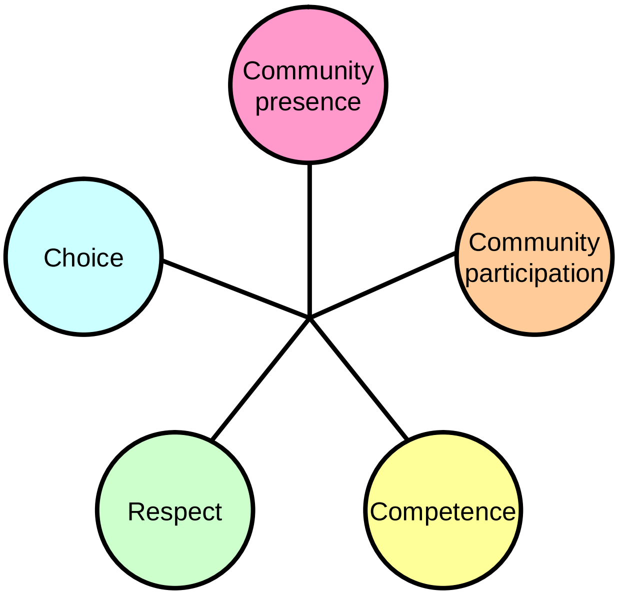
3. Beliefs about what society ought to be like: Service ideology and policy goals

Any professional who has worked in services for people with intellectual disabilities for any length of time will be able to list the formal ‘theories’, frameworks and models that have influenced their practice and the publicly stated aims of the services that they have worked in. Some of the key ideas that have had an impact on our thinking are a ‘family’ of related ideas, Normalisation (Wolfensberger, 1972); Ordinary Life (King's Fund, 1980); Social Role Valorisation (SRV) (Wolfensberger, 1983); PASSING (Wolfensberger and Thomas, 1983); and the Five Accomplishments (J. O'Brien, 1987).

We want to outline O’Brien’s (1987) Five Accomplishments in particular. This is because two concepts from the framework influenced how we were interpreting what we were observing at 64 Penny Lane and also how we understood the goals for the five residents to be.

O’Brien (1987) suggested that a person’s life experience could be defined by five linked outcomes. These indicate a balance of experience that constitute a quality adult life (Figure 2).

Figure 2. The Five Accomplishments.
Adapted from O’Brien (1987)



We are particularly concerned with community presence and community participation here, which need to be understood in relation to a third term, segregation. Community presence refers to the sharing of ordinary places, rather than the use of segregated facilities. O'Brien (1987) argued that people should be supported to increase the number and variety of ordinary places that a person knows and can access. Yet even if this happens, people with intellectual disabilities can remain in this 'distinct social space', going to ordinary places solely in the company of other service-users, staff, or immediate family members and only having fleeting contact with non-disabled people. The goal of community participation is to expand these restricted social networks to include non-disabled people, so that people with intellectual disabilities experience being part of a growing network of personal relationships that include close friends. Definitions of all five terms are given in Appendix 2.

Although the Department of Human Services does not explicitly refer to these 'theories' in the Victorian State Disability Plan 2002-2012[4], it is not unreasonable to suggest that the ideas contained within them have had an influence on it. Wolfensberger (1989) suggest that organisations have 'ghosts spooking within them' (p.25), by which he means, ways of thinking and doing things from earlier times. It is not too far fetched to suggest that the ghosts of normalisation, social role valorisation, an ordinary life and the five accomplishments are to be found within the State Disability Plan. Thus the Victorian government's vision for the future is that:

> By 2012, Victoria will be a stronger and more **inclusive community** – a place where diversity is embraced and celebrated, and where everyone has the same opportunities to **participate in the life of the community**, and the same responsibilities towards society as all other citizens of Victoria. (Department of Human Services, Victoria, 2002b, p.4, bold added).

This vision is a statement about what Victorian society should be like and the type of lifestyle people with intellectual disabilities could be leading. Macdonald (1998) suggests that the publication of a vision, together with a set of matching values, promises to set an organisation along the right road to success. Through such rhetorical devices staff see how to fulfil their professional goals in relation to the organisation's goals (Brody, 1993).

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[4] Hereafter described as 'State Disability Plan'

'The community' and 'communities'

More specifically the goal of building inclusive communities means, 'Strengthening communities so that people with a disability have the same opportunities as all other citizens of Victoria to participate [bold added] in the life of the community—socially, economically, culturally, politically and spiritually (Department of Human Services, Victoria, 2002b, p.9).

These two extracts from the State Disability Plan draw our attention to 'the community' and the notion of 'communities'. The former is generally used to refer to the Victorian community, to which we might add the Australian community, and is comprised of smaller communities. A close reading of the State Disability Plan allows us to suggest that the Victorian (and Australian) community is made up of regional, rural, and urban communities, which in turn may have community groups and community organisations. Communities can be understood in terms of geography (the Gippsland community); interests (arts – the theatre-going community); culture (community of Country Fire Authority volunteers); sport (the Collingwood Football Club community); tourism (the community of visitors at Sovereign Hill outdoor museum in Ballarat on any particular day); family background (Aboriginal and Torres Strait Islander communities), and religion (Muslim community). We might infer that the goal is for people with intellectual disabilities to be included and participate in all of these types of communities.

Even this brief examination of how 'community' is used in one document alerts us to the fact that it is a complex and possibly contested term. In his analysis of definitions of community, Hillery (1955) pointed out more than 50 years ago, that people are not always able to agree on the nature of the phenomena they examine. He analysed 94 definitions of community and beyond the fact that all the definitions involved 'people', there was no other common basis. Most of the definitions, listed in order of increasing importance, included area (similar to geography), common ties, and social interaction.

Since Hillery's article was published, how some people understand 'community' has been expanded to embrace virtual communities, such as an e-community or online community. Members of these communities do not really meet in a geographical area, but 'in the ether', making use of newer forms of communication, such as e-mail, the internet, and the mobile phone. This alerts us to the backdrop of an ever-changing Victorian and Australian 'society' (Hughes, Black, Kaldor, Bellamy, and Castle, 2007).

A potential issue with this fundamental understanding of community is that it can be attached to all circumstances where 'area, common ties, and social interaction' are present. We may therefore be obliged to make a judgement about whether a particular community is the type of community we want to strive for. As well as 'inclusive communities' the State Disability Plan advocates for 'aware', 'caring', 'safe', and 'strong' communities.

There can be no denying that Kew Residential Services was a community but the decision was made to dismantle and disperse its members, in other words it was a community that did not fit in with the vision of an inclusive Victorian community. This raises an important issue in relation to an organisation's policy direction and the practice of individual staff members. If human service organisations, individual employees, and many people with intellectual disabilities themselves are making choices about the type of communities they are engaging with, then it is also possible to form a judgement about the consequences of those choices for the goal of building inclusive communities.

Moving beyond surface understandings of 'inclusion' and participation'

An issue that surfaced as being important during the course of the research was the meaning that people attached to the key words 'include' and 'participate'. The latter particularly caused difficulties, because people's commonsense understandings did not quite match with the way it is used in community participation.

'To include' means 'to contain as a member of a whole' (OED Online, 1989). To include people with intellectual disabilities in the Victorian community means automatically understanding that they are part of the whole society, as opposed to seeing and acting in a way where they are excluded, isolated, kept out, left out, marginalised, or segregated. An inclusive community is therefore one that has the character of including a person or people with intellectual disabilities.

'To participate' means 'to share with another or others'. So 'participation' is the process of sharing in an action or event, or the action of having or forming part of something (OED Online, 1989).

One could therefore argue that a staff member supporting a resident to go shopping at the supermarket is both 'participation' and 'inclusion'; or a staff member supporting a resident to go to a concert at The Palais in St Kilda is also both 'participation' and 'inclusion'. However, both these activities may not meet the criteria to be classed as O'Brien's (1987) community participation. We need to move beyond these commonsense definitions to look at how people are being included and how people participate.

However, both these activities do meet the criteria for community presence, the sharing of ordinary rather than segregated places. This is what we believe some people mean when they state that people with intellectual disabilities are present in the community but not part of it (Myers et al., 1998; Rapley, 2000).

Yet even with community presence, it is important to reflect on what people are doing and how they are being supported whilst they are in these ordinary places. It is possible to go to activities that are in ordinary settings (community presence), but for community participation to be an unlikely outcome. A swimming session run especially for people with intellectual disabilities which is at the local pool would be one such example. There are also some places that people with intellectual disabilities go that reflect neither community presence nor community participation, but are segregated settings, such as Kew Residential Services, day programs for people with intellectual disabilities, and even other group homes.

The influence of other ideas

Although services for people with intellectual disabilities are still influenced by the family of ideas under the ‘normalisation’ umbrella, they have also been influenced, as have we, by other ideas that were being developed at the same time, most notably the social model of disability (Walmsley, 1997).

Much of the ambiguity that exists in relation to the goal of building inclusive communities arises from tensions in some of the language and ideas that coexist within the social model of disability and the broader social influences on which it draws. These tensions need to be teased out to understand why some people may take issue with the goal of expanding the social networks of people with intellectual disabilities, to include relationships with non-disabled people.

Universalism and Particularism: ideas in tension with one another

The social model of disability promotes universal concepts, such as citizenship and equal rights (Welshman and Walmsley, 2006). Ideas related to these concepts are reflected in the State Disability Plan, both in the earlier quotations and in this opening message from the premier of Victoria.

> The State Disability Plan 2002–2012 provides a strong and flexible agenda for change. It reaffirms the rights that people with a disability have to live and participate in the community on an equal footing with other citizens

> of Victoria. (Bold added, Department of Human Services, Victoria, 2002b, p.iii)

We see this as being consistent with the stance promoted by the self-advocacy movement, encouraging people to talk and see people with intellectual disabilities in a certain way, as ‘people first’, as ‘sharing a common humanity’, as ‘just like you or I’. It is also consistent with the campaigns of the major civil rights movements based on race and gender, which campaigned for political equality on the basis of essential sameness and a commonality of values, hopes and aspirations.

However, as well as promoting universal concepts the disability movement has also claimed cultural rights and practised identity politics (Anspach, 1979; Zola, 1987), which draws on a particularist viewpoint. This also mirrors the shift that took place in the broader political environment in the 1980s, where political struggles took a different tack and focused on culture, with an emphasis on preserving cultural differences.

Particularism is perhaps less well understood than universalism, but in claiming cultural rights and practising identity politics the disability movement promoted the term ‘disabled people’ and a much less ambiguous stance towards what some people would term ‘segregation’. The disability movement encourages peer-support, peer-advocacy, disability arts, disability pride, and disability culture (Gilson, Tusler, and Gill, 1997). ‘Disabled people’ can now be seen as a particular community, group, or population that have different experiences to non-disabled people, can promote their own interests, and have a particular identity. The fact that the social model of disability came from the disability movement gives greater legitimacy to these ideas, but also feeds into the idea that people with intellectual disabilities are a certain ‘kind’ of people who want to mix with their own kind and not with ‘the community’ in general.

We shall return to some of these ideas later in the report because they surfaced in opposition to both the goal of building inclusive communities and our research goal. Whereas the old arguments against segregated or specialist settings seem to have been weakened by the changed political landscape, the old view that people with intellectual disabilities are a ‘certain kind’ of people appear to have been bolstered.

We believe that some of the critiques of ‘normalisation’ have been useful in challenging some of the underpinning assumptions of this ‘family’ of ideas (see Brown and Smith, 1992b, for example). There is nothing wrong with people with intellectual disabilities mixing together or being friends with one another. The benefits of self-advocacy groups, which are founded on the principal of self-segregation, are self-evident.

However, we do not see our research goal as either devaluing people with intellectual disabilities or ‘privileging’ relationships with non-disabled people. It is not logically inconsistent to want to facilitate relationships with non-disabled people and to support and encourage relationships between people with intellectual disabilities.

Having said that, we do think that facilitating relationships with non-disabled people is a prerequisite to realising our understanding of building inclusive communities. It must surely be acknowledged that contemporary society, together with the organisation and operation of human services, does an exemplary ‘job’ of making sure that people with intellectual disabilities spend a lot of time with one another, which is how we have ended up being able to describe this ‘distinct social space’. We would also add that human services are often poor at facilitating and supporting friendships between people with intellectual disabilities.

However we also want to make the case that as well as being members of the human race it needs to be acknowledged that people with intellectual disabilities face some specific issues. These issues are lost or marginalised by terms like ‘disabled people’ or ‘people with disabilities’, and in documents like the State Disability Plan, which aggregates people with different impairments together: intellectual disability, physical disability, sensory disability, acquired brain injury, neurological impairment, and dual disability.

One of the consequences of grouping these different impairments and disabilities together is that differences in both the social barriers and the personal restrictions faced by people with different impairments are marginalised. For people with physical disabilities, campaigning for an accessible environment has been extremely important. However, a person with an intellectual disability may be able to step onto a tram without any adaptations being necessary, but not know whether it is going to take them to where they want to go. It is also the case that ‘people with intellectual disabilities’ are not all the same, an issue that we turn to in the section below.

What this suggests to us is that people who work in human service organisations, and particularly those individuals who are supervising the practice of employees directly supporting people with intellectual disabilities, need to be able to actively engage with the tensions within the complex ideas and perspectives that we have addressed so far. Not to do so means acting in a relatively unconscious or uninformed way.

4. Intellectual disability

In The Story So Far (Clement et al., 2007) we suggested that people with severe and profound intellectual disabilities are often talked about as a 'special population'. This manifests itself in at least three ways that are relevant to the goal of building inclusive communities. Firstly, people's understanding of the abstract ideas that exist in the goals and related espoused values and formal policy may be seen by some individuals as being irrelevant to the people to whom this label is attached. Secondly, some people may believe in the importance of these ideas but are struggling to apply them to the people they are supporting. Thirdly, some people may see issues other than building inclusive communities as being of far greater importance which means values that are more central to their belief systems get priority.

As we stated in Chapter 3, we are encouraged to talk and see people with intellectual disabilities as 'sharing a common humanity', as 'people first'. Yet neither the human race nor the 'population of people with intellectual disabilities' are homogenous. The labels of 'severe' and 'profound' intellectual disability point towards variance or difference within 'this population'.

The way in which people with an intellectual disability have been referred to has changed many times, as has the way in which intellectual disability has been explained (Luckasson et al., 2002). In 1961 the American Association on Mental Retardation (AMMR) distinguished between borderline, mild, moderate, severe, and profound mental retardation, which was based on IQ scores. The final four categories were kept until 1992, when the AAMR dropped the distinction between levels of intellectual disability, preferring instead to emphasise the supports that people needed.

References to levels of intellectual disability are also marginalised in the State Disability Plan. The words 'severe' and 'profound' appear once, in a section informing what the Government will do to build more inclusive communities (Clement, 2006). The Government will 'introduce a companion card scheme to assist people who have a severe or profound disability to access recreation and leisure opportunities' (State Government of Victoria, 2002, p.26). Neither do the words 'severe' nor 'profound' appear in the Disability Act 2006.

Although service workers are being encouraged to think in 'person-centred' ways, some staff members supporting people with severe and profound intellectual disabilities are more likely to be influenced by the evidence that is in front of their eyes (Clement, 2004). We may be encouraging staff to identify strengths, discover people's gifts and skills, and build on their capacities, but the older dominant understanding of 'mental handicap' based on personal deficits still has a hold on people's consciousness.

The references to level of intellectual disability may have disappeared from the AAMR's definition but they have not disappeared from the way we talk about, write about, or understand intellectual disability. Some of the research evidence seems especially salient here.

Allen, Pahl, and Quine (1990) investigated staff characteristics in two organisations in the United Kingdom, a long-stay hospital that was subject to a closure program, and a new local authority staffed housing service which was receiving some of the residents from the hospital and employing a number of its ex-staff. They reported the principal difference between the community and hospital staff's views as being based on two different kinds of judgement. For most community staff the issue centred on the rights of people with intellectual disabilities and for hospital staff the issue was largely one of practicality based on the potential and ability of people with intellectual disabilities.

With hindsight, this distinction between rights and practicality seems fundamental to the disagreements and misunderstandings that surfaced during this project, and touches on the areas of discussion we have outlined to date in this paper.

We need to distinguish between a person's attitudes towards people with intellectual disabilities in general and their attitude towards either a specific person or identifiable 'subgroup' (Jones, 1975). People can hold a global attitude towards people with intellectual disabilities, but attitudes change when the distinction is made between people with mild or severe intellectual disability (Antonak, Mulick, Kobe, and Fielder, 1995). Therefore we cannot infer from what a person says about people with intellectual difficulties in general that their attitude will be the same towards a specific individual.

People may therefore believe both in the goal of building inclusive communities for all people with disabilities and believe that it is not practical for people with severe intellectual disabilities or the particular person they support. Although the Allen et al. (1990) study is relatively old now, a sobering finding was that less than half the community staff were prepared to extend the rights-based perspective to all people with intellectual disabilities — more than half of the community staff group seemed to have some reservations about the practicality of the goals of community-based services. Within any human service organisation it is likely that employees will hold a range of different views about the goal of building inclusive communities.

There will be rights-based orientations and practicality-based ones. Employees will be making judgements on the basis of people’s ability and potential, whilst others may hold ‘progressive’ views independent of these characteristics. Some staff will hold optimistic views about ‘the community’ response to people with intellectual disabilities, whilst others will believe that people are not normally caring towards anyone who is ‘different’.

In writing this report we want to highlight the obvious, but sometimes ‘forgotten’ fact, that people with intellectual disabilities are not all the same and that the degree of intellectual disability is an important variable. Again, we do not see this as being incongruent with the universal, rights-based perspective that informs our work. Our instinct is to want to extend rights to all people with intellectual disabilities, but at the same time, and depending on the specific ‘right’, we must acknowledge that what this means for people with severe intellectual disabilities may be unclear and more than likely harder to achieve. As far as building inclusive communities goes, an aim of this research has been to focus on the practicalities of realising this goal for people with severe intellectual disabilities.

The research evidence informs us that one of the variables, shown to be associated with variations in outcomes for service-users living in community-based residential services, is the characteristics of the service-users (Mansell, 2005). People with more severe impairments and challenging behaviour tend to have more limited social lives and be excluded from community services (Felce et al., 1998; Mansell, McGill, and Emerson, 1994). We should therefore not underestimate the scale of the task facing those staff charged with building inclusive communities for people with severe intellectual disabilities.

5. Values and action research

Readers may be less familiar with action research methodology than with other ways of researching. It may be the case that you understand research to be ‘value neutral’ (see Hammersley, 2000).

In contrast to this view, action researchers tend to work intentionally towards the implementation of ideas that are consistent with values that motivate them to intervene. The intention is to bring about a situation that is congruent with the value position (McNiff, Lomax, and Whitehead, 1996). Action research therefore has a specific value base.

This is the major reason why we have written so much about the goal of building inclusive communities and our research goal. We have wanted to be entirely transparent about the values that underpin the research goal. The State Disability Plan is an important reference point for the research goal because it is the Department’s blueprint for action. It also serves as a compass for direct support staff who ought to shift or change their practice so that it is in line with the strategic plan.

Although the research goal is not ‘value neutral’ we have aspired to write an account of the research that is a ‘true’ and ‘objective’ description of the research process with the aim of adding to ‘knowledge’ about building inclusive communities.

Action research is a generic term for a wide and confusing array of related approaches (Coghlan and Brannick, 2001). A difficulty in implementing this project has been reconciling the tension between the type of action research we hoped we would do with the type of action research that we ended up doing. As we shall see this was a question of whose values should prevail in setting the direction for the research.

We had hoped to use an empowering conceptualisation of action research. This would have allowed the staff group to define the research issue and become co-researchers. We ended up doing organisational action research, trying to change staff practice towards predetermined aims that had been set by senior managers (Hart and Bond, 1995). This also established the potential for ‘conflict’, because the people who were going to have to make interventions needed to buy into our research goal (Coghlan and Brannick, 2001).

Early on in the fieldwork there were enough indications to suggest that the practices that we observed were unlikely to meet the goal of building inclusive communities (see Chapter 10). We believed that if the staff group's practice was to move in the direction of what we believed to be more 'balanced' practice, or move in the direction set by the department, then we would have to confront their thinking. Schein (1999) calls this confrontive inquiry. By sharing our own ideas about building inclusive communities we introduced new ideas, concepts, hypotheses, and options that the staff were forced to deal with.

This led to a further important research focus. Wolcott (1994) suggests that researchers can learn about a social system from its efforts to change itself and how the system seeks to maintain itself. What could we learn about trying to implement the goal of building inclusive communities?

From what we have written so far a reader might get the impression that the direction of the research was all one way. This was definitely not the case. Staff and family members shared their ideas about building inclusive communities, which challenged our own thinking about the goal. An important part of the action research methodology was adopting a critical stance towards our own work (Winter and Munn-Giddings, 2001). Examining our own work, specifically the research goal and how we were facilitating the work of staff, became an important part of the research process.

We have written about the research as occurring in five phases (Figure 3), based on this number of action research cycles (Figure 4). What we have tried to do is show how each cycle threw up different issues, in particular the challenges to the research goal and the implications for implementing it.

Figure 3. Research timetable

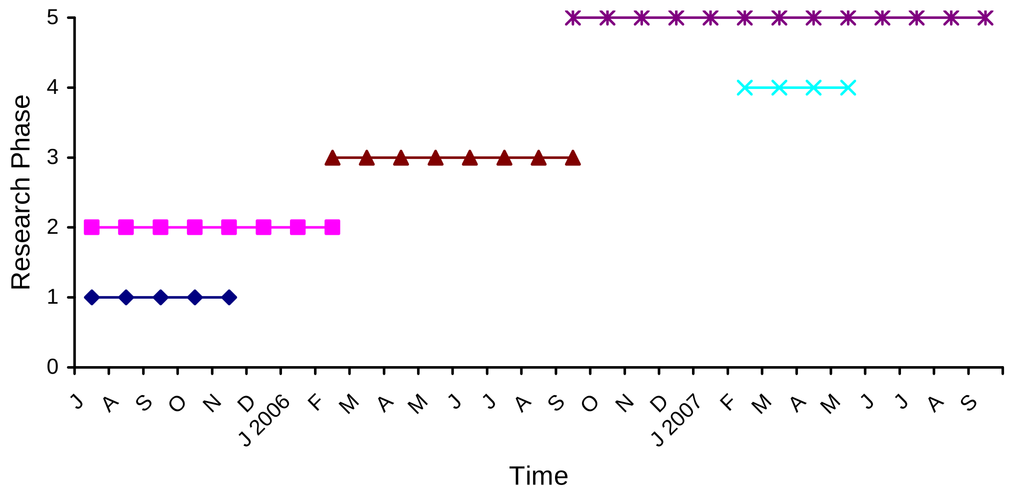
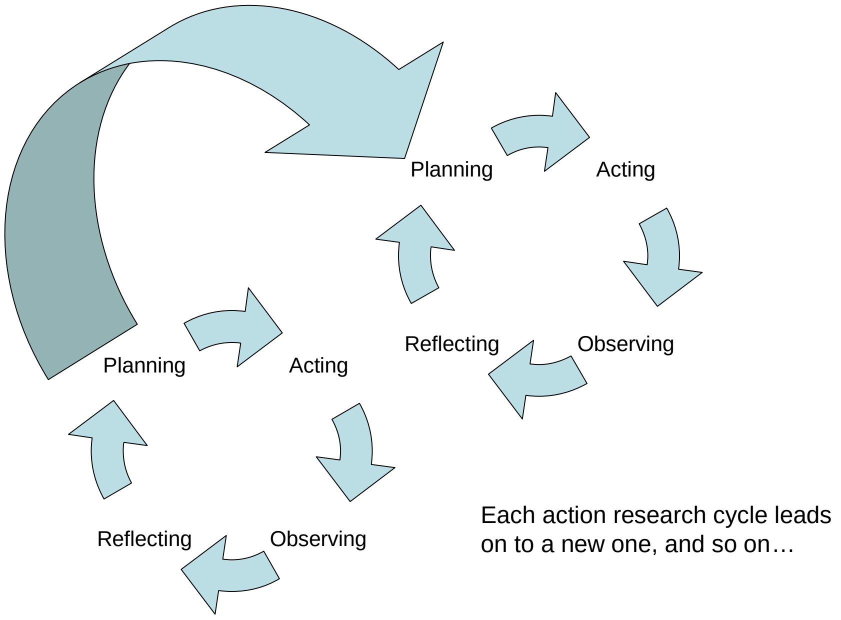


Figure 4. Cycles of action research. Adapted from Coghlan (2001)



Each action research cycle leads on to a new one, and so on…

Each cycle of action research has a period of reflection that informs the next steps to be taken. Although our reflections were not as neatly compartmentalised as we have suggested through the report's structure, reporting them in this way mirrors exactly the process we faced of having to address one 'objection' after another. In other circumstances people in positions of authority may simply be able to direct employees what to do and expect them to get on with it. As ‘outsiders’ our primary method of influencing staff practice was to try and persuade people that expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people was a goal worth pursuing.

A useful outcome of this research is that it allowed people’s problems, issues, and objections to surface. Modern managers often use persuasion before turning to other methods of influencing staff behaviour (Handy, 1993). Anticipating people’s ‘objections’ and having well-prepared counter arguments may help managers to persuade front-line staff of the benefits of facilitating relationships with non-disabled people. We probably haven’t exhausted every possibility, but many of these ‘objections’ and our counter-arguments are detailed in this report.

6. The research setting and residents

The house

64 Penny Lane is a purpose-built house, located in a multi-purpose neighbourhood (Wolfensberger and Thomas, 1983). It is situated at one end of a residential street close to a veterinary practice and joins a busy road, High Street, which is used by a large number of trucks. The west side of High Street is heavily industrialised. Many of the industrial units are related to the selling and repair of cars. There are two cafés on the road, which serve the workers on the industrial estate. There is no bus route that goes down past the intersection of Penny Lane and High Street. The closest bus stops are 10 to 20 minutes away by foot. The nearest facilities are a petrol station, squash courts with a small gym, and a public walk along Arthur's creek.

Reflections: On neighbourhood and 'being a neighbour'

The areas where services are sited have important consequences for how people with intellectual disabilities are seen and the type of skills that they can develop (Wolfensberger and Thomas, 1983). They also impact on two understandings of community and the role that people with intellectual disabilities can be supported to fulfil: the larger neighbourhood, the street where you live, and being a neighbour.

The King's Fund (1988) suggest that as a rule of thumb neighbourhood can be understood as the area within walking distance of the house. We would suggest that the limited range of community resources, such as shopping options, public services, spiritual centres, and recreational facilities within quick and convenient access of 64 Penny Lane hinder the residents' opportunities for 'knowing and being known in a neighbourhood' (King's Fund, 1988, p.32). Available community resources promote inclusion and allow people to develop skills in using them. Those individuals making decisions about where to buy or build community-based accommodation for people with intellectual disabilities must consider the implications for building inclusive communities.

As a consequence the residents at 64 Penny Lane are dependent on being driven to facilities that are some distance from where they live. This is, of course, typical of many other Australians. Higher car ownership means that there is less reliance on neighbourhoods than there used to be. We drive to other areas to undertake activities, visit people, and use large shopping malls (Hughes et al., 2007). Consequently communities based on geography or area are generally understood to be weaker and more fragmented than in the past. This has implications for how staff perceive and undertake their role.

Firstly, they may look outwards from the neighbourhood and fail to explore or use the possibilities that exist for building inclusive communities locally. In another house that is part of the Making Life Good in the Community project, the staff drove five kilometres to a church that none of the residents had any relationship with, when there is a church within walking distance at the end of the road they live in. Although many ‘corner shops’ have closed down, they still represent a better chance for ‘being known’ (so as to develop ‘acquaintance’) over a longer time-span, than the checkouts at a large supermarket where the faces change frequently.

Secondly, because the staff may not know their own neighbours they may not see it as part of their role to promote the residents as neighbours and engender neighbourliness. According to Hughes et al. (2007) most Australians do not know their neighbours, other than to say ‘G’day’. Even though we must acknowledge the changed nature of Australian society, the street where people live still offers possibilities for enlarging people’s networks of personal relationships. Table 1 gives three ‘rules’ about what makes a good neighbour (King's Fund, 1988).

Table 1

Being a neighbour (King's Fund, 1988)

Friendliness	Offering warm, polite greetings, and generally being interested and encouraging.
Helpfulness	An exchange of small services like keeping an eye on someone’s house if they were away, or taking in a parcel left by a courier.
Privacy	Not unduly intruding into the other person’s life; not making unreasonable amounts of noise; not being ‘nosey’; and respecting confidences.

We have chosen to illustrate some real experiences of ‘being a neighbour’ from interviews that we did for a separate strand of the Making Life Good in the Community project that illustrate some of these points. This is because an understanding of community based on the local area was not a strong feature of building inclusive communities at 64 Penny Lane.

These first extract reflects a view that there is an absence of ‘community’ in the area — that neighbours are ‘faces’ who know little about one another.

> [The neighbours] all keep to themselves pretty much. I actually live around the corner myself; people generally do just keep to themselves. I don’t

> really have much to do with my neighbours either. I don't know if it's just the area or if it's just us. (HS/16/I)[5]

A staff member who has little to do with her own neighbours may not see the neighbours of the people she supports as a place to look to expand their social networks. This 'absence of community' is reinforced by the next quotation, but the participant also hints that when the residents first moved in the reaction was more than indifference. This underscores the belief that some non-disabled members of the Victorian community have negative or hostile attitudes towards people with intellectual disabilities.

> [The neighbours] they're all fine, we haven't had any issues. It's fairly insular, they're all happy that we're here and we're not rocking the boat, we're not causing any trouble. They've all just gone back to being as they were before we arrived. They were very unhappy when we first came. (HS/15/I)

Negative attitudes can be created and reinforced by neighbours feeling that there has been an impact on their privacy.

> There were elements [of the house design] that they didn't really think about when they built the house, and that was the noise-level. We have a couple of guys that make a lot of noise. They don't do it constantly but when they do, it's quite loud. That's the way they communicate, they don't have formal words but they use this sound to communicate. Unfortunately we're fairly close to our neighbours on this side, and the noise just penetrated through and they were quite upset about it. We've managed to get sound-proof windows put in. (HS/18/I)

Other people have managed to be helpful to their neighbours and possibly as a consequence of this have established more friendly relationships.

> When I get the mower out, I mow the nature strip but I also mow the neighbours' bit. The Department might say, 'Oh well, that's not quite using departmental resources', however, doing that gets me in with the neighbours. So the neighbours, when they see the residents, are likely to say 'hello'. We have very good relationships with neighbours here. For example, that flower thing sitting on the TV is a Christmas present from one of the neighbours. That's how you foster [relationships], it's just the little things like saying 'hello' to people who live next door, getting the residents

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[5] The data we present have codes attached to them. They may contain an 'I' for interview; 'F' for fieldnote; or 'D' for document. All names have been changed in an effort to preserve anonymity.

> to say ‘hello’, getting one the residents to take the bins in. We’re getting our own bins in; we’ll get José to take the next door neighbour’s bin in. It’s the ‘one percenters’ that make the football match. (HS/4/I)

We agree with the authors of Ties and Connections (King's Fund, 1988) that ‘sometimes the relationship of casual acquaintance and polite friendliness of good neighbours may move towards real friendship – as people get to know each other better and discover common interests and concerns’ (p.30).

In the research where these quotations came from we identified ‘building inclusive communities and supporting residents’ networks’ as an area of house supervisor competency (Clement and Bigby, 2007). House supervisors are expected to have an active role in promoting positive relationships between residents, staff and neighbours. This may take the form of bending over backwards to make sure that you do not unduly intrude on a neighbours life.

> The guy who lives across the road he’s a bit of a ‘parking Nazi’. If someone parks where he likes to park his car, what he does he gets his car and he’ll park right up behind them and almost touch his bumper bar on them. So to keep the good relationships going you try to make sure you don’t pinch anyone’s parking spot and all that sort of thing. I think that’s very important, because once you get people offside, then the complaints start. You’ve got to see yourself as a good neighbour, don’t let it get to that, and if something does happen get over there and apologise. (HS/4/I)

Or it may take the form of overt friendliness from which real benefits occur.

> We had an afternoon tea and invited in all the family, friends and neighbours, just so that everybody could come in and meet us. To see what we’re about, that we’re often not that scary, and that our house is the same as their house, except that it’s got a few different things in it that suit us. The same as they have things that suit them. And from that [event we found out that] one of the gentlemen who lives in the street is part of the council. We back onto a park at the rear here, which is just terrific for us, but when they bought the house they built a fence, and because we have the girls with wheelchairs, pushing them [to the park] was really difficult. So we applied to the council to see if they would put in a path and with the gentleman’s help over the road, because he’s on some of the council boards, we had the path in within about six weeks. We can push the girls in there comfortably and enjoy it. (HS/19/I)

The residents

Before moving to 64 Penny Lane the five residents had lived at Kew Residential Services for most of their lives. When the house opened the residents attended four different day programs. Two of the men attended a day program five days a week, whilst the others were supported from home when they are not at a day program.

The residents' personal files recorded four of the men as having severe intellectual disability and one as having a profound intellectual disability. In addition, three residents had epilepsy, two were diagnosed with a 'psychotic disorder', and one a visual impairment.

Each resident was assessed prior to moving from Kew with a communication assessment designed for adults with severe intellectual disabilities, the Triple C (Bloomberg and West, 1999). One resident was assessed as being at Level 2 (Preintentional reactive), three at Level 4 (Intentional informal) and one at Level 5 (Intentional formal).

Reflections: Acknowledging the level of intellectual disability

The degree of intellectual disability and related level of receptive and expressive communication are important factors for a number of related reasons. Firstly, we have stated that building inclusive communities is likely to be harder for people with severe intellectual disabilities, who are more likely to be experiencing limited social lives. Secondly, Clegg (2006) makes the important point that people with severe intellectual disabilities have features that non-disabled people with little or limited direct experiences of disability find disconcerting. She writes:

> Secondary disabilities commonly found among people with intellectual disability do have a major impact on their lives: blindness, deafness, physical disability or epilepsy. Other difficulties or behaviours include incontinence, movement disorders, self-harm or assaults on others. The person may also have socially disconcerting features: dysmorphic faces, baldness, drooling, stereotyped behaviours, or they may make strange noises (p.127).

Thirdly, people with severe intellectual disabilities rely on other people to plan, organise, identify and coordinate resources to access the community (J. O'Brien, 1987). What this means of course is that the residents are relatively powerless in relation to the people that are supporting them and therefore the staff that support people with severe intellectual disabilities exercise a great deal of control over their lives. This brings staff performance into the research arena as an important variable, because differences in staff attitudes have been shown to be associated with variations in outcomes for service-users living in community-based residential services (Mansell, 2005).

Fourthly, it means that people with severe intellectual disabilities are neither likely to understand what the abstract goal of building inclusive communities means nor will they be able to express an opinion about it. Other guiding principles, such as the principle of dignity and self-determination and the goal of pursuing individual lifestyles (Department of Human Services, Victoria, 2002b) are less easily operationalised for people with severe intellectual disabilities (see Table 2).

Table 2

The principle of dignity and self-determination and pursuing individual lifestyles (Department of Human Services, Victoria, 2002b)

Principle	Definition
The principle of dignity and self-determination (Choice)	‘The Principle of Dignity and Self-Determination (Choice) is about respecting and valuing the knowledge, abilities and experiences that people with a disability possess, supporting them to make choices about their lives, and enabling each person to live the life they want to live’ (p.7).
Pursuing individual lifestyles	‘Enabling people with a disability to pursue their own individual lifestyle means ensuring that people have maximum control over their own lives. To achieve this, the Government will reorient disability supports so that they are more responsive and more focused on people’s individual needs and choices, and to the needs of their families and carers’ (p.9).

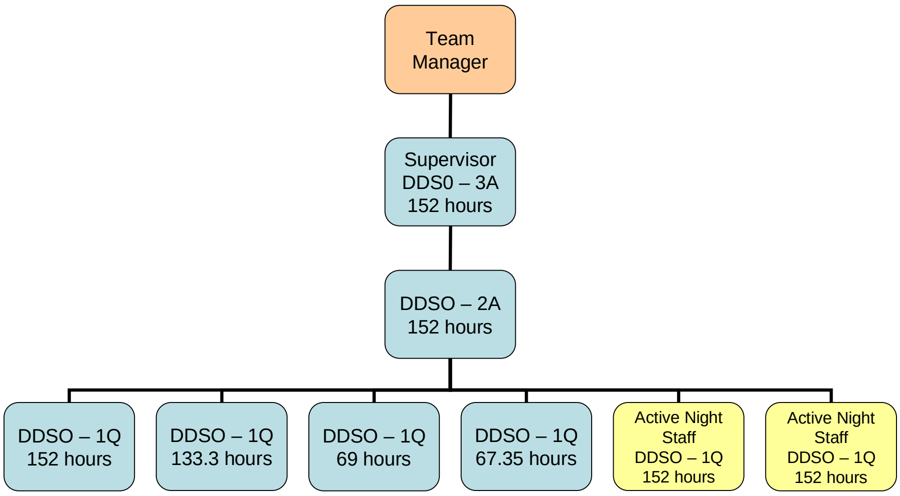
Rather than enabling people with severe intellectual disabilities to make significant choices, have control, and live the lives they want to live, it is more likely that other people, (primarily the staff who support them, but also family members, service managers, and researchers), are making choices about their lives, lifestyles, and the lives they think they want to live on a daily basis.

A fifth point is that involving the men at 64 Penny Lane meaningfully in the research project, one of the original research aims, was impossible. This underlines the importance of subjecting our research goal to intense scrutiny. We believe that building inclusive communities and our goal of expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people are beneficial for the five men in the house, and their level of intellectual disability is such that they are unable to directly question it.

The staff

The house has been set up to provide the residents with an extensive support intensity, which is characterised by long-term daily involvement of paid staff in the home environment (Luckasson et al., 2002)[6]. There is an 'active night' staff at the house. See Figure 5.

Figure 5. Staff structure at 64 Penny Lane showing staff grade and the number of hours worked on a four week roster



Resources allow for a minimum of two staff to be in the house when the residents are not at day programs. On occasions the staff-to-resident ratio is more generous than this. This is important because staffing resources are related to variations in the size and composition of people's social networks (Robertson et al., 2001). At 64 Penny Lane the resources allow for one or more residents to be supported outside the house, whilst those who remain in their home also receive adequate support.

When the house opened, five of the staff group had worked between six and 32 years at KRS. The ease with which staff made the transition to working in a community-based service is discussed in Chapter 12.

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[6] The American Association on Mental Retardation (AAMR) distinguish between four supports intensities: Intermittent, Limited, Extensive, and Pervasive.

Consent

Consent for the residents to participate in the research was obtained from a proxy, a named family member in all cases. Consent was also obtained from the staff team and five family members who had expressed an interest in participating in the research.

Although most of the data that we present in this report is taken from 64 Penny Lane, we have also drawn on relevant data from the Making Life Good in the Community project, which helps to illuminate important issues. In the next chapter we discuss the training that we observed for two different staff groups.

7. Phase 1: Training

The opening of 64 Penny Lane was preceded by a two week block of training, known as ‘transition training’. As part of their ‘orientation’ to working in the new setting the staff group received a training session on social inclusion. About four months later the staff team attended a one-day workshop called Developing Community Connections at a Local Level (Scope (Vic) Ltd., 2005) to support the goal of building inclusive communities.

In this chapter we present and discuss some of the course materials. The course materials and the fieldnote extracts are taken from training sessions that we participated in with other staff groups, not the staff group form 64 Penny Lane. The ‘social inclusion’ training delivered by a community agency was a standardised package that was repeated to a number of staff groups.

We want to discuss the course materials for a number of reasons. Firstly, the staff were given a number of definitions of ‘community’ and its derivatives. Presenting this material illustrates some of the different understandings of what building inclusive communities might entail and reinforces its complexity and multifaceted nature. Secondly, because training is meant to result in improved performance, the content is indicative of the working knowledge that staff might be expected to have to accomplish their roles (Egan and Cowan, 1979; Goldstein and Ford, 2002). Thirdly, unless it is specifically pointed out to participants, we would argue that participants can come away from this training without understanding that part of their role is to facilitate relationships with non-disabled people and therefore may concentrate on relationships with other people with intellectual disabilities, relatives, and staff members.

Orientation: Social inclusion training

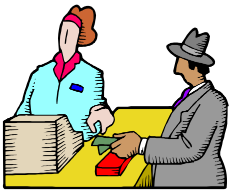
Three slides from the social inclusion session are given below (Figures 6 – 8). No course objectives were given by the trainer (F/AM/180805). The content implies that people with intellectual disabilities are no different from anyone else (that is, have common or universal needs), but because they lived at Kew they are likely to have experienced a segregated lifestyle.

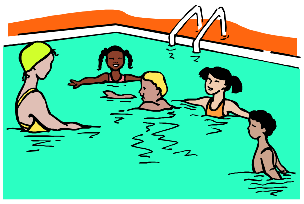
Figure 6. Community inclusion for people with a disability

- Being included in the community is just as important for a person with a disability as it is for the rest of the community.
- People who have lived in institutional settings may have been given limited access to the wider community.

Figure 7. What is community inclusion?

- Being involved in the community
- Being a valued member of the community
- Using services such as shops, hairdressers, etc
- Accessing recreation and leisure activities on offer
- Meeting people by visiting the same place over and over





The slides state that 'community inclusion' is about being involved and valued. By regularly using services and undertaking leisure activities you might meet the same people. Staff need to support people with intellectual disabilities to pursue their interests, use ordinary services, meet people, visit different places, and have new experiences.

Figure 8. Living in a community setting

The person needs to be provided with support to gain different opportunities

- Visiting different places
- Having new experiences
- Being able to use services provided by the community
- Pursuing interests in the community
- Meeting people

Workshop: Developing community connections

The course objectives for the workshop are given below (F/HS/290905).

Participants will:

1. Leave the workshop with an ability to describe the notion of community
2. Identify the value of community participation[7] for people with disabilities
3. Have an increased knowledge of ‘how to’ involve people with disabilities in their chosen community by using an 9 step process (Scope (Vic) Ltd., 2005, p.4)

We might infer from these objectives that after the workshop participants will know what ‘community’ is, why it is important, and how to ‘involve people in a chosen community’. Table 3 gives three definitions of ‘community’ that were presented to the participants.

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[7] ‘Community participation’ is not used in this course objective in the same way that we have used it. This reinforces our earlier point about the need for a common vocabulary. Efforts to instil a common language have not been helped by corruptions of O'Brien's (1987) five accomplishments being used in training sessions that we have observed during the course of the research. Reports commissioned by the Department of Human Services also use community participation in ways that differ from O'Brien's conceptualisation (for example, see McLeod, Stewart, and Robertson, n.d.; Radler, 2004).

Table 3

Definitions of ‘community’ given at the Developing community connections at a local level workshop

1. A group of people who share a common identity, such as geographical location, class or ethnic background, or who share a special interest, such as a common concern about the destruction of rainforests (Kenny, 1994)
2. A natural, functioning community, from its members’ point of view, is a small, interacting group who share something in common (McArdle, 1998)
3. For some people, community means the local neighbourhood and neighbours. Others describe community as the emotion felt when joining together with others during leisure experiences and exploring mutual interests. And still others might describe it as a complex social network that surrounds them and gives meaning to life. The personal definitions of community are diverse and yet they all have common threads (Hutchinson and McGill, 1992)

Defining a term is about setting limits, of stating exactly what a thing is. These definitions allow a person to understand community in terms of identity, geography, neighbourhood, class, ethnicity, interest, commonality, emotion, leisure, and social network. Given that ‘community’ is a complex term we would not disagree with them as abstract concepts. What is more problematic, and is a theme that runs throughout this paper, is the beliefs that people have about these concepts and how they act on them in relation to people with severe intellectual disabilities.

In the accompanying workshop notes it also states 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 to them’ (Scope (Vic) Ltd., 2005, p.6). This statement is even more problematic. To suggest allowing a person to construct their own concept of community is probably not that helpful to direct support staff. It establishes ‘community’ as a term without boundaries, and allows an ‘anything goes’ approach. It provides too little guidance to staff and has little use as an analytic concept. It even allows staff to imagine and pursue ‘communities’ that are contrary to the goal of building inclusive communities.

During the workshop staff were asked to use the typology given in Table 4 to think about their own involvement in different types of community and then to repeat the exercise for the people they supported.

Table 4

Types of 'community' given at the Developing Community Connections at a Local Level workshop: attributed to McArdle (1998).

Type of community	Example
Kinship community	Including family, extended family and their friends
Centre based community	e.g. students, teachers, parents and local residents involved with a school or staff and users of a recreation centre or people attending a day service
Issue based community	e.g. an environmental group and people who share their concern about a specific environmental issue; people with a common disability and their carers.
Interest based community	A sporting club, or craft group
Geographic community	Residents of an identifiable rural district, friends living in a particular street or neighbourhood.

Finally, Table 5 gives the nine-step process that staff were asked to work through for the residents that they supported. This process was subsequently revised to a five-step process, which is given in Appendix 3.

Table 5.
Process to connect people with disabilities to their local community (1)
(Scope (Vic) Ltd., 2005)

1. Identify the aspirations and interests of the individual or group of people
2. Identify the organisations who provide those opportunities in the local community
3. Contact representatives of those organisations regarding their ability and interest in meeting the aspirations of the individual or group of people
4. Visit the organisation, meet its representatives and observe the activity in action
5. Speak with the representatives of the organisations about their fears and limitations and gauge their level of interest to have the individual or group involved.
6. Negotiate support with the organisation from the outset
7. Facilitate communication between the person being supported and other members of the organisation
8. Ongoing support may be required for some time until all people involved feel comfortable, this includes the individual and the members of the organisation
9. Assist the individual to reflect on their participation in the activity, the level of support provided and the relationships developed

Fieldnote extracts from two of these training sessions, which are specifically related to the outcomes of the nine step process, are given below. They are instructive because they are indicative of the staff's frame of reference at the end of the respective sessions. For the final activity of both sessions the staff were asked to focus on the residents in the house where they work, to identify a community activity that the person can participate in, and then think about the steps needed to support the person. This first extract is from the social inclusion session.

> Mark and Adriana [the trainer] discussed an activity for Shane. He was described as a man who uses a wheelchair, whose body is 'tight' and he cannot use his hands. He spends most of the day in the wheelchair, but gets out on a mat for 30 minutes to do exercises. He 'chews' his hands, knees and socks. To discourage this he has recently been given some 'rings' that they hope he will chew rather than his hands. A tray has been fitted to his wheelchair that will stop him chewing his knees and socks. They proposed an exercise activity on a mat at a leisure centre. They talked about making some phone calls to see what equipment is available, whether there was wheelchair access, accessible toilets and what the cost would be. They

> would clarify what he would do there (that is, ‘what stretches’ and ‘how frequently’).
>
> John was described by the next pair as a ‘happy man’. He can walk for about 30 minutes, so they discussed a ‘walking program’.
>
> For Alan they discussed a trip to a shopping centre, where he could purchase a milkshake. Pushpa commented that this would be good, as ‘He is a little underweight’. They could organise a wallet with some small coins so that he could get the money out. He could have the wallet in his hand. The trainer commented that it was good to go to the same place in order to get familiar with it. Overtime he could be given a card for a particular ‘smoothie’, if he had a favourite. It could be put with his money. This was seen as a step along the way.
>
> An activity for the final resident was ‘short distance walks’. He was said to be overweight. He likes to hold someone’s hand. He likes eye contact with people, and people talking to him. The activity was seen as an opportunity for staff to interact with him. He also likes a swing, and I was unclear whether they thought it appropriate for him to use a swing at a park. They have purchased a garden swing for the house.
>
> ‘That was excellent’ said Adriana.
>
> One of the issues Adriana raised was of the four men always doing activities together. A man in another house likes to go bowling. It would be possible for a client from the house to go bowling with this other man. In this way they get to meet other people. (F/AM/180805)

Reflections on the training sessions

We would suggest that the most likely outcome of all four activities (exercising on a mat at a leisure centre, a walking program, purchasing a milkshake at a shopping centre, and short distance walks) is community presence. There is nothing ‘wrong’ with any of these activities, but any contact with new people is likely to be fleeting and based on encounters in service settings. The trainer highlights an important point that relationships are likely to be established when people go to the same place over and over again and the communication card may be a useful technique for facilitating interaction between shop assistants and the resident. This may result in acquaintances being formed, a particular type of community participation, but we would suggest that this is unlikely at a juice bar or café in a shopping centre, where you may see a different person each time you go there.

We suggest that the final paragraph is illustrative of a significant dynamic that leads to the creation of this ‘distinct social space’. There was nothing to suggest that the two men with intellectual disabilities with an interest in bowling knew each other. What is it that makes the people in that room see them as a possible match for one another? Is it the interest in bowling? Is it that they both have the label of ‘intellectual disability’ attached to them? Is it the two together?

We do not know for sure, but we believe that is safe to assume that of the nine people in the training session, one of them will know someone within their own social networks who likes bowling[8]. Why do the people in the room not even begin to consider a person from within their own social networks as a match for one of the residents?

What the trainer is suggesting is a bonding relationship (Putnam, Feldstein, and Cohen, 2004), a relationship between people who have things in common. Certainly they share an interest in bowling, but more specifically they are service-users and share the label of ‘intellectual disability’. We are not suggesting that there is anything intrinsically wrong with proposing these two people meet, and they may discover they enjoy each others’ company, but it is a practice that may enlarge and strengthen the boundaries of the ‘distinct social space’ surrounding these individuals, unless they are supplemented by other types of relationships. This is more evident in the next extract, which is from a Developing community connections at a local level workshop.

> After lunch we went through the nine steps and then moved on to the final activity which was relating the steps to the residents in the house.
>
> I went and joined a group who were working outside. They discussed Alberto, and of course the activity that they came up with was BOWLING! [I found this session so frustrating that I wanted to scream[9]]. It was not just that bowling came up as an activity again, but other issues which went unchallenged:
>
> 1. Contacting the bowling centre to see if they had a time for disabled people.

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[8] If no one else, then the researcher who was present likes and knows people who like bowling.

[9] In writing fieldnotes we often included personal comments in parentheses that we reflected upon once we had left the field. Feelings are a resource for understanding that express values and ideologies. In this example we would have spent some time thinking about why the researcher felt frustrated. It is also worth commenting why BOWLING is written in capital letters. There is nothing wrong with bowling as an activity, but we are interested in why it seems to have become such a key activity for people with intellectual disabilities. With a touch of humour we suggest that if an inquisitive alien visited earth, knowing nothing about people with intellectual disabilities, it would quickly conclude that people with intellectual disabilities like nothing better than going bowling and eating at McDonalds.

2. Creating a bowling group by contacting other houses to see if other people wanted to go bowling.
3. Discussions about independence, which meant residents could just be dropped off to do the activity on their own, whilst the staff sat in the bus or did the shopping whilst people bowled.
4. The fact that no one [including me] challenged these ideas.
5. The fact that a case manager was driving some of this discussion and the acting house supervisor was in the group.
6. The fact that Natalie [the trainer] came and listened and said ‘fantastic’. She also said of the exercise, ‘You don’t have to [implement] this. No one’s checking up on you’, although she then made a case for why they should do it.
7. [The other three examples were equally uninspiring.] For Aphrodite, cooking and walking were interests. She could do a cooking program at home before looking at a cooking class. Brian likes computers. They could try this at home. We could buy a child’s computer for $40.00 to see if he likes it. For Sarah, there was a debate about getting her hair cut, which moved on to pampering at a beauty salon. (F/HS/290905)

Reflections: Creating and sustaining the ‘distinct social space’

The three suggestions to support bowling are all likely to create and sustain the ‘distinct social space’, even if an outcome of using the local bowling alley is community presence. If a special session for people with intellectual disabilities is not available, then the staff will in effect create one if they gather people from other group home. The third suggestion is almost Robert Putnam’s (2000) Bowling Alone come to life. As in the previous fieldnote the trainer legitimises the staff suggestions by giving positive feedback, which is reinforced by the case manager and house supervisor’s presence. Of the other three activities, using a computer at home has no relation to the task the staff were given. Community presence is the most likely outcome of walking, getting a hair cut, or a one-off trip to a beauty salon. Beginning a ‘cooking program’ at home is indicative of the ‘readiness model’ or the ‘continuum trap’ (Kinsella, 1993). Here the resident either has to ‘be made ready’ or negotiate a stage before she can go to a cooking class. People have to be taught new skills and then prove themselves worthy before they can move on to the next stage. This either keeps people in the ‘distinct social space’ or delays the possibility for weakening its boundaries.

In summary we would suggest that the outcome of the activities that both groups identified for the residents would at best sustain the pattern of a ‘distinct social space’ or enhance it if a bowling group for people with intellectual disabilities is an outcome. Although another outcome is community presence, community participation is unlikely.

The long-term nature of the research gave us a privileged position from which to comment on the impact of these two training sessions, which were also delivered to the staff group at 64 Penny Lane. An impact evaluation to discover whether there has been a change in the practices of direct care staff or improved outcomes for service-users is rarely carried out by organisations as it is costly and difficult to do. In many organisations an end of training evaluation sheet is often the sole form of evaluation.

8. Phase 2: Evaluation

Action research may start by evaluating current practice (Winter and Munn-Giddings, 2001). Prior to identifying the specific action research project, a researcher spent time working at 64 Penny Lane. The primary reason for doing this was to get to know the residents and staff and to understand the relevant practice issues. As we suggested earlier, a second reason for working in the house was to collect enough data to allow the researcher and the staff group to evaluate current practice. The initial plan was to meet with the staff to reach agreement about the principal issues about which action would be planned and taken. At this stage of the research we still hoped to use an empowering approach to action research. In addition to collecting data using participant-observation methods we also conducted interviews with five staff members and five family members.

Interviews

The first interviews with the staff members were completed three months after the house had opened and immediately prior to the Developing community connections at a local level workshop. At this stage one may expect to find that staff views reflected ideas from the social inclusion training (see Chapter 9), but the impact of the Developing community connections workshop would reveal itself at a later date. These interviews were influenced by an ‘Appreciative Inquiry’ orientation, an approach that focuses on an organisation at its best (Cooperrider, Whitney, and Stavros, 2003). This extract from the interview protocol reflects both Appreciative Inquiry and empowering action research orientations.

> I am interested in discovering the positive core of the organisation, learning about the organisation when it is at its best, and hearing about what dreams you have for a better organisation and perhaps a better world.
>
> As the main aspect of the research is about improving practice I want to find out about what issues you may be interested in tackling. You have a view of things as they are now and what you think needs to change. (Clement, 2005a)

How people understand their role

One of the interview questions asked staff what they were trying to accomplish at the house. We would suggest that their answers reflect both ‘people first’ and ‘ordinary life’ perspectives, and beliefs about institutional living provide a contrast to the residents' lives in their new home. In short, people with intellectual disabilities are the same as everybody else and can live like anyone else.

> Our role and responsibility is to ensure that the fellas are given every opportunity to experience what community life is all about like you and I. (I/SD/021105)

> We're trying to provide them with a life that has some quality and happiness for them to experience. It doesn't have to be a big thing, something they love to do, like go for a walk everyday, or being able to play basketball, or having a choice, what to choose when you go to McDonalds or a café or takeaway. To see them smile. They deserve it, just like anybody else, and that might not have necessarily happened coming from an institution. (I/LW/102605)

> We basically want the guys to have a better quality of life and more opportunities to do things in the community. To live a more normal life, as opposed to a congregate, institutional [care], for them to be more independent. (I/SX/091105)

> People have a special disability [but] they are just like us, only they have some special needs. We are trying to help them get a normal lifestyle, going out shopping, having breakfast. (I/PP/091105)

We would argue that these views are more representative of attitudes towards people with intellectual disabilities in general, rather than the individuals they support. Staff expressed views that were tempered when they focused more specifically on the five residents.

> I'm proud of what we have done here so far. We've still got a long way to go. I had high expectations of where to go, I had come off doing active support [training] and my adrenalin was rushing because I had all these ideas of what I wanted to introduce, but I didn't take in to account the skills of the residents and their abilities. I've discussed this with the staff. In my mind I would have preferred more social inclusion. My expectations are probably too high for the fellas and I've realised that so I've had to cut back a little bit. (I/SD/021105)

The behaviour of one of the residents was seen as being especially problematic. This is consistent with the research that we cited earlier, which suggests that building inclusive communities is harder for people with challenging behaviour, and that the presence of challenging behaviour impacts on whether staff see community-based services as appropriate (Allen et al., 1990; Mansell, Hughes, and McGill, 1994).

> I don't want to sound negative towards Franco but it's difficult to take him into a group setting, particularly in a closed community area because he gets very anxious. So we've got to take every opportunity that we can so the other fellas can experience that type of community access, where we go down a different line for Franco[10]. We've got a long process that's in place for Franco. I've got a goal of 6 to 12 months we'll be able to take him into a restaurant or café without him getting anxious and wanting to get up and go. That's why it's very important that we [teach him to sit at the dining table in the house]. (I/SD/021105)

As we shall see more clearly below, we categorised most of the community activities that the staff at 64 Penny Lane supported as community presence, which were also group based. Franco's behaviour meant that he received a more individualised service, participating less in group activities with the other residents.

> The thing with Franco you really need one-on-one most of the time. He does get a lot of one-on-one, with walks and things like that. I don't know how many times they've taken him out, but he seems to be the odd one out. The other four are easy to take out for meals. Simon will take them out for dinner, but it's really hard to take the five of them out. With Franco you've got to have one person with him, you've got to keep an eye on him. Once he finishes his drink he's looking round to take other people's food. (I/JZ/141205)

Although there are occasions when it is appropriate to do things as a household, we were concerned that for this staff group it was the primary way of operating[11].

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[10] 'Community access' is a term that we have regularly come across during the course of Making life good in the community. It is probably very similar to community presence, the sharing of ordinary places. A manager, who we interviewed for a different element of the project, stated that the focus on community participation was relatively new and until recently the emphasis had been 'community access' (M/23/I). The following quotation, from a house supervisor, is from that project.

> We try and give Max swimming twice a week because he has some walking difficulty, and the exercise in the pool is really helping him with that. He goes to a music program once a week, which he absolutely adores. That's with a whole group of other people who have intellectual disability, but probably at a higher level than him. They're very welcoming and he is very much a part of that group. The other thing we do is community access, the market, the mall, lunches out, that sort of stuff, which he absolutely loves as well, because he's very social. (HS/15/I)

[11] Not only are group activities more likely to result in 'block treatment', a concept discussed later in this section, but they also make it less likely that there will be any meaningful contact with non-disabled people. Human service workers need to weigh-up a number of factors related to grouping people with intellectual disabilities together (see Wolfensberger and Thomas, 1983). It is easier to relate to people as individuals and get to know them in small groups.

Being able to take all five men out as a group was an issue that some staff thought was an important issue to tackle.

> Tim: What practices do you think need changing at the house?
>
> Shelagh: Probably taking them out, taking them out as a whole group, all at once. So far we haven't really been able to do that because of Franco. It's been two at once or one or three, and then [a staff member must] stay behind. Building up to a stage where they can all go out at once and they're okay.
>
> Tim: To what sort of places?
>
> Shelagh: To go to a restaurant to have dinner. To go anywhere where there are other people around. (I/SX/091105)

This staff member also identified all five men going out as a goal and envisioned a way of how this might be achieved.

> John: [The staff] try to take them out as a group, but whether you could start with a one-on-one with [Franco], just taking him out individually, instead of taking four you might be better off taking the two.
>
> Tim: What are the benefits of all five men going out together?
>
> John: I mean, I know it's not every night, I suppose, I don't know...When I was in the army we used to go out as a group, if you're friends and that...They seem to get on alright, I suppose it'd be nice just a smaller group...
>
> Tim: I'm not saying don't do it, I'm just wondering what the advantages are. (I/JZ/141205)

It is also worth noting the type of activities that populate people's comments to date, which we suggest are indicative of their frame of reference. Although a walk, shopping and basketball are mentioned, the majority are related to eating out (breakfast, café (2), dinner (2), McDonald's, 'out for meals', restaurant (2), and takeaway). The data that we present later shows that eating out was the second most common activity, behind 'bus trips'. Eating out is community presence, but is unlikely to lead to community participation when your other companions are other people with intellectual disabilities and paid staff. Indeed, community participation may not be seen as a goal. This interview extract suggests that residents' happiness, enjoyment, and security may be seen as important goals.

> One thing I do value and get the most enjoyment out of is, we took Dan, Joseph and Milan to Fasta Pasta, which is quite simple for most of us. However they have never been, or once or twice have been to restaurants. It was about them handing over the money and picking their ice cream and seeing Dan's grin of excitement when he paid over his money and wandered back. He just had a grin from ear-to-ear, although he had no understanding or knowledge of what the money was all about. All he was concerned about was his cup of ice-cream he had in front of him, and he really enjoyed that. [It's about] taking the boys out into the community so that they can have a walk around and not feel intimidated, not feel isolated. They're the things that I value. Hopefully in whatever period of time I'm here for they'll have the opportunity to experience new emotions or ventures. (I/SD/021105)

Skill mix of staff

In an earlier chapter we mentioned that five of the staff team had worked for a significant period of time at KRS. House supervisors interviewed for a separate strand of Making Life Good in the Community raised issues related to the relocation of staff from a 'hospital' environment to community-based services (Clement and Bigby, 2007). Although it was by no means inevitable that direct support staff in institutional settings became 'institutionalised', in a similar process to people with intellectual disabilities, some staff have undoubtedly struggled with the expanded role that is underpinned by a 'new' or 'different' service philosophy. The ease and speed with which former Kew staff can adjust to the new setting, develop their knowledge and skills, and align their practice to the community-based orientation impacts on the outcomes for service-users.

Implicit in the house supervisor's comments that follow is that the previous experience at Kew had not given people the confidence, knowledge or skills to support the residents in building inclusive communities.

> I don't think everybody has grasped the idea of social inclusion, but we've done bits and pieces....In my mind I would have preferred more social inclusion, more regular....Only the other day when I was speaking with Linda, I said, 'Come on we'll go out for morning tea'. She said, 'I never did that before'. She wasn't familiar with it and at this stage wasn't comfortable with it. I said, 'Don't worry about it, stay on board with me and you'll experience a lot more', because there wasn't a push for that [at Kew]. Social inclusion at Kew was a bus ride into the country for an hour; get out into a park area where there was nobody else around. (I/SD/021105)

Supporting people in the new setting also means jettisoning the institutional routines that may have been organised for the convenience of the staff.

> One day I said, ‘Take the boys out. Just take out Dan and Joseph, which he did. He went to McDonalds and he came back to the house quite chuffed that he did that. He’d never done that before. He’s from that group [of staff], they go out on bus trips they take everything with them, drink, biscuits. [At Kew the staff] wouldn’t go out for lunch because if they went at lunch time that means they would have missed out on their lunch. So they might go at ten o’clock or half-past ten after the staffs had their morning tea, and then be back by twelve o’clock because that’s when everybody was going for lunch. (I/SD/021105)

Reflection: Building inclusive communities requires knowledge, skills and motivation

There is no guarantee that any employee, whether they are new, or existing staff who have worked in community-based or institutional settings, will have the knowledge, skills and motivation to pursue the goal of building inclusive communities. House supervisors have a key role in helping direct support staff understand their job and should give direction so that the staff they manage understand and implement policy (Clement and Bigby, 2007). This house supervisor recognises that he must confront staff thinking about their understanding of what he calls ‘social inclusion’ and support and direct them in enabling it. ‘Going out for morning tea’ and eating at McDonald’s are both fine activities, but we would suggest that in the context of this house they are both about community presence and relate to what we have suggested was a dominant form of activity in this house, ‘eating out’. As we shall see, for the first 15 months that the house was open, the prevailing direction set by the house supervisor in relation to the goal of building inclusive communities was activities that supported community presence.

Community presence: A trip to the shopping centre

A separate report describing the interactions and styles of support between staff and residents in the house is available elsewhere (in Clement et al., 2007). In the initial report we usually only described what we had observed as a means of trying to encourage people to learn through reflection on their own practice. Some of the data related to ‘activities outside the house’ is repeated here, so that we can provide a more detailed critique.

The extract that follows, of an outing to a nearby shopping mall, is typical of the pattern of support that the residents received to participate in activities outside the home.

> We are going out. It is a hot day. The top temperature is forecast to be 31 degrees. Simon changes some of the men's clothes. Milan is wearing blue shorts, a blue and green Diadora t-shirt, white Nike pumps and white socks. Wally is wearing a pastel green short sleeved shirt, putty shorts, blue and white trainers and socks. Dan has a Slazenger t-shirt which has cranberry, black, and white stripes, blue jeans and brown boots with three Velcro fasteners (F/PL/021105).

The house supervisor placed a strong emphasis on making sure that the residents were dressed in a manner that is valued by other people in the community when they go out[12].

> The presentation of the residents flows on to everything we do. There are times where you can be a little bit relaxed, once the fellas are active in the community. Whether at the day program or going out to have a coffee around the corner it's all about their presentation and about their grooming. I think that's important to us as carers because that says if we take a little bit of extra time and care about the individual's grooming we care about them. That's been one of the things that I've been focused on. We still haven't got it right but we're getting there. I think it's important to make sure that we do that because when an individual goes into the community and they're not well dressed they could be standing next to somebody who looks just the same as them but because they have a disability that's honed in on very quickly. This is my view and people look at them and say look how shabby they are. That's how I look at things, we have to be quite conservative about how our residents dress. (I/SD/021105).
>
> Shelagh carries some money for the men. $5.00 each. The seven off us set out from the house at about 11.30. Shelagh walks in front holding Milan's hand. Simon suggests that I go in the middle as he is walking with Dan, who is the slowest. Wally walks by himself. Joseph wants to hold my hand. I let him do this some of the way, but as I have seen him walk around the block, I know that he can walk on his own.

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[12] This is consistent with guidance given in the Direct Care Staff Handbook (Department of Human Services, 2002) and Normalisation (Wolfensberger and Thomas, 1983).

We turn left into High Street. At the pace we are walking it would be at least 30 minutes to the bus stop. After ten minutes Simon decides we will catch the tram, which will takes us to the Swaffam shopping centre. It is very hot in the full sun. None of us have any sun cream on or sunglasses. No one has a hat. We cross the busy High Street. This takes quite a while to do as there is no pedestrian crossing. The road up to the tram stop is steep. Twice on the journey Milan sits down on the pavement.

After another ten minutes we near the tram stop. We miss a tram by a minute, which means that we have ten minutes to wait for the next one. There is a shelter that we can sit in. The tram is busy when it arrives. We do not need to purchase tickets. A man gets up for the residents and goes to the other end of the tram. Simon sits with three of the men. Milan sits next to a man who greets him and opposite two other people. Shelagh stands up. When someone moves Shelagh sits opposite Milan and the man and woman talk to her.

When we get to the shopping centre we are taken to a café/juice bar. The four men are seated around a table and Simon and Shelagh go to the counter. They come back with four identical drinks (orange-based drink) and doughnuts. I go and order my drink.

The seating area is quite tight, so Shelagh sits at a different table. Joseph clutches his trousers in the groin area. I confirm with Shelagh that this is his sign for wanting to go to the toilet. I take him to the toilet. We end up in the parent and child/disabled toilet.

Linda, who is working later that afternoon, passes the table where we are sitting and talks to Shelagh. Shelagh goes and buys herself a sandwich.

Simon and Milan go into the supermarket and come out with the trolley containing half-a-dozen plastic bags, containing mainly milk and bread. People are given a bag to carry. Milan refuses.

We go into K-Mart. Wally and later Dan take it in turn to push the trolley. The seven of us head off to the men’s shoe department. Simon wants to buy Dan some shoes. After trying on some shoes we go to look at the clothes. A number of items are put in the trolley, but I have no idea who they are for. They are mainly t-shirts and shorts. The four men are not closely involved in any decisions about what to buy. Joseph gestures at all the clothes as we pass them in the aisle. Caps are placed on Dan’s head. Shelagh and Simon debate whether a Holden or Jim Beam logo is

> preferable. Neither of these caps is eventually chosen. Hats are placed on Milan’s head, but he takes them off and pulls a face. He does not like wearing hats. Wally wanders off several times and people raise their voice to get him to come back.
>
> In the queue at the checkout Simon pays for the items in the trolley. Wally has wandered out of the store and is making his way onto the pavement. I hurry to him as he wanders out into the car park. (F/PL/021105).

Reflections on the outing

By referring back to concepts presented in the training (Figures 6 – 8) it is relatively easy to make a case that this is ‘community inclusion’. The four residents have been supported to use services (public transport, a supermarket) and access leisure activities (a café, clothes shopping), which we might safely assume they are interested in doing. Using the tram may be a new experience and the mall was place they had visited before. The house supervisor had tried to ensure that the men have a good chance of being seen as valued members of the community by being smartly dressed and they had met people whilst out.

On the other hand there are a number of cues that suggest that the four men may not be seen as valued members of the community and are on the margins of the experience. This is what we meant when we stated earlier that it is important to reflect on what people are doing and how they are being supported whilst they are using ordinary places. Some of these will be more obvious to readers with greater experience of working in services for people with intellectual disability.

The entire activity is reminiscent of ‘block treatment’, a term used by Goffman (1961/1978), where activities take place in the immediate company of other service-users, all of whom are treated the same and required to do the same thing. The activities were planned by the staff. A group outing was arranged for everyone; the four service-users were sat at the same table, and were given the same food and drink. Staff held the men’s money, decided what they should eat and drink, chose what new clothes were more suitable, and paid for all the items. Opportunities for more meaningful interactions between café and K-Mart employees were lost. Although there was some interaction between a member of the public and Milan, most of the conversation on the tram was between staff and other passengers. The longest interaction was with another staff member who happened to be doing her own shopping in the mall.

The men were going shopping, when most men of their age are at work. They were excused from buying a ticket on the tram. Even with clean, smart clothes the men look different and behave differently. They have the stigma of disability. Some of the men were escorted hand-in-hand, Milan sat on the pavement, Joseph used a special toilet, and the support staff raised their voices when Wally wandered off.

In an interview that I subsequently conducted with Simon, he commented on some of the interactions that he'd had during the outing, which indicate some of the general public's attitudes that the staff encounter:

> It was interesting today that one of our senior citizens was next to Shelagh and when she got up and went into the shop she said something like, 'You're wonderful' and 'God love you' or something like that. When I was at the check-out the young girl said, 'It must be a rewarding job'. You don't often get that. On the tram, as we were getting in, Joseph balanced and put his arm on another fella. I was quite surprised. The fella would have been in his mid-fifties. He got up for Joseph and I said, 'Thanks'. There was enough room to sit down. 'No, no, no, I'll go down the other end' he said. So he got as far away from them as possible. He was right down the other end of the tram. Those sorts of things you experience. (I/SD/021105)

There are two points worthy of note here. Firstly, if you have worked with people with intellectual disabilities for any length of time it is likely you will have been talked about as a 'saintly' individual doing a wonderful, worthwhile, rewarding job, which unfortunately positions people with intellectual disabilities as the object of your 'saintliness'. You will also have experienced what can only be interpreted as a 'negative' response or attitude to people with obvious disabilities, which is, as the house supervisor describes, to shun or move away from them. Some members of the Australian community will hold negative ways of understanding disability (see Yazbeck, McVilly, and Parmenter, 2004), which can result in extremely unpleasant experiences for people with disabilities and those who support them. As we stated in Chapter 3 the goal of building inclusive communities is taking place in a 'disabling society' where some non-disabled members of the Victorian community have indifferent, negative or hostile attitudes towards people with intellectual disabilities.

The attitudes of non-disabled people

In the interviews staff expressed views which identified the attitudes of non-disabled people as a barrier to the goal of building inclusive communities.

> I think there needs to be more public recognition. There needs to be more acceptance of somebody with a disability. I believe the development of a

> person with a disability, whether physical, intellectual, or even mental illness is in the hands of the ignorant. Until we are able to establish a better education for the general community, those with disabilities will always struggle with acceptance. (I/SD/021105)

> A lot of people in society don't know a lot about these guys, that there's nothing to fear, when you do see someone, just a smile or say hello or something, instead of being negative. Smile, be positive. Talk a bit about tolerance and acceptance. (I/LW/102605)

Identifying indifferent or negative attitudes within 'the community' as a barrier to the goal of building inclusive communities was a theme that the staff returned to throughout the research. Whilst it obviously is a significant problem, there are a number of important issues about the way in which staff frame and react to people's attitudes. Firstly, do staff see themselves as having an active role in educating the Victorian community? Secondly, what impact does having direct experience of indifferent or negative interactions have on staff's perception, willingness and motivation to build inclusive communities?

Family attitudes to building inclusive communities

Family members were asked what the goal of building inclusive communities meant for their son or brother. This relative begins by suggesting that, in general, the goal is good, but then adds some qualifiers when he thinks about his bother and people with challenging behaviour.

> I think it's good. There's more of that happening….If you took Franco into a crowded supermarket, somebody who doesn't like crowds, there's no real satisfaction for Franco. I think it's got to be positive for both sides. I've known experienced [staff] taking people into supermarkets and they've thrown things and I don't think that really helps at all. I think that outings or doing things, even just going for things like walks, it's got to be more of a focus on what's good for Franco. If it's good for society it's good, but I think the focus has got to be more on them. (I/FI/121205)

This relative, who has a visual disability, talks about his own mixed experiences and expresses his belief that variable attitudes to people with disabilities will always be an enduring fact of life. He also highlights an important point for people with an interest in building inclusive communities, which is supported by research evidence, that direct experience or familiarity with people with intellectual disabilities, whether mild or severe disabilities, is related to more favourable views of people with intellectual disabilities (Antonak and Harth, 1994; Antonak et al., 1995).

> I find meself, with my disability, some people are accepting, some people make a wide track of you. I think that'll always be the case. Some people accept it, they understand. It's mainly people who have had a lot of dealing with disability, or seen it, or seen someone or knows someone. People who've never had any dealings, or any knowledge of it, usually are very sceptical about people who are like that….They'll always be some people who won't accept it, but generally now people are starting to accept disabilities in the community, 'cause I think there's more made of it, through media and papers….Many disabled people come into the shopping centre round here. They do their shopping and everybody's accepting. They'll be the odd one that stands there watching them and wondering. (I/F2/0712105)

Drawing on her own experiences this mother has encountered variable attitudes and expresses a cautious view about building inclusive communities.

> We've had Down's syndrome kiddies been brought to church and things like that. I'm sure they don't understand it, they just wander around. Not very many people will accept them, some do, but not very many. It's not an easy thing. I see them around the shopping centres…I don't know, I really don't know whether that will work. (I/F4/061205)

In contrast, this relative has an upbeat perspective, a vision of how things might be, and emphasises the 'people first' and 'ordinary life' perspectives that were described earlier.

> I viewed [closing Kew] as a really good thing, mainly for the reasons of getting people with disabilities out into the public life, everyday normal living, not in an institution type setting….Putting people with disabilities in a house, an everyday street in an everyday suburb and getting them out into the public life will help. People will understand that they're no different to us. They may look different to us and they may have different actions to us, but inside, they're no different. I think this will help to educate a lot of people out there. I see them all the time, they stand out on the tram or on the bus or in the shops….What I would like to see is the neighbours in the street just pop-in for a visit. Don't just close your eyes and walk past that place, pop-in and say 'hello', find out some more information about the staff and the residents….Even if you only do it the once and it freaks you out and

> you don’t want to do it, but at least take that first initial step to see that these people live in this house, everyday normality, there is no difference in living in your home. I’d like to see a lot of people trying to understand and see these people are [like] us. (I/F5/071205)

Only in this final extract is there a sense of community participation, the hope that neighbours will ‘pop-in’ to the house where her brother lives and spend some time with him and the other four residents. All the other examples are much more indicative of community presence — supermarkets, shopping centres, outings, walks, and public transport. The church is an interesting addition to the list of settings that people have mentioned to date, because churches have often been singled out as places where an ‘inclusive communities’ are more likely to be realised (Walmsley, 2006)

Yet when people were probed specifically whether they thought it was possible that their son or brother might develop friendships with non-disabled people, that is, community participation, the answers were much more consistent and definite.

> 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? I don’t know, it depends. Someone with no communication skills, no verbal communication skills and things like that, that’s more…maybe voluntary people assisting? I think that’s just the way society is. But it may change I don’t know. We can have too high hopes. (I/FI/121205)

> I don’t know about that. I don’t think it will ever come like that….It’s hard to see that happening. It could I suppose….Our own family don’t visit him. I’ve got two boys don’t visit. (I/F3/0712105)

> No, I can’t see that, I can’t see that no. Not with any of the boys really….I think it would be pretty hard, unless people’s ideas change, which they will in the future, but it’ll be probably too late for people like Dan and Wally, maybe other people with disabilities younger….It would be nice, it would be really good wouldn’t it….I’ve got two other brothers don’t visit. They’ve got their grandchildren and what have you. They don’t see him as a person. He’s just one of these people with a mental illness, he’s away somewhere. (I/F3/0712105)

> It don’t think it’ll happen in my life time. (I/F4/061205)

Our evaluation

During the evaluation phase we had already begun to use O'Brien's (1987) distinction between community presence and community participation as an analytic framework to categorise the type of activities the staff group were supporting outside the house. We also thought it would be a useful framework that would allow us to direct staff to two facets of an 'inclusive community'. As we came to the end of the evaluation phase our judgement suggested that at 64 Penny Lane the staff focus had been on increasing the number and variety of ordinary places that the residents know and access. This is an important part of building inclusive communities, but one that on its own is unlikely to achieve community participation.

As the more extensive analysis of the trip to the shopping mall suggests, we thought that there were a number of practices that could be the focus for reflection and might form part of an action research project. Yet we were also concerned that the staff group might suggest projects that were not entirely compatible with our view of what was important. We certainly saw the issue of being able to take all five men out as a group as a low priority and a practice that would maintain or strengthen the 'distinct social space' occupied by the five residents.

Prior to the reflective meeting with the staff group the house supervisor identified 'Community activities and joining social groups' as the issue for discussion and action planning. By this time the men had been living in their new home for seven months, which was also seven months after the social inclusion training and three months after the one-day workshop. In preparation for that meeting we prepared an appraisal of staff practice and outcomes for service-users relating to this specific issue. The half-day meeting was held with seven staff members. All the family members we had interviewed were invited to participate in this day, but none did.

The reflective meeting

The half-day was based on a strategic planning process, using the five questions in Figure 9.

Figure 9. Five questions

- Where have we been?
- Where are we now?
- Where do we want to get to?
- How will we get there?
- How will we know when we have got there?

At the half-day meeting the staff group generated a list of the ‘community activities’ that they had supported since the house had been open, which reflects the pattern we have described. Table 6 groups these activities into rough clusters.

Table 6.
Activities outside the house as community presence (F/PL/030206)

Bus trips	Walking from the house	Community services	Shopping
• The beach at Ocean Grove • The airport • Phillip Island • Healesville • City (Federation Square) • Walking • Cinema • Dining out (Cafés, McDonalds, takeaways, Fasta Pasta, Smorgy's) • Barbeques • Christmas lights • Community Residential Services (CRS) Christmas party • DHS office • Visits to other CRUs and residents and friends[13]	• Walks around the block • Arthur's creek	• GP • Dentist • Hairdresser • People have also been on the tram	• Safeway • K-Mart – clothes shopping • Shoe shopping • Christmas shopping • Clothes shopping

Most of these activities support community presence. Going for a trip to the Healesville Sanctuary is an ordinary community facility, whereas a visit to another group home is an activity in part of the service system, i.e. neither community presence nor community participation. The possibility of forming close friendships with non-disabled people is unlikely as a result of participating in any of these activities. It is possible that acquaintances can develop by repeated use of the same dentist or hairdresser, which would be a form of community participation, but for most of the activities the end result was more likely to be community presence.

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13 Community Residential Unit (CRU)

It was only after the staff had answered the first two of the five questions (‘Where have we been?’ and ‘Where are we now?’), that we presented our analysis and introduced the definitions of community presence and participation.

We also used the half-day meeting as a place to validate or invalidate our analysis and interpretation of the fieldwork data (Creswell, 1998). The summary below, about which there was general agreement, has been adapted from a document that was written for the staff group following the half-day meeting.

> At a broad level the pattern of activities supported in the house was similar to that established at Kew. Groups of people left the house with staff to undertake an activity, which resulted in community presence. The biggest different 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. Given the degree of intellectual disability these activities were primarily determined by staff, and the staff interpreted the residents’ reactions to these activities and inferred likes and dislikes. After seven months, the move to the house had given the five men greater community presence. (Clement, 2005b)

As was stated earlier, the meeting was also a place to agree on the definition of the principal issues about which action would be planned and taken. This relates to the third question, ‘Where do we want to get to?’ Answering this question relied on the people in the room reaching consensus about the goal to be achieved. This was something that we were unable to do and so we reached something of an impasse in being unable identify a research goal and then plan how to reach it.

The fieldnotes from the half-day meeting reflect many of the issues that we have highlighted to date (F/PL/030206).

- The goal of building inclusive communities is not clear. ‘Linda questioned if community inclusion was really what the Department wanted’. ‘But how do we do it? We need to hear from someone who is doing it then we can understand’.
- Building inclusive communities was not really practical for this group of men and Franco in particular. ‘One staff member commented that we cannot expect much from these men because of the time they have spent in institutions. Easier to have inclusion with the next generation’.

- People gave examples of the men's behaviour that the non-disabled public were likely to find disconcerting. 'I took Franco out and I was trying on shoes. While I was doing that he was piddling'.
- A prerequisite to building inclusive communities was changing the negative attitudes of the Victorian community. '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' '.
- There were some suggestions that some of the men had to 'be made ready' before the task of building inclusive communities could begin. 'We try in the house with Franco to get him to sit at the table, eat properly and not steal other people's food'.
- There was evidence that some staff over-estimated the residents' degree of comprehension of speech. 'At the weekend we went to watch the planes come in at Tullamarine. Wally has a plane on the wall. We talked about it first. If there had been any negative response we wouldn't have gone'.
- The staff had found out information about specialist leisure facilities and were planning to use them. 'We got the Rec-Lines newsletter and thought about one resident going to a disco at the Oakleigh Centre, but we didn't quite get there'[14].
- An emphasis on trips out for all the residents. 'Usually everyone goes out. If we are going in the bus I take all the boys'. 'Bus trips are the whole family'.
- A view that the group of residents belong together and so there is no need to look elsewhere for relationships. 'The boys like going out together. They're very comfortable with each other. Joseph helps Dan. Franco helped Wally at the weekend when he was slow'.
- Lack of a common vocabulary. 'I see community presence as the guys just following us around at the supermarket. Participation is pushing the trolley'.
- Outright opposition or challenge to the goal of building inclusive communities. 'I don't really agree with it. Like getting the guys out in the community where everyone can see them'. 'They don't need to contribute to participate. They can just be there, absorbing what is around. I don't think there is a big push to participate. I'm not going to push them to contribute'.

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[14] Rec-Line is a 'supported recreation, leisure and holiday service for adults who have an intellectual disability' (Oakleigh Centre, 2006).

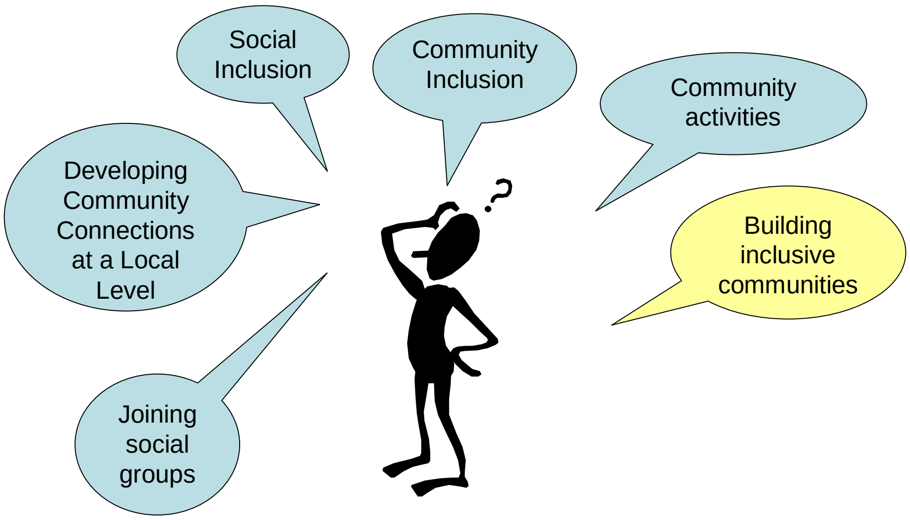
- A sense that the idea of building inclusive communities could not really be taken seriously. ‘There was some laughter and jokes about the possibility of setting up a yoga class at the house and asking the neighbours to join in. Milan could lead it, someone else could open the door, etc’
- The staff group were content with the general pattern of activities that they had established to date and saw this as building inclusive communities. ‘They’re always happy and chirpy when they come back from the bus’. ‘We took the men to see Christmas lights. Joseph really enjoyed this’. There was no need for a major overhaul of what they were doing, but simply to do more and newer activities. ‘We need more of the same things we are doing’. ‘More activities and new activities. As we learn more about the guys we can do different things’.

The meeting concluded on this impasse, but with a commitment to follow through on the discussions we had started.

Final reflections on Phase 2

Drawing out any differences between the different ‘inclusion’ buzz-words is an important task. Figure 10 shows a handout that was given to the staff group, which lists some of the terms that were being used to this point. It should be noted that from our observations the State Disability Plan had been little referred to by the staff group, and only passing reference had been made to it at the formal training.

Figure 10. What are we talking about?



It seemed to us that staff tended to see these terms as interchangeable and they were understood as only referring to the types of activities they were supporting and wished to do more of. The introduction of O'Brien's (1987) distinction between community presence and community participation confronted their thinking about the goal of building inclusive communities, which resulted in some mild conflict between ourselves and the staff group about the goal to be achieved and a degree of defensiveness about their practice.

We believed that their emphasis on creating community presence alone was unlikely to achieve the goal of building inclusive communities. This would require the staff to supplement this aspect of their work with supporting community participation. The point was made to the staff group that if we want people with intellectual disabilities to have the possibility of having close friends with non-disabled people, then it is important to look at the type of activities people were being supported to do.

9. Phase 3: Implementing the Community Inclusion Framework

In the end, the impasse over a suitable research goal was not overcome by arriving at a consensus through dialogue, but through the intervention of another Department of Human Services' employee, the Community Inclusion Officer (CIO). This post was created to enable people with intellectual disabilities relocating from Kew to 'make the most of [community inclusion]….and establish themselves as members of their local community' (Warren, 2005, p.1). As we were negotiating a way forward with the staff team, the CIO was making plans to implement a program known as the Community Inclusion Framework at 64 Penny Lane (see Leatherland and Warren, 2004).

Action research is well-suited to such 'messy' real-world situations (Robson, 1993) and it was agreed that the action research project should merge with the implementation of the Community Inclusion Framework. A consequence of this was that the action research agenda shifted from one that would emerge and be negotiated by the staff at 64 Penny Lane, to one where the issues were already defined by the aims of the Community Inclusion Framework. This decision marked the point where we moved away from hoping to employ an empowering conceptualisation of action research to adopting an organisational action research framework. In this 'type' of action research the aim is to try to change staff practice towards predetermined aims that have been set by senior managers (Hart and Bond, 1995).

This reduced the staff group's role as 'researchers', and the research project became a collaborative process between the authors. The CIO and the researchers were in agreement that building inclusive communities requires expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people, and so this became the research goal. Given that another goal in the State Disability Plan (Department of Human Services, Victoria, 2002b) is pursuing individual lifestyles, the focus for planning and taking action was based around each individual resident at 64 Penny Lane, rather than combinations of the men as a group.

Although there had been some changes in the structure surrounding the goal of building inclusive communities, (as another employee was driving the Community Inclusion Framework), the potential for 'conflict' remained. This was because the staff group retained the major role in implementing the Community Inclusion

Framework and they needed to buy into the research goal. The issues that we highlighted in the last chapter still had to be addressed by the CIO.

This phase of the project ran for seven months. During this period seven meetings were held with various members of the staff team, mainly using the rostered house meeting, and three reflective meetings were held between the CIO and a researcher. Three sources of data are used in presenting and discussing the findings in this phase: the fieldnotes that were kept of the meetings, a diary of the activities that residents took part in, and documents related to the Community Inclusion Framework (see Forster, 1994).

Outcomes of Phase 3

We want to begin by revealing that over this seven month period there was little change in practice at 64 Penny Lane that can be attributed to the implementation of the Community Inclusion Framework. Having done this we move on to describe some of the interventions that we made, present some of the qualitative data that we collected, and share some of our reflections about why this might be the case.

Eight weeks after the CIO's first meeting with the staff group they were required to complete a 'diary' of the residents' community-based activities on a form known as the Activity Learning Logs (Appendix 4). The aim of completing the logs was to:

- Document the types of activities occurring within a person's life.
- Gain a better understanding of a person's interests and choices provided.
- Share lessons and receive feedback from staff and the person.
- Incorporate this information into Person Centred Plans (Warren, 2004/2006,).

It was also hoped that the logs would help staff to plan and take action. It states on the Activity Learning Log that the information it collects should, '[allow] support providers to continually fine tune their information and plan differently'.[15]

Figure 11. Steps in using the Activity Learning Logs.
Adapted from Warren, 2004/2006

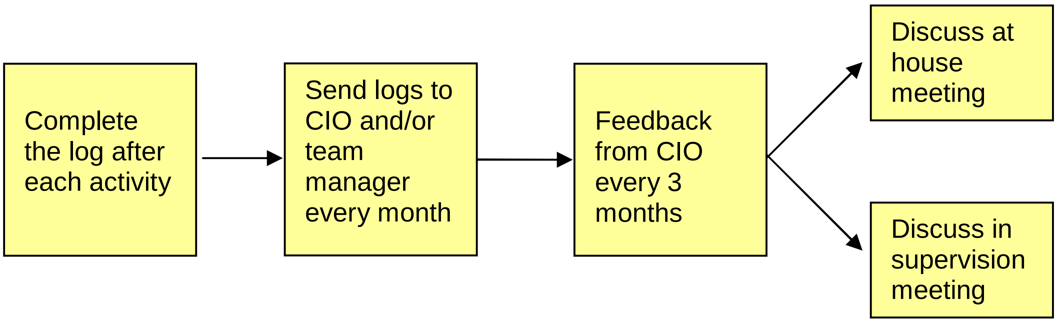


Figure 11 also highlights two important management forums, planned formal supervision meetings and the house meetings (Sines, 1992). These are spaces for the house supervisor to review how staff are doing, reinforce desired practice, and keep direct support staff 'in touch' with the aims of the service.

The information collected through the Activity Learning Logs allowed us to compare the pattern of activities at the end of Phase 3 (Time 2) with the pattern of activities that had been described seven months earlier at the half-day meeting (Time 1). The data from Table 6 and the Activity Learning Logs were categorised as community presence, community participation, or 'other'[16]. Figure 12 displays the 24 activities that were identified at the half-day meeting and the 52 activities that were on the Activity Learning Logs.

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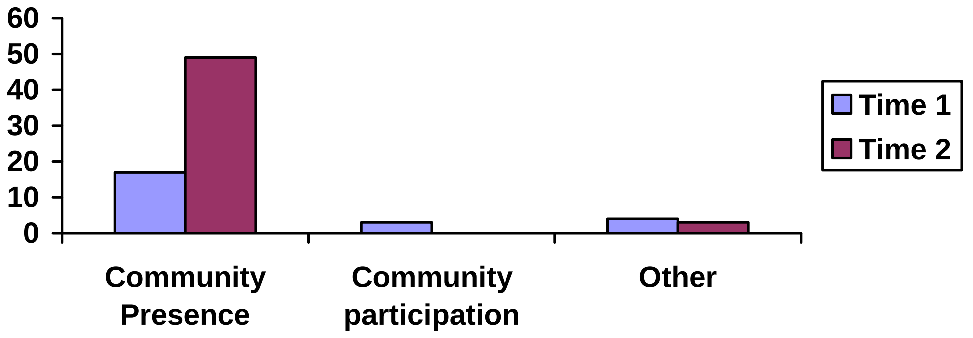
[15] Our reflections about this process suggested weaknesses that needed to be addressed in any revision. Our view was that in the long-term it was unsustainable for the CIO to be responsible to take the lead in analysing the Activity Learning Log data and giving feedback. As well as there being too much data from too many houses, the emphasis must be on staff within the houses analysing the data. An important quality of feedback is that it is 'timely'. Three months is far too long to wait for feedback, especially if people are filling in the forms incorrectly, or supporting 'questionable' activities. The onus is likely to fall on the house supervisor, with the team manager having a monitoring role, but this responsibility could also be delegated to competent keyworkers, who would need to learn how to summarise and ask questions about this data for individual residents. We presented the staff group with a number of examples of what this might look like. See Appendix 5.

[16] 'Other' really refers to activities that might be described as 'segregated'. Thus, in Table 6, visits to other CRUs, the regional office, barbeques at other group homes, and the Community Residential Services' Christmas party were all classified as 'other'.

Figure 12. Graph showing the type of activities supported at 64 Penny Lane at two separate times



Of the 52 recorded activities at Time 2, 15 were ‘bus trips’ (29%), 13 were shopping trips for household items (25%), and 9 were eating out (17%). This supports our earlier statement that eating out was a dominant activity at 64 Penny Lane (See Appendix 6).

We have to be very careful that we do not go beyond what we can reliably say from the data available to us. It is relatively easy to question the reliability and validity of the data. Diary records (the Activity Learning Logs) kept by direct-care staff have been shown to have limitations with regard to accuracy (Joyce, Mansell, and Gray, 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. Similarly, at the half-day meeting, staff may not have recalled all the activities that they had supported.

Yet we think that it is safe to claim that the broad pattern of activities remained unchanged seven months after the half-day meeting and facilitates community presence and not community participation. This is entirely credible and dependable, given the verification processes that are part of the action research methodology. We discussed the findings and the interpretation with the staff team (‘member checks’) and asked for non-confirming evidence (‘negative case analysis’). The staff group agreed with the broad pattern and could not identify an activity that they had initiated which would be likely to result in community participation. This suggests trustworthiness (Creswell, 1998).

We offer some extracts from the CIO’s fieldnotes as a form of triangulation, the process of using data from one source to assess the validity of findings from another source (Brewerton and Millward, 2001). For her first meeting with the staff group the CIO met without a researcher being present, primarily to begin the process of getting to know the five men. The fieldnotes confirm that the activities they supported around Time 1 mirror the activities in Table 6 and these mainly take place in groups.

> We had general discussion of the types of activities the residents have been involved in, these being –
>
> - Going to the movies
> - Playing the organ
> - Various bus trips – getting off the bus
> - Walking around the block
> - Dining out – McDonalds, local cafés, Fasta Pasta
> - Visits to other CRUs
> - Shopping
> - Hairdressers
> - GP
> - Shopping malls
>
> Most activities are occurring with most or all the residents involved. Staff had advised the need to focus on greater 1:1 activities. I asked if there has been any further exploration of individual interests. This is an area that the [house supervisor] would also like to explore, through PCP and IPPs[17]. (F/PL/050406)

At Time 2 none of the recorded activities were coded as community participation, whereas some activities had been at Time 1. Earlier we explained that we classified repeated use of the same dentist or hairdresser as a form of community participation because it is possible to develop acquaintances in this way. Even though these activities were still happening they were not recorded on the Activity Learning Logs, underscoring our earlier point about the limitations of the diary data.

The sections that follow are organised around some key ideas that emerged during Phase 3, which were the result of more rigorous reflection and analysis at its end. Rather than outline how we undertook this analysis in the main body of the report, which is usually of interest to a small audience, some details are given in Appendix 7.

The Community Inclusion Framework

When the CIO began her work at 64 Penny Lane the Community Inclusion Framework had been used and refined in over 20 other houses. It maps out a

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[17] Person Centred Planning and Individual Program Plans.

series of steps that includes training for a staff team, getting to know the residents in the specific setting, and the introduction of some planning and monitoring tools, until the CIO withdraws and hands over the monitoring role to the team manager (Figure 13)[18]. The team manager has managerial responsibility for a number of houses and is the person the house supervisor reports to (see Figure 5).

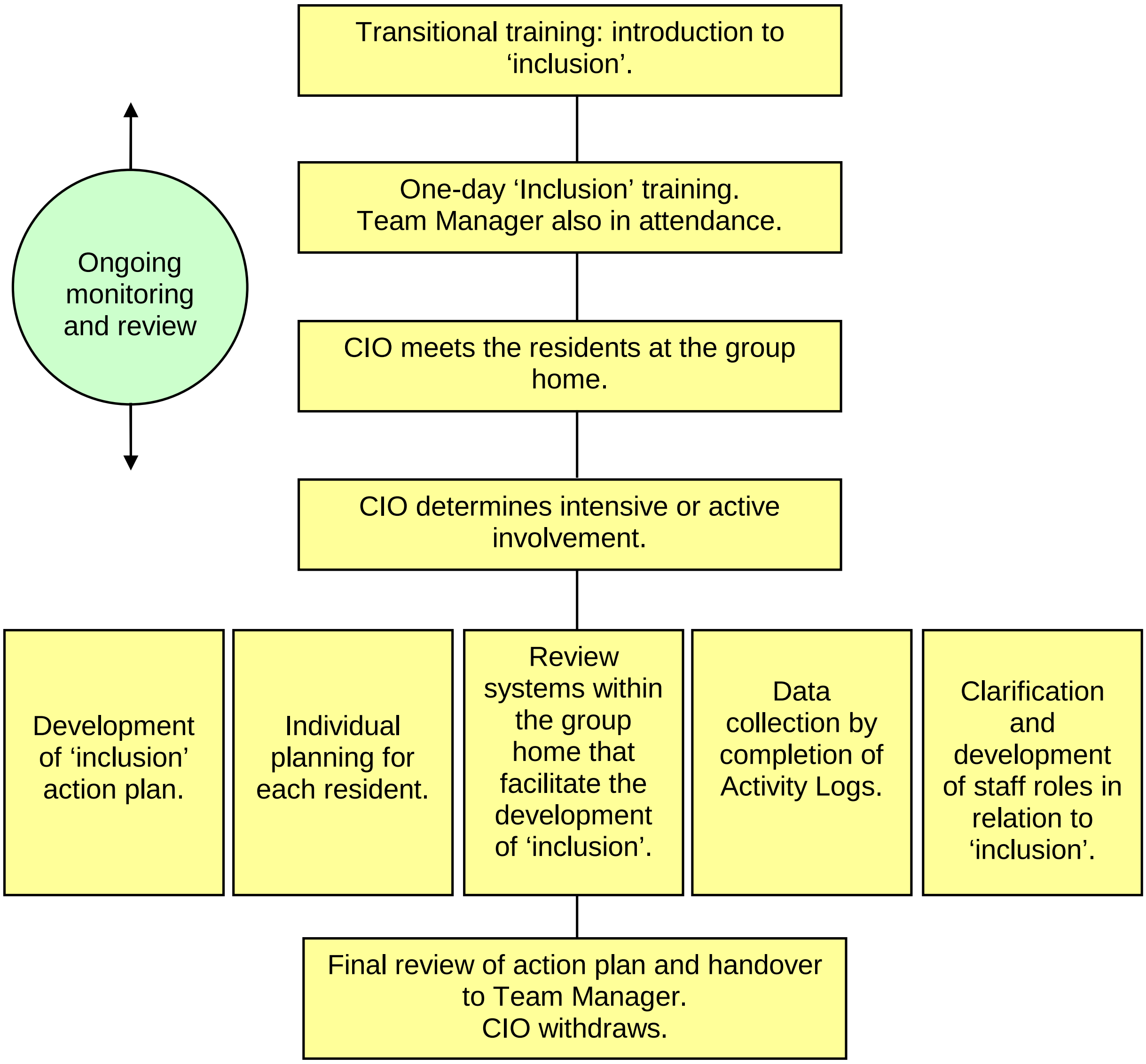

Figure 13. Simplified outline of the Community Inclusion Framework. Adapted from Warren (2005)

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[18] The CIO makes a judgement about whether 'intensive' or 'active' involvement is necessary at a specific house. Intensive involvement requires a greater commitment from the CIO. Her input at 64 Penny Lane was 'intensive'.

9. Phase 3: Implementing community inclusion framework

A difference between implementing the Community Inclusion Framework at 64 Penny Lane and other houses was the presence of a researcher and the interventions that had been made prior to her point of entry. This probably had advantages and disadvantages. The CIO's fieldnotes from her first meeting suggest that in sharing our own ideas about building inclusive communities and introducing the distinction between community presence and community participation we had at least made the staff think about these concepts, with the result that they were less 'certain' about their own practice. This is a necessary step to changing practice.

> Staff discussions were focused on the following –
>
> Staff queried the use of Rec-Line, and community presence vs community participation. (F/PL/050406)

Underlying principles of the Community Inclusion Framework

The Community Inclusion Framework spells out its underlying principles and makes links to key policy documents. The framework is driven by the goals in the State Disability Plan (2002b), especially building inclusive communities and pursuing individual lifestyles. Its espoused principles are linked to the universal concepts of citizenship and rights that we discussed in Chapter 3, regardless of the level of intellectual disability.

> Underlining principles:
>
> - Social Justice principles – People do have a right to live within the community
> - Citizenship
> - A belief that this is possible for all people of all abilities (Warren, 2005, p.1)

Like most of the policy documents that we have referred to, the Community Inclusion Framework does not define 'community inclusion' or what is meant by building inclusive communities, but does state its importance.

> There has also been considerable focus and discussion on community inclusion and how to make the most of this opportunity for individuals relocating from Kew….Moving towards Community Inclusion is a high priority for the redevelopment of Kew Residential Services. It will certainly be considered as one of the measures of success. (Warren, 2005, p.1)

The Community Inclusion Framework makes a distinction between service-based (or formal) supports and natural (or informal) supports. This distinction is important to realising the goal of building inclusive communities, links directly to community participation, and the goal of expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people.

A stated principle in the Community Inclusion Framework is that, ‘There is a need to focus on engagement with families and individual’s **informal and natural support** networks’ (Warren, 2005, p.2, bold added). This language reflects what has been described as a ‘supports model’, a concept that we have not discussed to date. In the next section we outline some of its key elements for two reasons. Firstly, it is a contemporary way of thinking about how to provide support to people with intellectual disabilities. Secondly, it adds weight to the belief that building inclusive communities requires us to move beyond service-based supports, and that using ‘natural supports’, pursuing community participation, and facilitating relationships with non-disabled people are all part of the same general ‘thrust’.

The supports model: Service-based and natural supports

Luckasson et al. (2002) describe supports as, ‘resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning’ (p.145), which can be oneself, other people, technology, or services (Table 7). ‘Supports’ are therefore **not** synonymous with ‘services’.

Table 7

Informal and formal supports (Luckasson et al., 2002, p.155-152)

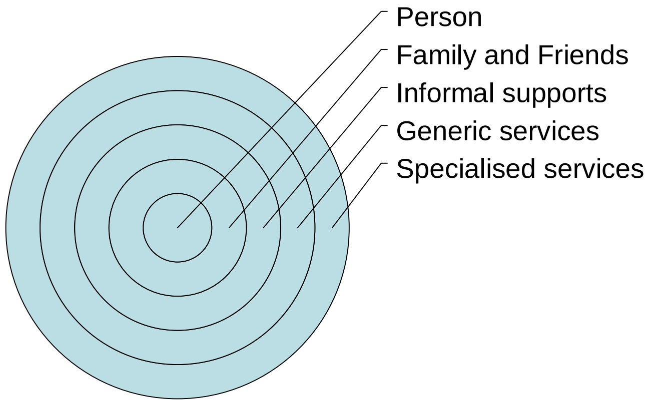
Natural supports	Service-based supports
Resources and strategies provided by people or equipment in a given environment that a) Potentially lead to desired personal and performance outcomes; b) Are typically available and culturally appropriate in the respective environment; and c) Are supported by resources from within the environment, facilitated to the degree necessary by human service coordination.	The same resources and strategies, but are provided by people or equipment that are typically not part of the person’s ‘natural environment.’ Such people include teachers, academically trained and certified health and habilitation professionals, direct-care staff or professionals, and/or paid volunteers.

An emphasis on natural supports represents a move away from service-centred thinking, where the outcome is the maximum use of specialised services. It is service-centred thinking that in part helps to create and maintain the ‘distinct social space’ occupied by people with severe intellectual disabilities, because in an extreme form it excludes the possibility of using natural supports. On the other hand:

> The goal of a supports-based approach is to facilitate the inclusion of individuals in the full life of the community. Appropriate supports lessen functional limitations and allow individuals to participate and contribute to community life while also having their needs addressed in a more typical societal context. (Luckasson et al., 2002, p.183-184)

This way of thinking about ‘supports’ emphasises the person with intellectual disabilities as an individual, rather than one of a group of ‘clients’ using a particular service. ‘The role of public systems becomes one of facilitating society’s responses to individual support needs’ (Luckasson et al., 2002, p.183). This view of ‘supports’ is therefore entirely consistent with the goal of expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people. A person-centred, community-based approach brings family, friends, and informal or natural supports more centre-stage and human service employees have a key role in engaging with them.

Figure 14. The nature of support systems.
Adapted from Luckasson et al. (2002)



An example of service-based and natural supports

At this point it may be helpful to give a concrete example in order to illustrate these different ways of thinking and possible outcomes.

Implicit in an earlier section is that Franco was often supported to go for walks, either ‘around the block’, along the local creek, or taken out in the bus to a place where he could walk. There was a consensus that ‘walking’ was an activity that Franco liked to do, and we used it as an example at the half-day meeting as a possibility for the staff group to facilitate community participation. It became an example that we all referred back to in our meetings.

For Franco, the most likely outcome of his supported walks was community presence. This was mainly because the staff group supported this activity in a service-centred way. A member of the staff ‘took’ Franco on a walk and ‘brought’ him back to his home. Let us also make it clear that Franco seemed to enjoy this and it will remain an activity that staff will continue to support. The use of natural supports will not remove the need for service-based supports.

In the months leading up to the half-day meeting one of the researchers had joined a bush-walking group in the area where he lived, which had a relatively large membership and arranged walks of varying lengths on a weekday and at the weekend. A bush-walking group is a community of interest (see Table 4). We suggested that if a similar group could be found close to 64 Penny Lane, such a group offered a reasonable chance for facilitating community participation. This is because relationships, including friendships, are more likely to be made when people participate in recurring activities where social interaction is high (Lakin et al., 2005). A walking group offers these possibilities. Although a staff member would have to support Franco initially, we could envisage the possibility that in time it might be possible for a member or members of the walking group to support him to walk once a week. This would require the staff members to ‘facilitate the walking group’s response to Franco’ in a way where the support shifted from being service-based to naturally available.

The transfer of training

As can be seen by referring back to Figure 13, by the time the CIO visits a house to begin the process of getting to know the residents, the staff group have completed the two training sessions that were outlined in Phase 1 (Chapter 7). Given that training is meant to furnish employees with the working knowledge to accomplish their roles and improve performance, it is not unreasonable to expect that the staff team will be some way to getting ‘on board’ with the goal of building inclusive communities. They should also have made some progress in using the ‘nine steps’ that they had been given to begin the process of connecting the five men they support to ‘the community’. This particular process model is specifically designed to aid the transfer of training to the job.

Understandings of building inclusive communities

At the first meeting with the staff group the CIO asked those present for their understanding of ‘community inclusion’.

> Simon: I’m racking my brain. We talked about directions with each resident….It’s many things, being included, how you are included. When we first went to the supermarket people stared, now they don’t. There is a good rapport with the hairdresser, he knows people’s names, and who likes the hair-dryers and who doesn’t. When we first moved here the men were intimidated. Last week we wandered around Bunnings. 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….We have discussed one-to-one. On people’s birthdays the men have had individual outings. We have the advantage here that all the men like one another, enjoy one another’s company. Milan can be a bit scared of Franco, but there’s not a ‘big blue’ on the bus. We’re looking at activities for Joseph and Dan at Rec-Line and [the Woodbridge community house].
>
> Linda: At the training we talked about involvement around shopping and dining out weekly or fortnightly. Looking at the guys as individuals, Joseph’s dancing and discos…. It’s been trial and error. Shopping doesn’t suit Franco. We were focusing on bushwalking or orienteering.
>
> Dawn: Contacting Rec-Line…. It’s really broad. It’s not only taking the boys into the community, it’s bringing the community into the boys…. It can be in-house. Slowing down the way they eat, then taking them out.
>
> John: Going down the pub, and having other friendships. Other people besides the guys. A church group… (F/PL/030506)

Reflections on staff understandings of ‘community inclusion’

Not surprisingly, given the complexity of the question, these comments are almost as dense as the ‘terminological forest’ that we presented in Figure 1. The extracts are dominated by activities (such as the supermarket), but these can be in ordinary places or specialist services (Rec-Line). Most of them are outside the house, but one person suggests ‘community inclusion’ can happen in the home. Activities can be based around individuals or groups. They can take place with other residents and other people. What is important is both how a resident feels (‘safe’) and how the other people respond (‘they do not stare’; ‘developing a rapport’). ‘Community inclusion’ is also be explained by another slogan that is equally hard to decipher (‘It’s bringing the community into the boys’). The comments do not provide us with either a working definition or the common vocabulary that we can use to guide us in building inclusive communities. We described our experience of these discussions as a terminological free-for-all, more indicative of the ‘anything goes’ approach. So although these extracts reflect practices that are important elements of building inclusive communities there are also suggestions that create, maintain, and strengthen the ‘distinct social space’ that the residents live in.

The State Disability Plan: The community of our dreams

A point that we have made repeatedly throughout the course of Making Life Good in the Community is that the Department of Human Services produces numerous documents that inform employees about practice standards and desired outcomes for service-users. We do not want to overplay the importance of the State Disability Plan, but it is a significant document in attempting to define what the future might look like for people with severe intellectual disabilities, and does contain the goal of building inclusive communities. We see it as the work of the staff team to make the State Disability Plan the day-to-day reality of people’s lived lives; led and managed by the house supervisor.

At one meeting the CIO asked the staff group why the State Disability Plan is an important document.

> It keeps us in line, influences what we do, and where we are going. (F/PL/030506)

The reality was that there was not a copy of the plan in the house and the staff group were unfamiliar with its content. Summary and full copies were left for the staff group to read for a future discussion. The staff group’s subsequent reaction to the plan suggests that it offered the staff group little motivation to strive for goals that they perceived as being unrealistic and unobtainable (see Proehl, 2001).

> Linda said she did not believe that by 2012 that things would be ‘hunky dory’.

> People suggested that if 'will have to involve the whole of society' and that 'it will come from the community'.
>
> Martin said that he had taken Joseph and Dan to a restaurant.
>
> Dawn had done a unit on the Certificate IV course about the State Disability Plan. They had been given the information on the plan and asked what they would change. She remarked, 'The issues are bigger than the timeframe'.

Some members of the staff group returned to the theme that the indifferent or negative attitudes of the 'Victorian community' were a significant barrier to its success.

> Simon: There needs to be more education. My experience is that the residents are overlooked. People never speak to the residents…. Younger people are more receptive. They don't have fear. They should be educated, throughout the school system….People under twenty-four are more accepting. People can be quite ignorant. A person brushed by Dan and nearly knocked him down. It can be frustrating at times.
>
> Linda: Some adults behave worse than children. (F/PL/310506)

Reflections: On goals, plans and planning

We have focused on the State Disability Plan and the specific goal of building inclusive communities because planning, the process for establishing goals and courses of action for achieving those goals, is one of the cornerstones of modern organisations (Stoner, Freeman, and Gilbert, 1995). However, planning is unlikely to be successful if the people who are charged with meeting goals are either unaware of a goal or attach a different meaning to it.

Although the State Disability Plan was published in 2002, until the intervention of the CIO the staff group were generally unaware of its specific content. In such circumstances it is unlikely to keep the staff group 'in line' or influence staff practice in the way that one staff member suggested. We would also suggest that the training had not imparted a common understanding of what is meant by building inclusive communities. This may not be surprising given its contested nature, but this questions the value of the training if staff are not leaving with skills, rules, concepts, or attitudes that result in improved performance (Goldstein and Ford, 2002). We have tried to show that following the training and considerable input from us there was still an 'anything goes' understanding of the broad goal of building inclusive communities.

9. Phase 3: Implementing community inclusion framework

It seems probable that the absence of a common vocabulary and shared understanding of the Department's goal is a major obstacle to building inclusive communities. Fournies (1988) identifies a number of reasons as to why employees do not perform in the way that managers want them to. Two reasons are relevant here. Firstly, employees do not know what they are supposed to do. Secondly they think they are doing what they are supposed to be doing. Lack of a clearly articulated and communicated goal accounts for the first reason, and inadequate feedback in relation to the goal for the second.

These reasons could not really be said to apply to the research goal. 'Expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people that include the possibility of making close friends' seems reasonably clear. What may be less clear is how to achieve this goal, but this reflects the appropriateness of the action research methodology, where the intention is to bring about a situation that is congruent with the value position (McNiff et al., 1996). Our feedback had also made it plain that the staff group would have to supplement their efforts to support community presence with supporting community participation.

If the goal is clear, then there is a further reason why any planning that is done in relation to it is unlikely to be successful. It is this: People disagree with the goal (Fournies, 1988).

Our appraisal of staff practice, together with the space to reflect, was an opportunity to share assumptions about ways of thinking and acting in relation to this goal (Coghlan and Brannick, 2001). This reflective space allowed people's beliefs about the goal to be publicly aired and brought to the surface a range of attitudes and values that impacted on it. As we suggested earlier, the staff group might be able to agree that building inclusive communities is a laudable over-arching goal, but they may only act on those elements that they believe to be important and understand, such as community presence. They may not believe that it is practical or important to facilitate relationships with non-disabled people for the five men at 64 Penny Lane. It seemed to be the case that that during this phase we did not get the staff group to buy into the goal of expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people.

9. Phase 3: Implementing community inclusion framework

Planning tools

During the research the staff group were presented with a number of planning tools to help them achieve the goal of building inclusive communities. The Developing Community Connections workshop in particular presented the staff group with the ‘nine step’ process, which explicitly aimed to connect people with intellectual disabilities to ‘the community’.

Six months after the workshop the CIO asked the staff group to produce the booklet with this tool in it, but no one could. One staff member candidly stated, ‘I’m just being honest’ (F/PL/310506). This is more evidence suggesting that a lot of training does not transfer to the workplace or sustain itself over time (Horwath and Morrison, 1999).

By this time this process had been revised to five steps. We chose to radically overhaul this document to produce a new planning tool that we gave the lengthy title, ‘Actions to develop individual lifestyles and build an inclusive community for a person with a disability’ (see Appendix 8).

In producing this document we tried to do a number of things:

- Align the language with the State Disability Plan
- Emphasise an individual focus
- Direct people to take real actions
- Steer staff to facilitate activities that could lead to community participation.

Although the introduction of this tool enabled us to have some conversations around what was required, by the end of Phase 3 it had not prompted any significant outcomes. In part, this was a repeated failure of the staff group to identify suitable activities that might lead to community participation, a task that was left to them. As can be seen, the planning tool begins with a specific activity that the person will participate in.

The important first step

A number of authors have claimed that community presence is a precondition to ‘being part of the community’ (Myers et al., 1998; Rapley, 2000). This claim needs a more thorough interrogation, because we maintain that many activities that can be classed as community presence are highly unlikely lead to community participation. As we stated at the end of Chapter 8, if we want people with intellectual disabilities to have the possibility of having close friends with non-disabled people, then it is important to look at the nature of activities people are being supported to do. A hairdresser may become an acquaintance — someone who has knowledge and experience of his customers — but the relationship is unlikely to grow into intimacy and friendship. As a community of interest, the bushwalking group seems to present a greater possibility of forming close friendships with non-disabled people. We reached a point where some staff understood this.

> I compare walking with a staff member along Arthur's Creek to going out with a walking group in order to ask why we might do the latter.
>
> Linda makes the point, with a smile, that the walking group is about [community] participation. Of course she, or someone adds that, a member of the public might say 'hello' on Arthur's Creek. (F/PL/310506)[19]

In order to make this clear we have re-worked O'Brien's (1987) definition of community participation to distinguish between circumstances when acquaintances are likely to remain as acquaintances and situations where it might be possible to move from acquaintance to friendship (see Figure 15).

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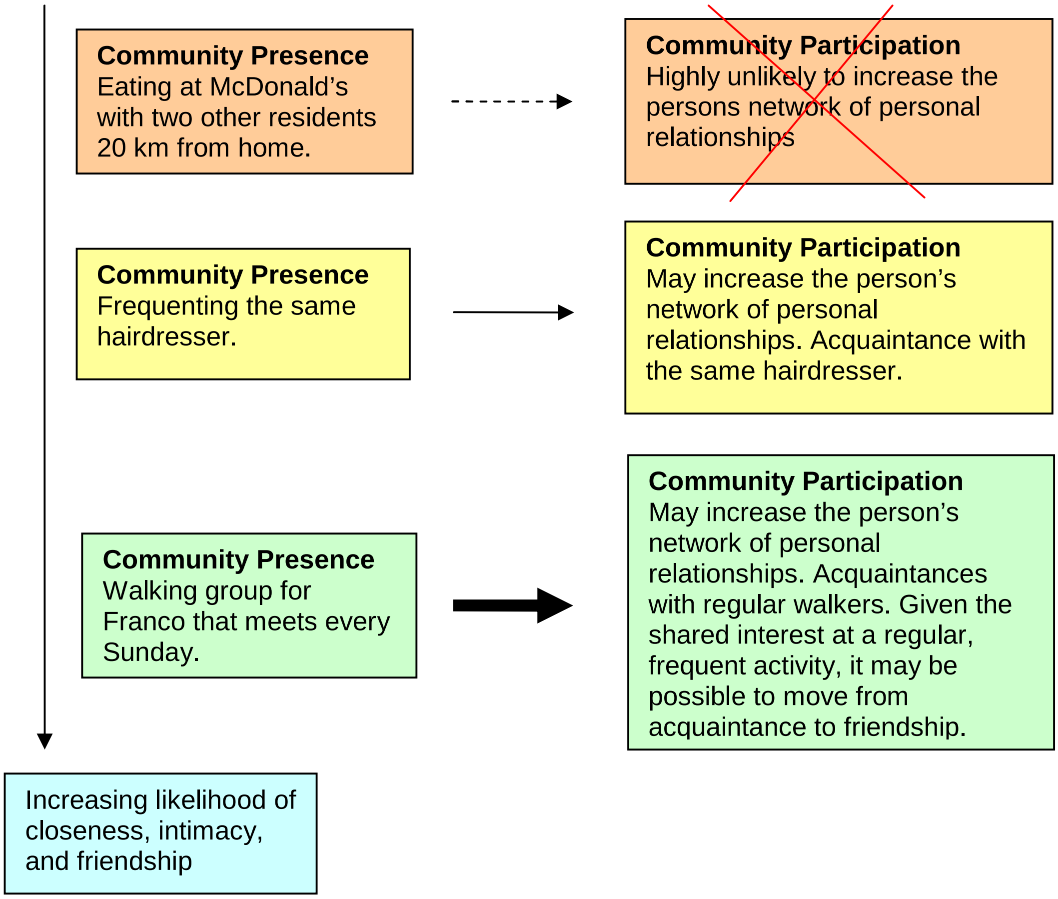
[19] This fieldnote is laden with 'irony' that is indicative of the mild conflict that characterised some interactions and the writer's 'frustration' with how slow progress was.

Figure 15. Possibilities for moving from acquaintance to friendship



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 (P. O'Brien et al., 2005).

Given that people with severe intellectual disabilities rely on the people who support them to identify which community resources they will use, these individuals will need to become good judges of these activities. If community participation is a desired outcome they must learn to select activities where this has a greater likelihood of happening.

Attempting to steer staff towards community participation

The Five-step planning tool started with the question, 'What is the person interested in?' whilst the new tool started with, 'What is the specific activity that the person wants to participate in?' (Appendices 3 and 8). How the 'interest' or ‘activity’ is framed and thought about seems important as to whether the outcome is solely community presence or whether community participation is also likely.

Staff supporting people with severe intellectual disabilities may identify a general interest that is unrelated to an activity (food, trains, swimming) or a more specific interest that is related to an activity (cooking class, train spotting, watching competitive swimming events). If an interest is general, then staff need to think through possible activities where the interest can be pursued.

> We begin to talk about a walking group for Franco. I say that, ‘Walking is Franco’s ‘interest’ and somehow at the half-day meeting we came up with the walking group as an idea where it could be pursued. (F/PL/310506)

An obvious interest that most people have is food. There are various activities that a person can pursue where food is involved — shopping, eating out, cooking at home, a cooking class, markets, food and wine exhibitions, inviting friends for meals. Through a series of directed questions on the planning tool (Appendix 8), we asked people to judge whether their chosen activity would lead to community presence, community participation or another outcome. Even though we were trying to steer people towards activities that might give the five men the possibility of making relationships with non-disabled people, we would return to the next meeting and be met with options that resulted in community presence or ‘segregation’.

This example is taken from a typed document that informed us how some of the staff group planned to implement the goals of building inclusive communities and pursuing individual lifestyles, a task that had been set by the CIO.

> Building Inclusive Communities: Before going out into the community we ensure that the residents are aware of their personal appearance and presentation. Before going out to dinner staff will prompt the residents to ensure that their face, hands and clothes are clean before leaving the house. This helps to promote a good perception from the community about people with disabilities.
>
> Pursuing Individual Lifestyles: We provide and support activities within the community by enhancing the resident’s presence, knowledge and understanding of the particular activity such as shopping for their individual items and identifying what they would like to buy, then paying for these items. This activity is also continued inside the house by the resident then putting their individual items away in the correct place. All aspects of the

> task are broken down so the resident can participate confidently and fully understand the task. The resident's presence within the community is promoted by these activities as it gives the community a chance to see the residents experiencing the same things as the general public and that they are relaxed and comfortable doing so. (F/PL/170706)

The extract specifically refers to [community] 'presence', and two examples from the house's favoured activities (eating out and shopping) are used as illustrations. The idea that the residents' appearance should help them to be valued by other people in the community is put forward, a view previously expressed by the house supervisor (Chapter 8). Rather than any interaction with members of the public, their role is to passively watch people with intellectual disabilities being 'part' of the community.

Identifying interests

Our own experience suggests that services have numerous ways of recording people's interests, likes, and preferences. We have seen specific documents such as strengths/needs lists, likes/dislikes lists, assessments, and more global documents like GSPs, IPPs and PCPs[20] that list specific objectives or goals. We tried to avoid creating another list, but directed staff to places where this information ought to exist.

We sought to use language that was more aligned to working with people with severe intellectual disabilities, who typically have poor receptive and expressive communication. We have already suggested that there was evidence that some staff over-estimated the residents' ability in this area. The men at 64 Penny Lane are unable to give their 'view' or 'opinion' about an activity. They may react to an activity, and it is from that reaction or behaviour that we infer that they want to participate in it, have an interest it, or seem to show a preference for it. We thought it was important to underscore the reality that it was staff who were taking the lead in making these decisions. Ware (2004) makes the important point that, 'The ability of others to 'read' the expressions of people with profound and multiple learning disabilities correctly has a real impact on their quality of life' (p.177).

The men at 64 Penny Lane could not be asked to verbally generate a list of activities that they liked doing and would be unable to choose one activity from even two choices that were offered verbally. The Triple C (Bloomberg and West, 1999) communication assessments suggest that one man might be able to be

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[20] General Service Plans, Individual Program Plans, Person Centered Plans

taught to make a choice between two photographic representations of two activities taken from a larger list that had been developed by a keyworker[21]. However, the most likely scenario for all the men was that a keyworker could generate a list of activities that reflected the men's preferences, but the staff would have to decide which activity or interest to prioritise.

Our experience suggests that, in general, the greater the level of intellectual disability, the harder the task of identifying an 'interest' or 'activity' is. The information about the men that was held in documents at 64 Penny Lane was of limited value in generating a useful starting list of activities. The staff group seemed to have more information in their heads, but even this was restricted. The fact was that even though the staff knew these residents better than anybody, the reality was that they still did not know them that well when it came to generating a list of their interests. In time, if Person Centred Planning is implemented thoroughly, then better activities might be identified that can be used to build each resident's place in 'the community'.

Failure to overcome people's problems with the goal

Over time we were sure the staff group had understood what was required of them. An earlier example suggested that a staff member could see the benefits of a walking group. Although the next example illustrates the forming of an acquaintance, it does show that the participants understood that expanding the men's network of personal relationships was a key part of the research goal.

> Silvia: Why is working through people's interests a good place to start?
>
> Simon: So we can have positive rather than negative outcomes.
>
> Linda: Like Joseph going to the petrol station to buy a magazine.
>
> Silvia asks the group what Joseph would get out of this activity.
>
> Linda: He loves magazines and newspapers. He would get to know the petrol station staff and the neighbourhood. He would say 'hello' to people. In his own way he would end up having a chat. It's getting him out of the house. He would learn the value of money. (F/PL/030506)

The research goal had been stated in a way that was clear to the staff; we had given them some feedback about their performance in relation to it, but we would suggest that we did not manage to address their 'problems' with it. This was particularly the case with the incumbents in two key positions, the house

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[21] A keyworker is a named staff member who has the responsibility for making sure that a particular resident receives a high quality individualised service. This system was not operating in any real sense at 64 Penny Lane during this phase of the research.

supervisor and the DDSO2, best understood here as a ‘deputy’ house supervisor (see Figure 5).

Leadership

In the Community Inclusion Framework it states that, ‘Leadership is required at all levels within the organisation’ (Warren, 2005, p.2). The house supervisor’s post is seen as being a key one in the delivery of high-quality services in any group home, because the biggest influence on how a person actually behaves in an organisation is the ‘leadership’ of the person’s immediate supervisor (Georgiades and Phillimore, 1975).

In a separate report we have discussed house supervisors as practice managers (after Reynolds, 2003) or practice leaders (after Mansell, Beadle-Brown, Ashman, and Ockenden, 2004) who have a key role in supporting the effective performance of the direct support staff (Clement and Bigby, 2007).

The house supervisor was candid enough to give his view that, ‘I don’t think that we will ever get to community participation’, whereas the ‘deputy’ was more circumspect, saying ‘I’ve got an issue with presence/participation’ (F/PL/030506), a view that she had hinted at previously.

> There was consensus that the men should not be pushed into community inclusion. Linda said that she could say more about this but wouldn’t. (F/PL/030206)

Towards the end of this phase of the research we received this written outcome of a staff meeting, which clearly indicates that community presence and not community participation is their priority.

> During the meeting and discussion prior to the meeting with those not present, we [decided that we] would focus on the theory of ‘presence’. The aim would be to assess at a later date to ascertain the ‘participation’ aspect. All staff felt that we still need to develop a better working understanding of the participation aspect of the approach to social inclusion. (F/PL/090806)

It is hard to get the tone ‘right’ in writing this part of the report. We are not trying to single out these two staff at 64 Penny Lane as either ‘bad’ or poorly performing people; indeed it was very apparent that they cared for all the residents at 64 Penny Lane. Yet it must be acknowledged that their position endows them with greater responsibility than the direct support staff for developing good practice that is in line with the Department of Human Services’ policy. Unless we are completely ‘off the mark’ in suggesting that people with intellectual disabilities should be helped to expand their social networks to include relationships with non-disabled people, their failure to do what was being asked of them by the CIO, a more senior employee, must be partly explained by resistance and opposition to the goal. We characterised the overarching character of this phase of the research as one of ‘mild conflict’ between the staff group and the CIO and researchers. The Community Inclusion Framework is quite correct in stating that, ‘There needs to be acknowledgement that the work is complex, and that at times it may not be well understood, or may be resisted’ (Warren, 2005, p.2).

We should not see this opposition or resistance to the goal in isolation. It should be remembered that in the United Kingdom study more than half of the staff in a community-based service had some reservations about the practicality of the service’s goals. Although human service workers are keen to point their fingers at ‘the unwelcoming and hostile community’ as a barrier to building inclusive communities, it would seem to be the case that resistance and practices within their own ranks are significant contributors to the creation and maintenance of the ‘distinct social space’ that people with intellectual disabilities find themselves in. Before members of the community can behave with indifference, hostility, or even in a welcoming way, staff members have to take people with severe intellectual disabilities to places where these interactions might happen. Another significant barrier seems to be that some staff members avoid these places and therefore the possibility of any meaningful interaction with non-disabled people, whether it is indifferent, hostile or welcoming.

Emerson and Hatton (1994) claimed that the leadership and management in relatively isolated, dispersed services is likely to be 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 in the case of people with severe intellectual disabilities, ‘silent’ clients in unobserved settings. The ‘isolation’ of these settings allows relatively autonomous work groups to be established (Handy, 1990). At worst, staff groups may set norms and goals that are not congruent with those of the organisation, or as in this case, the staff group are selective about which part of the building inclusive communities goal they will address.

Handy’s (1993) conceptualisation of negative power allows the distinction to be made between positive and negative leadership. Handy writes, ‘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 we categorised the leadership at the house 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 the CIO, a senior employee. During this phase there were various examples of tasks either not being completed or done poorly, which delayed and disrupted the implementation of the Community Inclusion Framework[22]. It seemed to us that the leadership in the house was not conducive to the successful implementation of the Community Inclusion Framework because the house supervisor had different priorities (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 were little more than exhortations.

Understanding our 'hesitancy' to use specialist facilities

One area in which there was a competing priority was over the use of specialist leisure services. We want to dwell on this issue because it is important to understand how they create and maintain the 'distinct social space' and we would suggest that in this particular case the staff were drawn to use them because of their beliefs about people with intellectual disabilities.

At the half-day meeting we first tried to steer the staff team away from planning to use specialist leisure facilities. We were obviously unsuccessful in this, because nearly four months after the half-day meeting we were told, 'We're looking at activities for Joseph and Dan at Rec-Line and Woodbridge' (F/PL/310506).

Rec-Line is the aforementioned recreation, leisure and holiday service for adults who have an intellectual disability, whereas Woodbridge Community House was a venue for a monthly activity for people with intellectual disabilities. It has now disbanded, but its story is instructive, because it is a good illustration of how the 'distinct social space' can be created. What started out as an ordinary place where anyone might go became transformed into a segregated activity that inadvertently reinforced the boundaries between people with intellectual

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[22] For example, at the first meeting the CIO identified that the men's levels of receptive and expressive communication were going to be important factors.

> During the conversations I had queried the individuals' communication strategies. Simon advised most are non-verbal, and the main focus is gestures and assumptions often made by the staff. (F/PL/050406)

At a subsequent meeting the CIO requested that the speech therapist be contacted. Six weeks later we were told that this had not been done. A meeting was arranged, which was then legitimately postponed by the house supervisor, but not rearranged. No meeting took place in the four months following the original request.

disabilities and non-disabled people. This account is given by the house supervisor who helped to establish the ‘activity night’ at the community house.

> We’re really lucky here in that we have a community house at the end of the road, which we’ve managed to make some partnerships with. They’ve really been fantastic, we’ve got great networks with them and that’s been a baby-step for the people we support here in that it’s close, it’s somewhere you can go to repeatedly, to show that it was safe. It was non-threatening and they’ve got an excellent community café there which is just wonderful, so you access that a lot. It’s been a good stepping stone to going out into the community. I meet with the manager of the Woodbridge Community House fairly regularly. For two years, we’ve just finished, we ran an activity night once a month, for all of the local CRUs and quite a lot of the new Kew houses, because in conjunction with Sylvia Warren we were finding that a lot of the houses perhaps weren’t going out very much. It was seen as a stepping stone for support staff, as well as the people we support, in providing an activity that was seen as a safe venue. So we did things like a movie night, then a disco, scrap booking, massage and aromatherapy, and it was fantastic. We stopped doing it because instead of being inclusive it actually ended up being exclusive. We were getting up to 100 people turning up to our monthly Friday night activities, but we weren’t actually drawing anyone in from the local community. It was quite daunting for other people in the community to come in with a large group of people that all knew each other. I think it was effective in encouraging staff to go out and look at their local community houses and what they’ve got to offer. (HS/6/I)

We do not hold an absolute position regarding the use of specialist leisure services, but it should be evident from our argumentation that these services do significantly contribute towards the creation and maintenance of the ‘distinct social space’ that people with intellectual disabilities typically occupy. Given that many people with intellectual disabilities spend most of their time in this ‘distinct social space’, our instinct is to want to look at the numerous other possibilities that ‘the community’ has to offer for supporting people to spend their leisure time[23].

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[23] A quick look at the “accessible and inclusive sport and recreation’ (ERLS Inc., 2006, p.7) opportunities published by the Eastern Recreation and Leisure Services Inc. indicates this ambivalent approach to building inclusive communities. Generalist clubs and venues sit alongside specialist clubs, such as Club Wild, “an organisation run by and for people with disabilities…[that] creates opportunities for people with disabilities to express their unique cultural identities, to celebrate and affirm these within their own communities’ (p.20).

It is also the case that people with mild intellectual disabilities may choose to use specialist leisure services like Rec-Line. Not supporting such choices would contravene the principle of self-determination. But at 64 Penny Lane, given the men's level of intellectual disability, choosing to use a specialist leisure service or an ordinary venue indicates something about the beliefs of the people making those choices and the lifestyles they think the residents should live on a daily basis.

Intellectual disability: A label and social category

Most of the understandings of community that we have encountered so far are can be applied to the five men who live at 64 Penny Lane and the places and activities they participate in. It can be argued that as a group the five men share something in common (intellectual disability); share a common identity (person with intellectual disability); attend a day program with other people with intellectual disabilities (centre-based community and geographic community). For these five men, other people have decided that intellectual disability is the salient characteristic that binds them together, which makes them a certain 'kind' of person, who should live their lives in the company of other people with the same 'label'.

In the case of these five men any individual or group identity based on the term 'intellectual disability' or a derivative (people with intellectual disabilities, intellectually disabled, disabled) is unlikely to have any personal meaning; their severe level of intellectual disability means that the abstract concept will not be understood or recognised by the men. What is important about this fact is that the diagnostic label and the social category are more salient to the people that support them and the people they come into contact with. We are back where we started: beliefs have consequences. If you believe people with severe intellectual disabilities are certain kinds of person, who want to stick together with other 'intellectually disabled people' or who will be safer and more secure in the company of other intellectually disabled people, then you will look to use specialist services.

It should also be noted that the research that has focused on how people with milder intellectual disabilities perceive themselves reveals that the greater proportion do not include themselves in the social category of people with intellectual disabilities (Davies and Jenkins, 1997; Finlay and Lyons, 2005).

It is true that self-advocacy organisations are established on the basis of belonging to the social category 'people with intellectual disabilities' (an issue-based community), but again it should not be assumed that members of those organisations share that group identity although some may (Finlay and Lyons, 1998). Indeed, as we have suggested, a strong theme running through the history of self-advocacy has been an identity based on a common humanity, ‘People First’; a rejection of labels through slogans such as ‘Label Jars Not People’ and the promotion of ‘people first language’, i.e. <u>people</u> with disabilities (Clement, 2004).

There is an obvious tension in establishing a self-advocacy group on the basis of belonging to the social category ‘people with learning difficulties’ and values which emphasise being part of an inclusive society (Simons, 1992). Such a group reinforces the very category that people are seeking to downplay. The aforementioned concepts of peer-support, peer-advocacy, disability arts, disability pride, and disability culture championed by the disability movement are evident in self-advocacy organisations, but it is hard to make the case that these concepts are the inspiration for taking groups of people with intellectual disabilities on a train trip to Sandringham, the Mornington market, the cinema, Circus Oz, or to see The Pirates of Penzance, all activities offered by Rec-Line (Oakleigh Centre, 2006).

Asserting a common humanity was in part a response to the belief that labelling individuals ‘intellectually disabled’, ‘mentally handicapped’ or ‘mentally retarded’ had detrimental consequences for them. ‘Labelling Theory’ suggests that the label ‘intellectually disabled’ defines an individual as a particular type of person. The term contains an evaluation of the person so labelled, and has a ‘master status’ that clouds all other characteristics of the person. Other people view the person, and respond to that person, in terms of the label. For people with mild intellectual disabilities being labelled may change the person’s sense of self (Haralambos and Holborn, 1991).

Although labelling theory has been criticised, we can see that ascribing the social category to the five men, (for it is not a label or category they have chosen for themselves), has consequences for them. Most people in their lives see the label as being an important fact about them, if not the most important fact, and most of their lives are organised around the social category, home, leisure, and where they spend their weekdays. Thus, we suggest that at 64 Penny Lane, a factor in wanting to use Rec-Line and Woodbridge community house is because the staff that support the men believe the label of intellectual disability is more important than an outlook that emphasises a common humanity. Even when an interest is identified, as bowling was in Chapter 7, the importance attached to the label directs some people to seek out bowling clubs for people with intellectual disabilities or find a group of people with intellectual disabilities that might want to bowl together.

There are numerous other bases of identity, but all are ignored in favour of ‘intellectual disability’. As Finlay and Lyons (2005) write, ‘[The] power of the label to determine perceptions is so strong it prevents people seeing the individual’ (p.1280).

Final reflections on Phase 3

In this section we want to present some of the other lessons that we learnt during this phase of the research. Strategies such as establishing a clear goal, providing resources in the form of training or people, and the use of planning techniques did not produce the desired outcome. As Maher (1984) points out, and experience had shown, implementing programs in organisational settings is a complex and challenging task.

This phase of the research came to its own natural end, when the house supervisor left to manage another group home for 12 months. This provided us with a definite break and space to reflect on what we had learnt to date about implementing the Community Inclusion Framework. We also had to prepare to brief the new house supervisor about the project’s current position and plan what we were going to do next.

Organisational readiness

Table 8 lists eight dimensions that managers can gather information about that will help to clarify the extent to which an organisation is ready to implement a program (Maher, 1984). Although this can be done prior to implementing a program, we used the framework at the end of Phase 3 to help us reflect on the ‘readiness’ of the setting to implement the Community Inclusion Framework.

Table 8

Important factors in evaluating 'organisational readiness' (Maher, 1984)

Dimension	Related questions	Our evaluation at the end of Phase 3
Ability	Do staff possess knowledge, skills, abilities and orientations prerequisite to successful program implementation?	No. The negative orientations that existed at the start of Phase 3 were still evident at the end.
Values	Is the program consonant with the prevailing philosophy and goals of the organisation? Is the program consonant with the professional values of staff and others?	Yes. No.
Idea	Is it clear to staff and others as to the nature and scope of the program? Is the idea behind the program 'tryable' and of potential usefulness?	Not initially. The training had not delivered this. It was clear during Phase 3. Yes.
Circumstances	Does the present leadership and administrative situation at 64 Penny Lane appear to be conducive to implementation of the program?	No. The house supervisor and DDS02 were not fully supportive of the goal.
Timing	Is this the appropriate time to implement the program?	Yes, in relation to the five men. Our view was that the residents did not need to be 'made ready' in any sense.
Obligation	Is the need for the program apparent to staff and 'the community'?	No. There is no need to look elsewhere for relationships. The residents have each other, staff to support them, and interested family members.
Resistance	To what extent will individuals or groups resist implementation?	It was evident that at the start of Phase 3 that there would be some resistance.
Yield	Are the expected positive consequences of the program apparent to staff?	No. We did not manage to convince the staff group that the five residents would benefit from relationships with non-disabled people.

In summary, the Community Inclusion Framework is consistent with the goals in the State Disability Plan, the ideas behind it have been tried elsewhere, the residents were ‘ready’, and the goal had been made clear to the staff group. However, the program’s values were incongruent with those of the staff, and their attitudes, including the house supervisor’s, were negative towards it. The need for the program was not apparent to the staff, nor could they see any benefits to themselves or the five residents. It was not surprising that we encountered resistance and had made little headway in implementing the program.

These questions can be applied in the future to assess the ‘readiness’ of other settings to implement the Community Inclusion Framework and may help in identifying strategies to overcome resistance. Maher’s (1984) ‘framework’ was useful in consolidating our experiences and underlined the areas that we still had to overcome.

Demonstrating the existence of the ’distinct social space’

An important part of the action research process was scrutinising our underlying assumptions (Coghlan and Brannick, 2001). We had tried to operate in a reflexive manner from the project’s outset. An insight we had during this phase of the research was that the Community Inclusion Framework was based on the assumption that all people with intellectual disabilities occupy the ‘distinct social space’. A consequence of this is outlined by Perske (1993):

> A large number of visionaries and technologists have set off a wealth of ideas – all subsumed under the term inclusion. They say 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. According to these visionaries and technologists, good inclusion takes more that caring parents, committed professionals, and carefully matched volunteers. **It also takes friendships – lots of friendships** (p.2, bold added).

The danger of assuming that all people with intellectual disabilities occupy this ‘distinct social space’ and require lots of friendships, is that you can end up treating people as a homogenous group and lose sight of 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 does not start with an assessment of the structure and function of the resident’s social network. The data collected from the Activity Learning Logs did confirm these underlying assumptions about the structure of the residents' social networks, (that they did occupy this 'distinct social space'), but this may not always be the case.

On their own the structural features do not tell us about the quality, amount, and experience of social support (Tracy and Whittaker, 1990). Undertaking lots of activities and having lots of friends will not be the solution for all people with intellectual disabilities. Some people like to dash from one activity to another, others are happy with a slower pace and fewer activities (Cummins and Lau, 2003). Some people may benefit from a large social network, whilst others may be content with small network that contains close friends. Shakespeare (2006) suggest that some people with autism may prefer 'self-exclusion' to 'inclusion' as they 'may find even the most well-meaning and respectful crowd of people…a disturbing and confusing invasion' (p.49).

If we had begun with an assessment that we could subsequently have used to enhance people's social networks, we wondered if it may also have assisted in overcoming people's resistance to the goal of building inclusive communities. If we can unequivocally demonstrate to a staff group that a person mainly has contact with other 'clients', paid staff, and family members then it may be easier for them to see why we should put some effort into trying to expand people's networks to include relationships with non-disabled people.

Closer supervision and more frequent monitoring

Most of our interventions during this phase were made during meetings that we held with members of the staff group. With hindsight we came to realise that although we tried to give clear instructions about the tasks to be completed at these meetings, we also turned over responsibility for accomplishing the tasks to the staff group between these meetings. Although we felt we were delegating, our behaviour was more akin to 'abdicating' (Blanchard, Zigarmi, and Zigarmi, 1986).

We may have been more successful if we had a much closer role in supervising the staff group's performance. Adopting Blanchard et al.'s (1986) understanding of 'directive behaviour' might have been more fruitful. Directive behaviour involves, 'Clearly telling people what to do, how to do it, where to do it, and when to do it, and then **closely supervising their performance**' (p.46, bold added). Our expectation was that the house supervisor would provide the necessary planned formal supervision to the staff he managed, although our period of participant-observation had highlighted low levels of this type of supervision (Clement et al., 2007).

Blanchard et al. (1986) state that turning over responsibility for accomplishing tasks is for employees who are highly competent and committed. We were faced with employees who lacked competence in building inclusive communities and were lacking in commitment to the goal. In these circumstances directing and coaching would have been more appropriate options. Both these management options require close supervision and frequent monitoring, at levels which were beyond the capacity of both the CIO and the researchers. This reinforces the need to have competent house supervisors who can give direction to the direct support staff they manage. 'Building inclusive communities and supporting residents' networks' is a competency area that we identified in our earlier report, The Importance of Practice Leadership and the Role of the House Supervisor (Clement and Bigby, 2007). See Appendix 9.

Involving the team manager

Although closer supervision and more frequent monitoring are beyond the capacity of the CIO there is another employee who could and should take on some of this load, the team manager. To date we had made little use of the team manager. Part of the team manager's role is to manage the practice of the house supervisor.

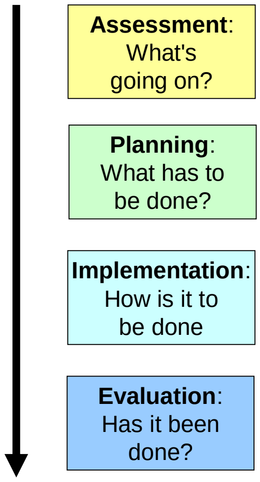
10. Phase 4: Assessing people's social networks

We finished the previous section with some of the lessons that we had learnt during Phase 3. This thinking informed the next action research phase. In constructing this report we have identified two separate phases, 4 and 5, to assist with the report's structure, even though they took place at the same time. Phase 4 deals with a more discrete project to undertake social network assessments, whilst Phase 5 presents the ongoing work to build inclusive communities for the residents at 64 Penny Lane.

Most 'interventions' with people with learning disabilities should begin with an assessment. Although we have outlined how the CIO went to meet the residents at 64 Penny Lane and gathered information about activities they were involved in, interests, and level of expressive and receptive language, the process was not accompanied by a thorough assessment of their social networks.

We stated earlier that an assumption underlying the Community Inclusion Framework was that all people with intellectual disabilities occupy the 'distinct social space'. As a consequence, intervening to expand the quantity of their relationships by connecting them to other people becomes a 'given' action. Implementing the Community Inclusion Framework therefore begins closer to the planning stage of the process shown in Figure 16, which is based on the assumption that any person with intellectual disability is in some sense 'isolated' and in need of more relationships.

Figure 16. The structure of practice
Adapted from Howe (1987/1992)



We decided to complete a number of social network assessments for two reasons. Firstly, because as we suggested above, carrying out an appropriate individual assessment ought to precede the provision of a 'service' or 'intervention' (Howe, 1987/1992). Secondly, we wondered whether the outcome of such an assessment might be helpful in overcoming people's resistance to the goal of expanding residents' social networks to include relationships with non-disabled people.

We completed three social network assessments — one for a resident at 64 Penny Lane, and two with residents living in other group homes that we had met during the Making Life Good in the Community project. We selected residents in other group homes because we thought it would be useful to undertake assessments with people with varying degrees of intellectual disability.

Joseph's personal file at 64 Penny Lane stated that he had a severe intellectual disability. He had also been assessed as being at Level 5 (Intentional formal) on the Triple C (Bloomberg and West, 1999). A person assessed at Stage 5 uses at least five words, signs, or gestures and relates pictures or photographs to real objects. Jim, a resident in another house had the greatest level of receptive and expressive communication of the 26 residents involved in the action research component of Making Life Good in the Community, and Mathew had a more profound intellectual disability.

We opted to use the social network map (Tracy and Abell, 1994; Tracy and Whittaker, 1990), which has been used extensively in research involving people with intellectual disabilities (for example, see Robertson et al., 2005), and is also being used in the survey element of Making Life Good in the Community. The assessment tool is given in Appendix 10.

Undertaking the assessments[24]

We completed the three assessments somewhat differently, using various ways to gather the information. We used single face-to-face interviews, group interviews, and telephone interviews. The primary sources of information were direct support staff at the group homes and the day programs. No family members were contacted as they had indicated their desired level of involvement in the project at the outset. Some information was obtained from the one resident that had speech, which was acquired by a member of the staff group after Simon made it clear he did not want to speak with either the CIO or a researcher. No meaningful information could be gleaned from the interactions with the resident at 64 Penny Lane. Although Joseph had some gestures, we concluded that he would need to learn to use a tool such as ‘Talking Mats’ (Murphy and Cameron, 2002) if preferences were to be obtained from pictures or photographs of real objects. Time constraints precluded this from happening. The assessments took five, six, and eleven hours to complete, which included writing time and travel to and from interviews.

All three social network maps showed the generalised pattern of social relationships that is typical of many people with intellectual disabilities, that is, this ‘distinct social space’. Figure 17 shows the social network map of Jim, who lives at 96 High Street. We chose to include this map because of the three assessments we completed, it contained the median number of relationships.

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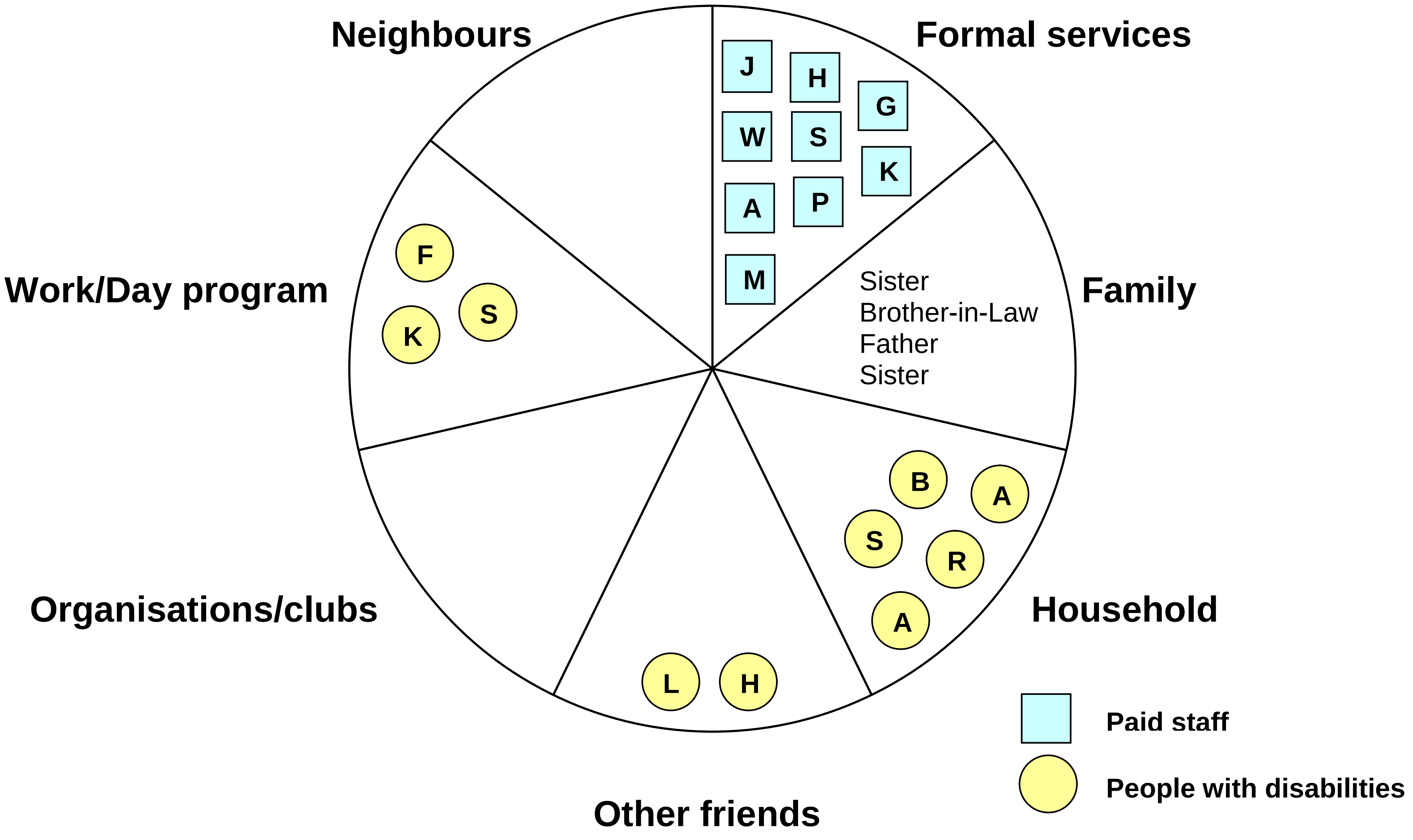
[24] We would like to acknowledge the contribution of Charles Clark, a Community Inclusion Officer, who took the lead in completing one assessment and participated in the subsequent discussion about their use and worth.

Figure 17. Jim's social network map

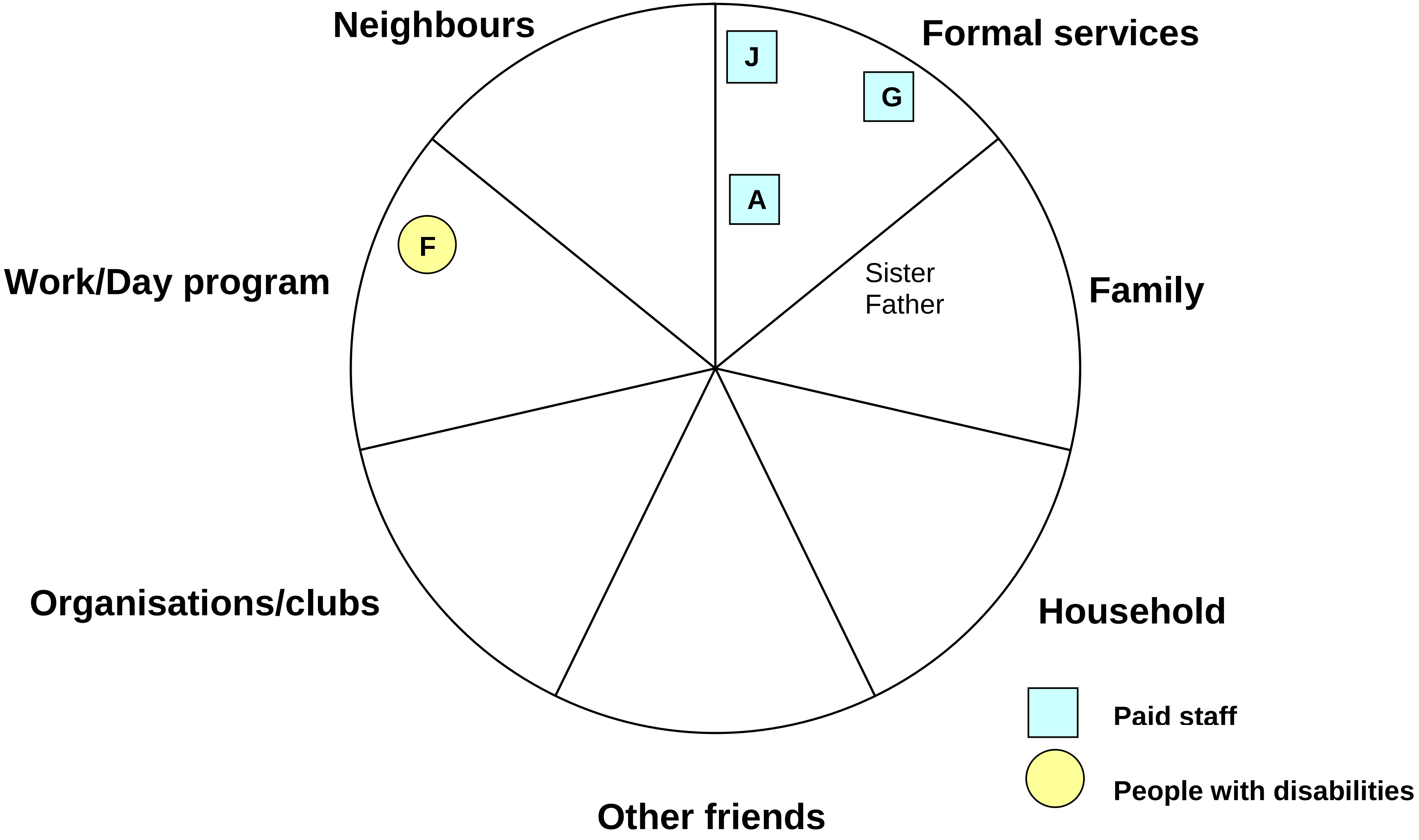


All the people in the network are other people with disabilities (10); service workers who support Jim at his home and the day program (9); and immediate family members (4). The assessment focuses on important people in an individual’s life who have had active contact with them. The map therefore does not imply that there has been no contact with non-disabled people, but as they were not included as active contacts, then it is likely that any interactions will have been fleeting, such as customer-based exchanges in shops and leisure settings.

Although the social network map gives a visual representation of Jim’s network, it tells us very little about the functions of the relationships in the network. A strength of this assessment is that it also gathers information about both the types of support and the nature of the relationships within the network. For example, we asked informants to state how ‘close’ Jim felt to members of his network. Figure 18 shows a revised network with only those members that informants perceived Jim to be ‘very close’ to. It should be noted that the assessment collects information about the nature of the relationships from Jim’s perspective, so it may be the case that those feelings of ‘closeness’ are not reciprocated.

Jim was reported to not feel ‘very close’ to any of the people that he lives with, and three of the people he is close to in Figure 18 (50 per cent) are paid to support him. Again, this reflects the generalised pattern of social relationships that is typical of many people with intellectual disabilities — relative loneliness and an absence of meaningful relationships which are characterised by intimacy and friendship. The assessment report is given in Appendix 11.

Figure 18. Jim's revised social network map leaving only members identified as being 'very close'.



Reflections on completing the social network assessments

Completing the social network assessments raised a number of issues that are important for building inclusive communities for people with severe intellectual disabilities.

Closeness

An interesting observation during the assessment process was that informants struggled with the notion of 'closeness'. The point has frequently been made that some people with intellectual disabilities name as 'friends' individuals who would probably not regard that person as a friend, for example staff members or general acquaintances. The boundaries of 'friendship' are expanded to include people normally outside a more generally accepted definition. We noted a similar process when staff were rating the residents' degree of closeness to individuals in the respective social network maps[25]. Initially staff consistently over-estimated the degree of closeness, which they revised downwards when they were prompted to use relationships within their own lives as benchmarks. These related processes help to suggest an over-reporting in the degree of intimacy and reciprocity compared to the actuality.

The staff – service-user relationship

Human service organisations often give out ambivalent messages to staff about the 'type' of relationship that they should have with service-users. One message is that relationships should be 'professional', which can be interpreted as being detached, objective, and maintaining a social distance. Yet promoting an overly 'detached' relationship can be problematic for a number of reasons.

Firstly, staff-resident relationships are inextricably related to service-users' quality of life, given that for people living in group homes, service workers are often the residents' most frequent and stable relationships (Marquis and Jackson, 2000). Maintaining a social distance may therefore ignore the reality that some staff develop emotionally involved and close relationships with the people they support, to the point where they are described as 'friends'. It may also marginalise the fact that staff relationships that enhance the residents' quality of life need to be positive, friendly, and relaxed, not simply task-orientated.

Secondly, Myers et al. (1998) suggest that a key factor in enabling what they term 'community integration' is the importance of support staff linking people with intellectual disabilities to their own social networks. They suggest that staff

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[25] The three options are, very close, somewhat close, and not very close.

act as conduits. This is especially important for people with severe intellectual disabilities. Human service organisations may discourage such thinking and action if the maintenance of a social distance is encouraged. In an earlier chapter we suggested that the staff members present at the social inclusion training did not appear to consider people within their own social networks as potential links.

Issues of reciprocity

The social network assessment asks informants to comment on reciprocity. Tracy and Whittaker (1990) distinguish between concrete, emotional, and informational support. Informants have to identify whether the direction of 'help' goes both ways or is unidirectional[26].

We want to offer some thoughts about reciprocity because it is mentioned as being an important quality of friendship and is said to have an impact on the strength of a person's relationships with others. Bayley (2001), for example, writes that, 'Reciprocity is at the heart of all relationships of any emotional depth….[and] the extent to which relationships can be reciprocal, even with severely disabled people, is a critical element in how enduring the relationship is' (p.29).

In a similar vein Table 9 shows the four qualities identified by the King's Fund (1988) as impacting on the strength of a person's 'ties and connections' with others.

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[26] Concrete support might be giving someone a ride to the airport. Emotional support might be comforting a person that is upset. Informational support might be giving some advice about a big decision.

Table 9 Things that impact on the strength of people's ties and connections (King's Fund, 1988, p.3)	
Time	The amount of time people have spent together and the length of time they have spent together in the past.
Intensity	Some ties and connections are invested with a lot of emotion. They mean a lot to us, perhaps more than anything or anyone else. Others are not important, and some not very important at all.
Intimacy	We share confidences with some people more than others. Some of our ties and connections involve a lot of trust.
Reciprocity	The exchange of services between people. This may range from simply following the rules of politeness, to providing practical help, to sharing major parts of our life and work.

Although Jim relies on other people, particularly staff members, for concrete, emotional, and informational support, the assessment identified that he is capable of reciprocity, especially in the area of concrete help. We identified this as an area that might be exploited in developing relationships. In Chapter 7, for example, a house supervisor reported how residents offered concrete support to neighbours by taking in their garbage-bins, which he suggested fostered positive relationships.

It is hard to imagine ways in which Mathew, the person with the most profound intellectual disability, could give any of these types of support to someone else, given that he is completely reliant on others to wash, dress, and feed him, interpret how he is feeling, and make the major decisions about his life. Everyday gestures of 'friendship', such as buying a drink for someone at the pub, or phoning an acquaintance to invite them for dinner are beyond Mathew's capabilities.

If reciprocity involves a relationship in which there is mutual giving and taking between two parties — where two people have the same feelings for each other (OED Online, 1989) — it may be that the term has very little realistic application for some people. If you were to take Mathew to the pub, you would have to decide that he would like to buy you a drink. We do not really know Mathew's thoughts, feelings and other inner mental states, but it is probably the case that the concept of 'friendship' has no meaning to Mathew or other people with severe intellectual disabilities.

Of the authors we quoted in Chapter 2, Kennedy et al. (1989) seem to be nearer the mark in suggesting that individuals with severe intellectual disabilities may have more difficulty providing the reciprocity that is needed to maintain relationships, rather than O'Brien and O'Brien (1993) who assert that, 'People with developmental disabilities have just as much capacity for friendship as any other people do' (p.13).

We are not trying to make some obscure philosophical point here, but to acknowledge that there is a real issue that is likely to impact on the relationships that a person like Mathew has. We know from our own experiences of recruiting direct care staff and monitoring turnover in group homes that working with people with severe intellectual disabilities does not suit everyone. Exit interviews reveal that people leave because they do not like providing high levels of 'care', the absence of speech, or the perceived lack of progress as measured by concepts such as skill development and 'independence'.

This is not to say that people with severe intellectual disabilities cannot have friends or that the concept of reciprocity is completely irrelevant. We hope that a person will spend enough time with Mathew so that an emotional and intimate bond will form. If that person chooses to call Mathew a friend, then who are we to dispute it? Such a person is also likely to be skilled at extracting meaning from 'a look', or a response to a touch, and this level of reciprocity may be enough to help sustain the relationship.

Only by acknowledging the personal restrictions of severe intellectual disabilities and recognising that non-disabled people with little direct experiences of severe intellectual disability find some of its features disconcerting (Clegg, 2006) can we think about how to address these issues. We recognised how superficial some of the conversations we had with staff were around this issue.

> Simon: My experience is that the residents are overlooked. People never speak to the residents.
>
> Silvia: As staff members can you do anything differently to promote interactions? In what ways are you educators?
>
> John: Talking to people in the community, especially if they come over.
>
> Simon: Getting the boys out there and getting them to interact with other people.
>
> Silvia: So a guy comes up to you and introduces himself to you, what do you do?

> Linda: You introduce him to Franco.
>
> Silvia: Great, yeah. The role of facilitator, have you heard of it before?
>
> People explain it as 'A go-between…promoting…involving'.
>
> [I asked a question hoping to get people to think beyond 'the introduction'. Of course you'd introduce the client, but then what? My experience of the men at the house suggested that a staff member might say 'This is Franco' and the person might say 'Hello Franco' and that would be the extent of the interaction. It is easier when people have speech. Clegg (2006) asks: What difficulties do people without disabilities experience when they first encounter somebody with significant disabilities? It's a useful question that hasn't been too much researched.] (F/PL/310506)

Eric Berne, the originator of Transactional Analysis, wrote a book called, What do you do after you say hello? (Berne, 1972/1975). The title, rather than the content, seems particularly apt for those people interested in enabling individuals to have relationships with people with severe intellectual disabilities. Our limited discussions with direct support staff revealed that they struggled to generate suggestions as to what they might do after introductions had been made.

Direct support staff who say that they do not know how to facilitate relationships between people with severe intellectual disabilities and non-disabled people are raising a training or coaching need. It may also say something about their own skill-level in regard to communicating with people with severe intellectual disabilities. We offered to facilitate a workshop with the staff at 64 Penny Lane during Phase 5, but other priorities prevented them from accepting this proposition. We have no outcomes from such a workshop to present in this report, but can offer some ideas that might start people thinking about this important issue.

We thought that saying that you do not know how to facilitate relationships might also reflect a related belief that non-disabled people do not want to be 'friends' with people with severe intellectual disabilities, or have unpaid relationships that are not based on kinship.

In order to counter the negative views of people with intellectual disabilities Wolfensberger (1988) provides a useful counterpoint, listing a number of 'assets' found in people with intellectual disabilities, such as 'heart qualities' and 'natural spontaneity'. This list may be useful in opening people's eyes as to why persons may want relationships with people with intellectual disabilities. Perhaps more useful are studies that have reported on the 'satisfactions' of caring. Table 10 provides a list from a study of family carers.

Table 10

Family carers satisfactions of caring.

Adapted from Grant, Ramcharan, McGrath, Nolan and Keady (1998).

Interpersonal dynamic	Intrapersonal dynamic	Outcome dynamic
• Expression of love • Brought closer to relative • Closer family ties • Appreciation from others • Appreciation • Relative does not complain	• Knowing I've done my best • Altruism • Showing faith • Provides a challenge • Feel needed/wanted • Test own abilities • Fulfilling duties • Provides purpose in life • Stop feeling guilty	• Develop new skills/abilities • Made self less selfish • Widened interests

Although not all the 'satisfactions' listed in Table 10 are applicable to people who are not relatives, it is quite possible that many unrelated non-disabled people would report identical satisfactions. The point is that even when reciprocity is minimal, people will still choose to have relationships with people with severe intellectual disabilities. We also think that some of the early formulations of Citizen Advocacy (for example, Wolfensberger and Zauha, 1973), envisioned as a more protective relationship, may have some useful lessons regarding relationships between non-disabled people and people with severe intellectual disabilities.

People with an interest in building inclusive communities need to know what to do after introductions have been made — after people have said 'hello'. This may be, for example, coaching people to interact with people with severe intellectual disabilities, or helping them to find the personally satisfying rewards of engaging with someone.

The lack of reciprocity, or more the fact that the direction of 'help' is uni-directional, is a further reason why expanding the social networks of people with severe intellectual disabilities to include non-disabled people is especially important. Anyone who has worked in a group home for people with severe intellectual disabilities knows that residents learn who in that environment will help them get their needs met. The men at 64 Penny Lane did not take another resident by the hand and escort him to the bathroom to indicate that he wanted support to have a shower. At 16 Temple Court, we observed Mathew spending most of his day disengaged unless staff came and interacted with him. If people like Matthew are to have a better quality of life it will require people actively engaging with him, people with specific knowledge, skills and abilities. The people he lives with do not actively engage with him unless staff attempt to facilitate this[27].

Completing the assessments

The goal of building inclusive communities and the introduction of Person Centred Planning within the Department of Human Services’ supported accommodation has focused attention on the importance of relationships for people with intellectual disabilities. This has led to the creation of tools to map residents’ social networks. Figure 19 shows a ‘wagon-wheel’ from the Department’s template, My Lifestyle Plan (Department of Human Services Victoria, n.d.).

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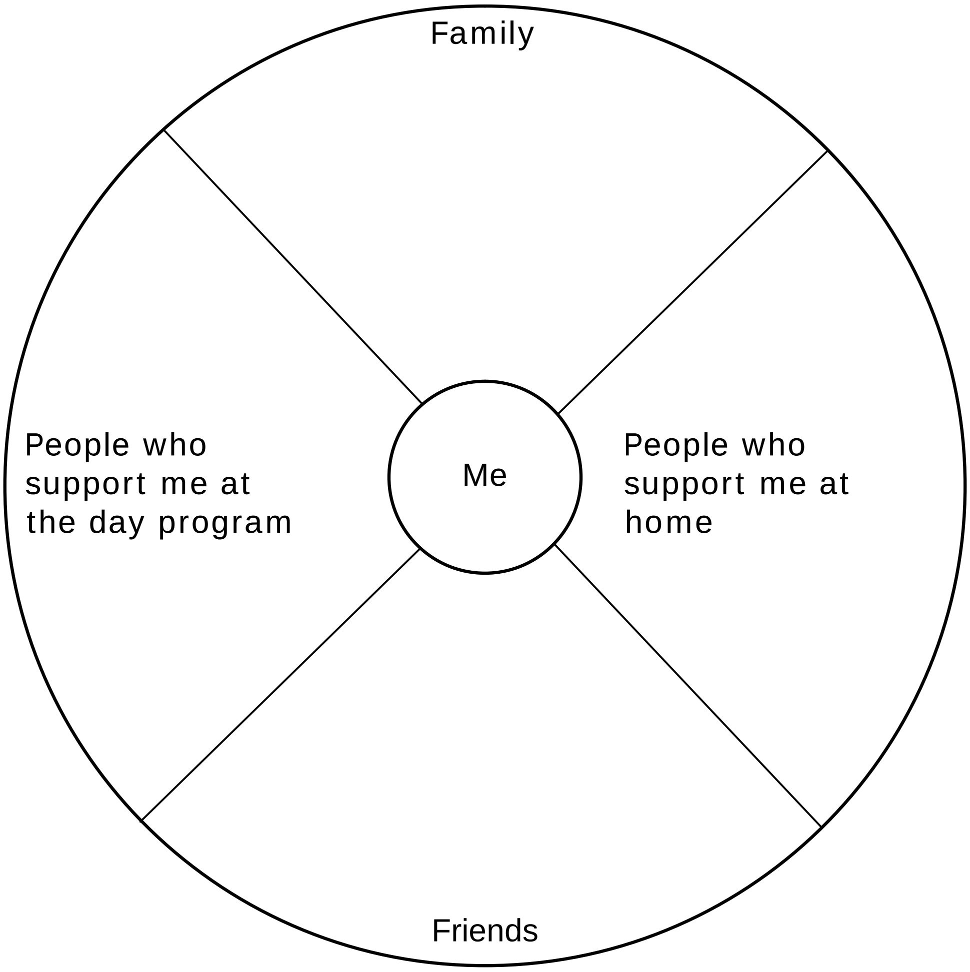
[27] Again we are not suggesting that people with intellectual disabilities cannot make friends with one another or support one another (see MacAndrew and Edgerton, 1966). In the institutions ‘patients’ with milder intellectual disabilities often had ‘jobs’, which may have involved ‘caring’ for other residents with higher support needs.

Figure 19: Important People in My Life.
From My Lifestyle Plan (Department Of Human Services, Victoria n.d.)



In regard to mapping people’s relationships we believe the social network assessment to be a superior tool to the Important People in My Life wagon-wheel. This is for three reasons. Firstly, we think it is helpful to have the larger number of domains. The categories of ‘organisations and clubs’ and ‘neighbours’ prompted informants to consider these two domains, which also reflect two important types of community, one based on ‘interest’ and another on ‘geography’ (see Table 4). There may be other domains that could be usefully added. Secondly, identifying people with disabilities and staff members is helpful if ‘breaking out’ of the ‘distinct social space’ is a goal. Thirdly, the assessment also gathers information about the type of support and the nature of the relationships within the network, which did provide some useful pointers about how building inclusive communities might be progressed for the three men in our sample.

Although it might be useful for people to know about the social network assessment, and for people to use it if they wish, we suggest that it might be more sensible to revise the Important People in My Life wagon-wheel, rather than promoting the social network assessment. Having too many tools around can make it confusing for direct care staff to choose which one they should use.

The social network assessment requires a reasonable degree of literacy and the ability to analyse the collected data. Assessments of this type are typically completed by people that know a resident the best. In an ideal situation this could be coordinated by a keyworker. However, some direct support staff may find completing and writing-up the assessment difficult.

This task could also be undertaken by competent house supervisors, but we are reluctant to suggest that this task be added to those already carried out by incumbents, given that they are often stretched to capacity (see Clement and Bigby, 2007). Having said this, the successful implementation of Person Centred Planning will also require a similar level of detail to the social network assessment, and will similarly require people with good literacy and analytic skills. A house supervisor that we interviewed thought that many direct support staff would struggle to complete a Person Centred Plan.

> There's a certain part of me that says that [developing Person Centred Plans is] really beyond the role of [direct support] staff in particular. It's quite complex, and you need to have a lot of knowledge of what's available, what's out there. People who work in this field aren't necessarily the most activated people in their own right, yet we're expecting them to be very activated in the lives of others. I think we really need to resource [Person Centred Planning] very well, if we want that bigger picture, because like I said, I don't think people are often resourceful in their own lives, so how can we expect them to be resourceful in the life of a person with a disability? (HS/15/I)

We thought that the Important People in My Life wagon-wheel could be enhanced by supplying some guided questions for people to think about. The version we looked at simply presented the diagram in Figure 19. The social network assessment provides guidance as to what questions or probes might be useful.

Social network assessments as a means of overcoming resistance

We do not really know the answer to the question as whether such an assessment could be used to overcome people's resistance to the goal of expanding the residents' social networks to include relationships with non-disabled people. As we shall see in discussing Phase 5, the assessment made little difference in getting things moving for Joseph, the focal person of the assessment at 64 Penny Lane.

We think that all three social network maps clearly illustrated the restricted social networks of the three residents. Creating social network maps such as these may be useful in training and coaching contexts. We used them in our meetings with three staff groups to discuss the notion of a 'distinct social space' and they appeared to be helpful in explaining this concept and making links with more grounded terms such as 'exclusion', 'isolation', 'segregation', and even community presence. However, time to make the most of the social network assessments with the staff groups competed with a range of other issues, some of which had greater priority for the staff group. Throughout Making Life Good in the Community we have commented on the limited amount of reflective space that exists for staff groups to discuss practice issues (Clement, Bigby, and Johnson, 2006).

Overcoming inward-looking social networks

Yet it may be the case that seeing and understanding an analysis of someone's social network map may not motivate staff to work at community participation. We hinted at one reason for this in Chapter 7: the belief that a group of residents in a house belong together, so there is less of a need to look elsewhere for people with whom to have relationships. This inward-looking tendency becomes greater when the numbers in a social network are larger, when a person can meet more, most or all of their 'needs' within the boundaries of that system (Wolfensberger and Thomas, 1983).

The relationships that staff have with residents is also part of this inward-looking tendency. Some staff may believe that there is no need to look elsewhere for relationships when staff are paid to have relationships with the residents. We recall a comedy sketch about an aged-care home that promoted the slogan, 'We care, so you don't have to'. Although intended to be humorous it also accurately reflects an enduring political issue, which is how much 'care' should be a private matter and how much should be undertaken by the state (Midwinter, 1994). Without an understanding that a contemporary task of the direct support role is to engender natural supports some staff may feel that it is their job to 'care' for people with intellectual disabilities, and the rest of society 'doesn't have to'. This is implied in this interview extract:

> Tim: Do you think the Department of Human Services makes a larger contribution to Victorian society...Are you making the world a better place?
>
> Shelagh: I guess so. I don't know about the Department so much. I know that we are; the staff. To tell you the truth I don't really know a whole lot about the Department. I just know what we do. Obviously we're doing a good thing, we're looking after people that can't look after themselves, and their families can't look after them. I feel that, it's like good karma; it's just a positive thing. (I/SX/091105)

If people perceive that the relationships within this 'distinct social space' can meet most or all of a person's needs then what reasons are there for stepping outside its boundaries or inviting 'outsiders' across the border? We thought answering two questions may be helpful here.

- What can (non-disabled) friends provide us that families cannot?
- What can (non-disabled) friends provide us that staff cannot?[28]

It had been our intention to explore these questions with the staff group in a workshop, but other priorities for the staff group meant this did not take place. Perske (1993), however, begins to answer these questions. He 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. It is possible that 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 the staff at 64 Penny Lane thought service-based, family, and peer support to be more important than other sources of support.

Is the bias towards expanding people's social networks a 'bad' one?

It may be the case that the assumption underlying the Community Inclusion Framework, that all people with intellectual disabilities occupy the 'distinct social space', is not necessarily a 'bad' one. Given that building inclusive communities is hard, and that the aspiration to engender friendships is harder still, we should not be overly concerned by overwhelming people who are content with either a small network or a slower pace to their lives. Nor should some people with autism be overpowered by a process that is most likely to be built painstakingly, one

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[28] We have written '(non-disabled) friends' given that we have focused on expanding people's social networks with non-disabled people in this report. We think that friends with disabilities will provide things that families and staff cannot, but these relationships are within the 'distinct social space'.

relationship at a time. Given that people with severe intellectual disabilities in particular are more likely to be experiencing limited social lives, then making plans to connect them with other people is unlikely to be far off the mark. This issue ought to become redundant if Person Centred Planning is implemented thoroughly, as helping people with intellectual disabilities to make connections is integral to this assessment and planning process (Sanderson, Kennedy, Ritchie, and Goodwin, 2002).

11. Phase 5: Implementing the Community Inclusion Framework (2) – a new house supervisor

As we stated previously, Phase 3 came to a natural end when the house supervisor left to manage another group home. Phase 5 ran for 12 months, the duration of the new house supervisor's contract. As well as having to brief the new house supervisor about the nature of the project, we were also able to share our analysis and reflections about Phases 1 to 3. We felt that we had learnt a number of lessons about implementing the Community Inclusion Framework, particularly those related to 'leadership', involving the team manager, and the need for more directive behaviour, which we wanted to apply in the next cycle of research.

During this period we made greater use of meetings with the house supervisor alone, or with the house supervisor and team manager together, and less use of the rostered house meeting. This was a deliberate attempt to strengthen the house supervisor's role as the person primarily responsible for the effective performance of the direct support staff at 64 Penny Lane. Involving the team manager was an attempt to instil a sense of leadership for building inclusive communities in the next managerial layer. We were also reinforcing the fact that part of the team manager's role is to manage the practice of the house supervisor, which includes coaching and other supportive behaviours. We also tried to encourage the need for greater directive behaviour from the house supervisor and team manager.

Four sources of data are used in presenting and discussing the findings in this phase; the fieldnotes that were kept of the meetings, a diary of the activities that residents took part in, documents related to the Community Inclusion Framework, and interviews with five staff members that were completed as the final act of data collection.

Orientating the new house supervisor to the project

The new house supervisor had limited experience in the role. Not only was she learning about being a house supervisor and the specific context of managing at 64 Penny Lane, but she also had to learn about the implementation of the Community Inclusion Framework and the project's longer history.

In order to maintain some momentum with implementing the Community Inclusion Framework we sent the house supervisor the first report to read (Clement, 2007), and arranged an early meeting with the house supervisor and team manager to share information about the project. This was followed closely by a house meeting, where the team manager was present, and feedback was given to the staff present about the current ‘state’ of the project. This included an analysis of the Activity Learning Logs. In addition, a document explaining the concept of keyworking and outlining the role of a keyworker, which had been developed at another group home, was also shared with the staff group (Clement and Bigby, forthcoming).

Outcomes of Phase 5

As before, we want to begin by revealing the changes that occurred in practice at 64 Penny Lane during this phase before offering some reflections and making links to interventions that were made. Table 11 shows activities recorded on the Activity Learning Logs. It is a continuation of the data shown in Appendix 6, which was discussed with the staff group at the end of Phase 3 and the beginning of Phase 5.

Table 11

Number of recorded external activities at 64 Penny Lane by month

Activity	Phase 3				Phase 5							Total
	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	
Bus trip		1	8	5	1	7	12	5	3	1	2	45
Eating out	2	2	2	3	3	6	5	4	4	2	2	35
House Shopping	3	4	4	2		1	4		1	2	1	22
Personal shopping			1	1		2		1	2		1	8
Cinema		1			1	1		1	1		1	6
Visit another CRU		1				1		4				6
Walk		1	4						1			6
Library			1	1	1	1					1	5
Yoga										3	1	4
DHS office (Box Hill)		2							1			3
Swimming										1	2	3
Bowling				1	1							2
Haircut						1	1					2
Basketball			1									1
Buying take-away food				1								1
Holiday (Urban camp)									1			1
Total for month	5	12	21	14	7	20	22	15	14	9	11	150

Continuing to support community presence

Initially, the pattern of activities continued much the same as it had during Phase 3. The three dominant activities were bus trips, eating out, and house shopping.

> Went for a drive to Sunbury and to the airport, then to McDonald's for lunch. The [five] guys enjoyed a long drive. This was shown by them all relaxing and laughing. When we got to McDonalds the guys picked a seat, sat down and ate lunch with no issues. The guys picking their seat worked well because they chose to be away from people but where they could see the playground and children. (D/PL/130507)

Other activities, such as a trip to the cinema, the library, or bowling alley were recorded as occasional activities and were more likely to reflect a single resident supported by one staff member.

> Joseph loves popcorn. He ordered it himself by pointing, then paid the money and collected the change. Joseph also picked his lunch by pointing out a dish from a shop in the food court. When we went to pick up Franco's birthday present he chose a back-scratcher for himself then went to pay for it. [He] collected the change and hasn't put it down since. We saw Shrek 3 at the movies. (D/PL/230607)

These activities are indicative of the pattern of support that the residents received outside the home, either an individual or group of residents undertaking an activity supported by staff, which resulted in community presence. It is important to note that individual activities were being supported by staff, but the emphasis was on community presence, as a consequence of short-term planning or more spontaneous practice. Community participation needs more focused planning and a longer time-line.

Bonding: Visits to other group homes

Table 11 also shows that the men at 64 Penny Lane were supported to visit other group homes. In December, the season of Christmas parties, four visits to three other group homes were recorded on the Activity Learning Logs. This is another instance of what we described as bonding relationships (Putnam et al., 2004). In The Story So Far (Clement et al., 2007) we highlighted the fact that energy had been put into developing links with staff and residents in other group homes and suggested that this is unlikely to further the goal of building inclusive communities.

Sometimes such links were driven by pragmatic concerns, such as sharing a bus ride to a day program. In other instances it was concerned with maintaining contact between residents and staff who used to know each other at Kew. Yet in other instances it has been driven by the dynamic that underpins bonding relationships, bringing together people who have things in common, such as being service-users and having the label of intellectual disability. The important point here is that it is the staff at 64 Penny Lane who have focused on ‘intellectual disability’, ‘DHS service-users’, and ‘proximity’ as the important characteristics that binds people from different group homes together. By virtue of these qualities people who might otherwise be strangers to one another end up having lunch or afternoon tea together.

> Dan, Joseph and Milan went to [another CRU] for Xmas lunch and party. All guys were introduced to the other residents and staff then chose their own lunch from a table set up with all the yummy food on it. All guys were very relaxed and polite the entire time. (D/PL/091206)
>
> Dan, Joseph, Milan, and Wally went to another CRU for afternoon tea. The guys met the five residents and their families. They shook hands and then sat down to the birthday cake. The residents at [the CRU] were very interactive with the guys trying to engage them in chats. The guys were very eager to eat the party food and cake. One of the (CRU] staff arrived with her dog causing anxiety to Dan, Joseph and Milan. Moved the dog into the staff’s car but Dan was still anxious. Dan started pointing to the bus and the rest of the guys followed. We left shortly after. (D/PL/241206)

As we have suggested, this is practice that enlarges and strengthens the boundaries of the ‘distinct social space’ surrounding these individuals. During the transition training we observed managers actively encouraging bonds to form with other group homes. This was referred to as a ‘buddy system’ and another house might be termed a ‘sister house’ (F/LA/031005). What is important is that people understand the consequences of such actions. We do not disapprove of them outright, but reiterate that breaking out of this ‘distinct social space’ requires the development of bridging relationships, that is making links between people who do not seemingly have things in common (Putnam et al., 2004).

One can argue that a number of group homes in an area are a ‘geographical community’. In developing ‘Emergency Management Plans’ or ‘Disaster Plans’ people think about using members in this network, perhaps to the exclusion of other options. In one metropolitan region the fire evacuation policy is to put the residents in the bus and drive them to the nearest CRU (F/PL/200705).

It does seem that for some staff there is a strong need to develop and maintain links with other staff members.

> [Kew was] A little community. For the staff it was like a little community, everybody knew everyone, it was very social and fun, and we'd go for walks with the guys and meet up with people from other units. It was a social thing for the staff and the residents. More fun and more warmth than now. At Kew you stepped outside the unit there were 300 people you could choose to talk to. You felt that you were more supported, more like a little community and you knew that if anything went wrong there would be someone there to help. Here it's more - don't get me wrong here's not bad, it's just a different environment. One house in a street and the next house that we know is twenty minutes down that way. In that way it's different. More isolated. (I/SX/091105)

Certainly for staff that have worked in an institutional setting, developing links with other group homes may engender a feeling of 'community' and of being more supported. Such links may be important to individuals or may serve a functional purpose, but unless they are supplemented by other types of relationships then residents are likely to remain within the 'distinct social space'. If your frame of reference is such that the next house is twenty minutes away, you may miss the possibilities for developing 'community' and supportive networks that are much closer.

One of the authors was preparing lunch for friends when his oven packed-up. He went to his next-door neighbours and asked whether he could finish cooking the meal in their oven. Later the same week, his neighbour on the opposite side of the road, who has two small children, called to ask whether she could use the washing machine as hers had broken. People who work in group homes should not lose sight of the fact that people who live in the same street and the immediate neighbourhood are potential sources of help and friendliness.

Individualised activities with the aim of developing individual lifestyles and building inclusive communities

The introduction of yoga and swimming in February 2007, the sixth month after the arrival of the new house supervisor, marks a defining moment. These activities were the first real outcomes of the planning tool that we had introduced as a first draft towards the end of Phase 3 (see Appendix 8). In April, Franco was supported to attend an urban orienteering event, and the following month Wally joined a music group at a neighbourhood house. Over a four-month period four of the five residents attended an activity on an individual basis that was a direct consequence of implementing the Community Inclusion Framework. The one resident without an individual activity was Joseph, for whom we completed the social network assessment. Just as significantly, these activities were happening on weeknights, Tuesday, Wednesday, and Thursday. Previously, most leisure activities happened at the weekends and in groups.

The way in which the staff group used the Activity Learning Logs changed once these individualised activities had started. Staff no longer recorded all external activities, concentrating on these four individual activities and group outings at weekends. We have made the point that these 'diary records' have limitations. Unfortunately, there was not a detailed entry for each time a resident went to these activities. A staff member said:

> The problem is that I'll write [details] in the communication book and then I might not feel like doing it straight away on the log. Then you know what happens, September the fifth turns out to be September the twenty-seventh, and before you know it Sylvia will come. She didn't get upset the last time she was here, a few days ago, but she got upset the last-last time, which is understandable because she has to go through [the communication book] and write everything[29]. (I/LW/180907)

In addition, staff members were more or less skilled at writing useful entries on the Activity Learning Log. The following section presents some descriptive data from the Activity Learning Logs, other documents, and final interviews about these individual activities. Our intention is to give readers a sense of each activity, the successes, and the issues facing everyone involved, which includes the resident, the supporting staff member, other participants, and the person leading the activity.

Extracts from the Activity Learning Logs are presented chronologically, which reveal that a resident's involvement in an activity did not always follow a smooth trajectory. Extracts from the interviews have been included to provide additional commentary.

Yoga: Milan

Milan was enrolled on an eight-week yoga course at a neighbourhood house close to 64 Penny Lane. There were four entries on the activity learning logs, each

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[29] As Figure 11 indicates, the Activity Learning Logs should be sent to the CIO at the end of each month. The CIO completed some 'audits' at 64 Penny Lane and ended up having to extract details of the activities from the communication book. Figure 13 shows that as part of the Community Inclusion Framework the CIO reviews recording systems in the house. The guidance given was that staff should not be writing the same information in more than one place and that they should write this information on the Activity Learning Log not in the communication book (F/PL/220506).

supported by a different member of staff, two of whom were casual staff. We were advised that Milan did not want to go to yoga on one week and that the tutor cancelled another session (F/PL/040507).

A question on the Activity Learning Log is, ‘What did you learn about what worked well?’ After Milan’s first session the staff member wrote,

> Physical gestures/role modelling. Positive reinforcement, verbal praise, soft clapping, head massage for reassurance and appropriate active participation….Allowing Milan to walk around the room and watch other participants/teacher for approximately thirty seconds before gesturing Milan to sit back down on mat. Allowing Milan to participate/learn at his own pace, within half an hour Milan started to imitate the teacher/carer with stretching movements. Indicators of what worked well: Milan smiling, imitating actions, calmness, positive interactions. (D/PL/140207)

The extract suggests that people with severe intellectual disabilities may participate atypically in ordinary settings. A staff member should expect to prepare other participants for this and model ways in which they might engage with the person.

> Milan’s gifted in yoga and bending, but when I was in the room and you’ve got [the tutor] talking gently, telling us what to do, it’s quiet….I said, ‘If Milan gets up and goes to stand in the corner, or if he wants a pat, just let him, he’s happy to do that’. You really have to work very hard with Milan and in the end if he didn’t want you touching him, you just had to leave him, because he’d get upset and then that’s where he’d go to the corner of the room. The other women there were really good with him, they say ‘Hello’, but then everyone kept doing their yoga, because that’s what they’re there for. I can’t tell you if Milan got something out of it or not, I’m being honest about that. (I/LW/180907)

On a positive note the interviewee suggests that the other participants in a small class were tolerant of Milan’s behaviours and extended the rudimentary courtesy of saying ‘hello’. This was echoed in another entry in the Activity Learning Log.

> Milan liked the other ladies saying hello to him and also [the tutor]. He showed it by walking up to the others and looking and smiling at them. (D/PL/280207)

Milan is unable to give his ‘opinion’ of yoga, so staff must interpret his behaviour. In the interview quotation above, the staff member stated that she was unable to reliably interpret his behaviour. However, we might read the following extract and conclude that Milan did not want to be at the yoga class.

> As soon as we got to the [neighbourhood] house Milan was trying very hard to get me to leave. He was pulling on my arm and slapped himself on the head. He settled when the ladies spoke to him, but as soon as the class started he was walking around slapping himself on the head and distracting the other women. It was very difficult to show Milan the moves and he was very disinterested. (D/PL/280207)

Yet on another occasion, after another reluctant start, Milan did not want to leave.

> What worked well? Reassurance and talking to Milan in a soft voice. Rubbing his head. Having our mats touching. He reacted well to the yoga instructor helping him one-to-one. I took over from there.
>
> What didn’t work well? Milan was reluctant to go [to the neighbourhood house]. Couldn't feel comfortable once there. Approached instructor - she helped him and he settled. Taxi arrived and he didn't want to go home - class pretended to pack up and finish and eventually we left. (D/PL/140307)

The unusual end to Milan’s yoga class, a false ending, was discussed by one of the permanent staff.

> I was on the one night with a casual. If Milan doesn’t want to do anything, he’s pretty strong-willed like, he’ll push you away. And apparently this girl had a lot of problems because the cab came ten minutes early. They were trying to get Milan out but he knew the lesson hadn’t ended. He wouldn’t go and the only way they could get him into the taxi was for these girls, because I think they were all ladies in the group, they had to pack up their mats and then Milan realised that it was time to go. Apparently the lady taking the class gave ‘em a bit of bit extra time after Milan left. If it was me, and you’re not working in the field, you get a bit annoyed if you’re paying money for things like that. (I/JZ/190907)

Without interviewing the other yoga participants we do not know whether they were annoyed with having Milan in the class. Some of the other extracts suggest a willingness to engage and a degree of tolerance. If the taxi was early, rather than manufacturing a false ending, it would have been reasonable to ask the taxi-driver to wait until the end of the lesson.

The house supervisor provided a brief statement about each person's individual activity prior to leaving 64 Penny Lane.

> Milan participated in a term of yoga at the Neighbourhood House at the start of the year. This was successful in the early days but due to a variety of staff supporting Milan [it] did not seem to have the desired results. He still participates in yoga at his day placement with good results. We purchased a purple yoga mat for Milan as it was the same as the ones at [his day program][30]. The Neighbourhood House was a good location due to close vicinity to 64 Penny Lane [and had a] comfortable atmosphere. Unfortunately this did not allow too much interaction between the participants and it was decided that the next term would be sourced at a larger centre. We did not end up sourcing another appropriate venue. (D/PL/300807)

Swimming: Dan

Dan was supported to go swimming at a leisure centre, a short drive from 64 Penny Lane. In time it was hoped that he would join in an aqua-aerobics class. There were six entries on the Activity Learning Logs, supported by two members of the permanent staff, one of whom was the house supervisor. She supported five of the six visits to the swimming pool. In the four extracts that follow, each one about four weeks apart, there is a sense of the resident settling into a routine, becoming more comfortable and being supported in a way that tries to enhance available choices and a degree of control.

> Once Dan was in the pool he made lots of movement in the water with his hands. He was happy for me to lead him through the small kiddie pool, sliding along on his bottom. He waved his arms and smiled a lot when we were sitting near the water jets. The small pool had a gradual decline to the water so Dan was able to sit down and scoot forward on his bum. He picked up a flotation device and held it up to a jet to deflect the water. With a small amount of encouragement, Dan put his head under water and lay on his stomach. Dan scoffed down chips as a treat on the way home, smiling a lot and pulling my hand and pointing out the window.
>
> We arrived half-an-hour before the session to give Dan time to get used to the surroundings. An hour would be better. Dan was very reluctant to get into the small pool by going down the step. After a while in the small pool,

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[30] Purchasing the yoga mat was an effort to provide Milan with an 'object of reference' that would communicate to him that the yoga class would be happening in the near future. An 'object of reference' is a term that describes the use of an object as a means of communication.

> we headed to the larger pool. Dan was very unsure on his feet getting down the eight or so steps. Once at the bottom Dan was clearly uncomfortable, grinding his teeth and had a very anxious look on his face. We moved out of the larger pool. He was happy however to spend another half an hour in the small pool. (D/PL/150207)

When the same person supports a resident over a period of time, she is much better placed to make evaluative judgements about a person's behaviour.

> Dan is becoming more comfortable in the surrounds of the pool. He will now decide where we put our bags. Dan was not anxious until we were two metres from the pool. Dan feels more comfortable sitting on the ground and scooting his bum down 'the beach' to the shallow part of the kid's pool.
>
> Dan became anxious when it came to getting in the pool. He didn't want to move from the very edge of the pool. I tried to get him to the calmer parts of the pool, where there were no kids. Dan was really reluctant to move anywhere. I sat next to Dan for ten minutes to see if he would calm down or become more comfortable. After a while, I asked Dan if he would like to leave and he stood straight up and grabbed my hand to leave the pool. In the water of a total of forty minutes. (D/PL/150307)

The same staff member is not always able to support a particular resident at an activity. When the Activity Learning Logs are filled in well, they provide some excellent information for other staff members.

> Went to [the leisure centre] for a swim. Dan likes to sit down near the handrail to the pool when entering. He then likes you to be close to him whilst he is in the water. If you support Dan from around his back he will lean back to you which will allow you to walk around the pool with him relaxing. He will also float on his stomach as long as you are supporting him. Dan really enjoyed the hydro pool.
>
> Everything was great. Just make sure Dan is confident that you are there. Dan will not enter the pool without being able to hold the hand rail. Excellent time. (D/PL/190407)

When Dan first moved to 64 Penny Lane he used to get changed into his pyjamas immediately after tea, indicative of a learned routine where external activities were highly unlikely (Clement, 2007).

> You know that after dinner Dan likes his routine, he goes and does his pyjamas, but if we say he's going swimming he won't do the pyjamas, so

> that tell us that he wants to swim. Otherwise he'd put his pyjamas on in order to get out of it. And there were some nights in the winter when that did happen, and so we didn't go, but that's his choice. By him not putting his pyjamas on, that is saying to us that he does like [swimming]. (I/DF/190907)

As with Milan's yoga mat, the staff group had obtained an object of reference for Dan, to signal to him that swimming is going to happen.

> He's got his own backpack now and he puts his towel that he got for his birthday in his backpack. (I/DF/190907)

Over time, by interpreting Dan's behaviour, the staff have a developed a degree of confidence that swimming really is a preferred activity.

> Dan was eager to attend. Directed me to where he wanted to get ready. He indicated he wanted a drink, bought at the kiosk. Excitedly stuck his head under the water jets. Is becoming more confident entering the hydro-pool. Dan was happy to listen to the music played at the aqua aerobics. Dan indicated that he was ready to leave. (D/PL/170507)

The house supervisor's summary indicates the hope that, in the future, joining in a class at the swimming pool will become a reality.

> Dan has attended [the leisure] centre on Thursdays in the hope that he will move towards participating in an aqua aerobics class. Dan loves to play in the water. At this stage Dan has not participated in a while due to staff restrictions. [The returning house supervisor] seems happy to continue with this activity as it will fall on him to support Dan three out of four weeks….He has just been paying for access to the general pool, but would need to pay more if he was to participate in Aqua Aerobics. (D/PL/300807)

Orienteering: Franco

Franco was supported to go street orienteering in suburbs close to 64 Penny Lane, which were organised by an orienteering association. The spring, summer, autumn and winter seasons have separate series of events. There were two entries on the activity learning logs and one in the communication book. Franco was initially supported by a casual staff member and then the same permanent member of staff.

> Orienteering at night-time. Franco was eager to go in the bus and on arrival paced until we picked up the map and card, and off we went, with the help of a kind woman. We walked for nearly one hour, Franco started to tire but

> went really well. We walked to different points and punched our card. He did not seem to mind at all about walking in the dark. I definitely think this activity should be repeated. (D/PL/250407)

Sadly, the Activity Learning Logs are rather ‘thin’ in relation to this activity. During the final interview, Franco’s keyworker talked positively about the activity, and the shoes they had purchased as an object of reference for orienteering evenings.

> He’ll go and get those trainers in order to go orienteering. He’ll show you, and put them on, and give you his foot to do up the shoelaces. He even grabs my handbag and my keys, like, ‘We’re going orienteering tonight’. He’ll have dinner and then come in [the office] and get my handbag. He knows. (I/DF/190907)

> Franco was very excited before leaving the house as he was told prior that he was going on the bus. Once there I got Franco to hold the map and torch. Franco didn’t really enjoy being near everyone else when it was starting as there were a lot of people but once everyone started to walk it was better for him and he relaxed a little. Very good night. (D/PL/170507)

Franco’s involvement in an ordinary activity is especially encouraging. At the start of the project his behaviour was seen by the staff group as being problematic, particularly in a group context.

> Franco walked around the streets and got the markers of the sheet. Once back he had a coffee with the others from the group then we went home. Franco doesn't really like to be around at the group of people. (D/PL/150807)

The rolling program of activities through all four seasons provides a recurring activity where there are possibilities for social interaction. Franco’s keyworker had begun to act in a way where she was facilitating the group’s response to him.

> The people that run [orienteering] know Franco now. At the presentation night there was a trestle-table set up and it had quite a lot of food and drinks. So, obviously not the ideal situation for Franco to sit in a room full of people with a trestle table full of food and drinks. I did speak to the guy that runs it and he said. ‘You know, not a problem’. If by chance Franco did win [an award] he would do a presentation of who Franco was, where he’d come from, and how he’d come to winning this thing, and that in turn makes everybody else more aware of Franco. He’s there and he may have an

> intellectual disability but he'll still be there every week and he'll still do exactly what they're doing. (I/DF/190907)[31]

Music: Wally

Wally was enrolled on a music program at neighbourhood house. It turned out that the program was run by Able Music Therapy[32] and was only attended by other people with disabilities. Wally's keyworker explained,

> It was very hard looking for an activity, because it was a guess if he was going to like it or not. We wanted him to try cooking, then there was a barbecue at a neighbourhood house, then there was something else, and then music was the fourth one….I thought it was for people from a wide range of the community and then I found out it was other disabled people. Sylvia said that was okay, as a start. Wally likes music, so that was a positive, and we see where we could take it from there. Wally started three, four months ago. (I/LW/180907)

There were five entries on the activity learning logs, supported by three different members of staff, one of whom was a casual staff member. The same casual staff member supported Wally at three of the five sessions.

> What worked well? Calm atmosphere. The music instructor let him walk around to get familiar with surroundings, introduced him to other people, had the chance to hold and experience new instruments, however put them in his mouth. Liked and enjoyed 'Waltzing Matilda' when it was sung. Staff member to wait outside, so was less of a distraction for Wally and others. Wally was a little agitated his first session. Mentioned bus a few times. (D/PL/020507)

The tutor's preference was for the staff member to wait outside and not be part of the group. The staff member was therefore dependent on getting feedback from the tutor.

> Attended music program. Two others (both women) and teacher. Involvement in class, early days yet but teacher seem to think Wally enjoyed the class. He particularly enjoyed listening to Waltzing Matilda. He was most eager to leave when I picked him up and kept repeating 'Others'. Keen to get back in the bus and returned home to have dinner with the

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[31] Franco did not win an award; but there's always next season.

[32] Able Music Therapy is run by Able Australia, which used to be called The Deafblind Association. Able Australia Services provides services for people with a range of multiple disabilities including deaf-blindness

> others. Apparently the drums were very noisy and Wally didn't like the loud sound. The teacher said Wally was quite anxious at times. (D/PL/090507)

A member of staff did sit in on one occasion.

> I don't think Wally's really into banging musical instruments. I sat in on one of these classes and my God I was struggling to stay awake, the whole place is so relaxing. She sings individually to the residents, and I think that's what Wally likes, rather than the music so much itself, because what she does isn't really music, she doesn't play a song or anything like that. She puts all the guys on beanbags and stuff like that, and she'll come right up and she'll strum on the guitar and sing, 'Hi Wally, how're you going today?' She's got little chimes hanging off this 'T' thing, and she just runs her hand and then she'll get Wally to do it? There's something about the aura in the room. I think that's what Wally likes, the relaxation side of it, the down time, more so than the music side of it. (I/DF/190907)

As with the other residents, people are interpreting Wally's behaviour as indicating that he wants to go to the music group.

> I believe it's a positive thing for Wally. He enjoys going, he goes to the door, he waves, and he's eager, he's not drowsy or sleepy. You'll go up to him and say, 'We have music this evening' and then he'll start vocalising and he'll say, 'Bus', so it's connecting. (I/LW/180907)

> What worked well? The interaction of musical instruments with Wally, the sensory involvement, participation during songs, choosing an instrument to play. Wally really enjoys these music lessons. I think they are fantastic and Wally should continue going - perhaps others too? (D/PL/010807)

The house supervisor concluded:

> Wally seems to enjoy this activity. It was sourced with the understanding that it was an activity for the general public; unfortunately it seems to be specifically for people with disabilities. Another activity, possibly another music activity, will need to be sourced in the coming future. (D/PL/300807)

After this house supervisor had left, Wally's keyworker explained that she had enrolled him for another series of music classes.

> His contract would have ceased at the end of September, but because I've spoken to [the tutor], she said to me, 'He's starting to open up and there's certain songs that he likes and he'll join in with the rest. There's other songs where he might not be familiar with and then he retreats and holds

> back'….I've extended the contract until the end of the year and that will give us a better idea of where he's at, and maybe that will take him down another avenue or path. I feel like Wally needs a little bit more time to see where he's going with this music group. I'm aware that it's not a non-disabled group, but we discussed that here, so I feel for Wally it's right, it's a good thing for him. (I/LW/180907)

In the next section we offer some reflections about these activities in relation to the goal of building inclusive communities and discuss some issues that seem to be important in making this change of practice come about.

Reflections on the four activities

Although these four activities all contribute to the broad goal of building inclusive communities, we would suggest that they have little potential for facilitating community participation, and there is even less chance of making close friends with non-disabled people, with one exception.

All four activities reflect community presence, the sharing of ordinary places, two neighbourhood houses, a leisure centre, and the streets in an urban environment. The activities could also be described as communities of interest: people with an interest in music, orienteering, swimming, and yoga.

Given that the music class turned out to be for people with disabilities, facilitated by a music therapist, the activity helped to enlarge the 'distinct social space' that Wally inhabits. The more likely outcome of swimming and the yoga class, even if Dan joins the aqua aerobics class, is the formation of acquaintances.

Unless you attend with a friend, then the general nature of these activities is that single people turn up to participate in a class and return home soon afterwards. Milan may be greeted by other participants; Dan may be recognised by the leisure centre receptionist; but they afford little opportunity for the type of interactions where non-disabled people can make a judgment about whether they want to spend more time with Milan and Dan. The same dynamic is true of the participants in the music group. If Wally is to have the opportunity to see whether he will interact with other participants in the class, then he would need to spend more time with them in a different context.

Another important factor that is common to the music and yoga classes is that they are both time-limited. Milan's yoga class, for example, ran for eight weeks, of which we know he attended at least four classes. This is similarly unlikely to be long enough for other participants to get to know Milan and make a judgment about whether they want to spend more time with him.

Orienteering on the other hand seems to offer better opportunities for community participation and greater opportunities for moving from acquaintance to friendship. Not only does orienteering have a rolling program of events, which are likely to be attended by regular participants, but the nature of the activity allows for interactions between people. Less competitive participants can walk and talk between control sites and presentation evenings allow for more social interactions.

Activities or places where the same people can meet routinely, over an extended period of time, seems to be a prerequisite if non-disabled people are to make a judgment about whether they want to spend time with people like Dan, Franco, Milan and Wally. Given that we know that people with severe intellectual disabilities have features and behave in ways that non-disabled people with limited direct experiences of disability find disconcerting, then fleeting or short-term interactions may actually reinforce a person’s view that he or she does not want to spend time with *any* person with intellectual disabilities. Participants in the yoga class had to contend with Milan slapping his head and standing in the corner; other swimmers may have heard Dan grind his teeth or seen a middle-aged man scooting along on his bottom in the children’s pool, in both instances accompanied by people who are there to ‘care’ or ‘support’ them. Given that people with limited direct experiences of intellectual disability are likely to have prejudiced and stereotypical views of ‘intellectual disability’, then witnessing such behaviour or having a short ‘uncomfortable’ interaction may confirm the prejudice rather than challenge it[33]. Only over time do people move away from a relationship based on categorical knowing to one based on personal knowing, i.e. ‘intellectual disability’ becomes less salient and the qualities of the individual person becomes more pronounced (see Bogdan and Taylor, 1987, 1989).

It is worth repeating the point that we made earlier. Service-workers must learn to identify activities and places where the same people can meet routinely and where friendships are more likely to happen.

The way in which activities are supported impacts on whether community presence is the only outcome, or whether community participation, and in particular the move from acquaintance to friendships has any chance of happening. Milan was supported by four different members of staff at the four

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[33] A relatively ‘old’ article by Davis (1961) contains some still relevant ideas about short interactions between non-disabled people and individuals with a visible disability. He describes awkward interactions, characterised by embarrassment, which convey the message that the non-disabled person is having difficulty relating to the person with the visible disability.

yoga classes, whereas Dan was supported by the same member of staff, the house supervisor, on five of the six visits to the swimming pool.

High-quality services need adequate resources and for those resources to be well organised (Emerson and Hatton, 1994). Crucially, how staff are deployed will impact on the success of building inclusive communities. A fixed roster, which operates at 64 Penny Lane, is unlikely to provide enough flexibility in the allocation of staff resources. The house supervisor could support Dan to go swimming because she worked three Tuesday evenings out of four on the four-week roster.

When Wally began his music class on a Wednesday, this was also the same evening that Franco went orienteering. This meant that they ended going alternate weeks, or coming to another arrangement.

> In the case of Franco and Wally the activity shared the same night. If it was really crappy weather one week, then it really wouldn’t have been good for Franco to go. We’d just swap it over and Wally go that week and then Franco go the week after. (I/DD/180907)

If more flexible staffing arrangements existed then an additional staff member could be allocated to support both activities and support the residents remaining at home.

Direct support staff have a better chance of acting like a facilitator when they have got to know a setting, the people who inhabit it, and how the person they are supporting behaves in that setting and interacts with the people in it. Even with excellent Activity Learning Logs to read and good supervision, a member of staff who supports orienteering occasionally is disadvantaged in relation to the goal of building inclusive communities compared with a staff member who attends every event. A casual member of staff is even more disadvantaged. This will not always be the case. Once an activity becomes well-established, strong natural supports will compensate for weaknesses in service-based supports.

It may seem that we have given these four activities a strong critique, especially as we have suggested that this was a genuine attempt to undertake some individualised planning, which also reflected a significant change in practice. Yet it seems to us, that staff in any group home must adopt a similarly strong position in relation to their own work if they are to learn from other people’s ‘mistakes’. This strong critique must take place at the start of the planning process. As the experience of Wally’s music group suggests, it is much harder to change direction when energy has been invested and steps have been taken down a particular path.

One of the hopes of the project's research methodology was that staff would become better at learning 'practice' lessons through reflecting on their own practice. There was evidence in the final interviews that staff were critiquing the activities.

> [Swimming] would have been an all-right activity had Dan actually got to the point of moving from just being in the hydro-pool with the staff to participating in the aqua-aerobics. I think there could have been a better activity. Actually I'm sure that there could have been a better activity….If [implementing the Community Inclusion framework is] to continue for a lot longer I think it would be more successful. In terms of making those connections with people only Franco would have those ongoing experiences. I think [the residents] all got good things out of it, but in terms of making those relationships and forming those bonds with people, I think it would have to go for a lot longer. That's probably what's going to happen in the house. To say that there were new people brought into their lives at this stage, I would have to say no. (I/DD/180907)

Issues that seemed to be important in making this change come about:

Practice leadership

In an earlier report, house supervisors were portrayed as practice leaders (Clement and Bigby, 2007). We defined this term using everyday words, such as coaching, directing, role-modelling, and supervising. In contrast to the first house supervisor whose 'leadership' we suggested developed and maintained the pattern of community presence, the new house supervisor gave a strong 'lead' in trying to change this pattern. This leadership role was evident at her first house meeting.

> The meeting ran out of time and we reached the same point that we seemed to have reached at every other meeting. Deidre, [the house supervisor] made an intervention. She didn't think that we would resolve [these issues] today, so we should leave it with her[34]. (F/PL/270906)

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[34] This is a good example of why we think house supervisors are primarily managers rather than leaders. Although the house supervisor has 'given a lead' to the staff team she has essentially behaved in a way that is consistent with implementing the Department's goal. Day-to-day practice became congruent with the aspirations of the wider organisation.

We were content to give the new house supervisor some time to implement the Community Inclusion Framework. This was entirely consistent with our view that the house supervisor has the main responsibility for the effective performance of direct support staff and the implementation of the Department's goals. Giving the house supervisor some space to do this allowed us to complete the social network assessments that we described in Phase 4. Although there was a significant delay before the first activity happened, (an issue we discuss below), credit should be given to the house supervisor for facilitating the change in practice that we have described.

Keyworking

The house supervisor was the keyworker for both Milan and Dan, who were the first residents to have activities arranged for them. As a keyworker, the house supervisor had the responsibility for making sure that they received an individualised service. We claimed earlier that the keyworking system was not operating in any real sense at the house up until the end of Phase 3. We gave the house supervisor some information about keyworking soon after she arrived. Not only did she take on board the responsibility for planning and organising for the activities to happen, but she also personally supported Dan to go swimming on five of the six recorded occasions. Whether you want to call this 'role-modelling', 'leading by example' or 'practising what you preach', the house supervisor demonstrated to the staff group how they were expected to behave.

> For a couple of the staff I think it was probably good to see how, once you got over the initial research of finding the activity, getting it up and running wasn't a big deal. Some staff were really keen to go, 'Okay, now I've seen that can happen it's given me a bit of an idea of what this is all about'….So, Linda and Dawn they organised activities for Wally and Franco. (I/DD/180907)

As practice leaders, house supervisors have a key role in supporting the effective performance of the direct support staff. This means making clear to direct support staff what they should do and how they should do it. In this instance it meant demonstrating that you could organise the house so that a resident could go out, everyone would still be fed, and the house would be kept acceptably clean and tidy.

> When I first walked in the mentality was just, 'This is going to be huge; it's going to mean so much work'. On those nights when the guys are actually participating in activities, the staffing [levels are enough] not to have any

> concerns about the house not being clean, or tea not being cooked, or whatever was the concern. It proved that wrong after we got things up and running, that they were not valid concerns, or they weren't reasonable. (I/DD/180907)

We have also made the point that practice leadership needs to be considered in a group context. The house supervisor had begun to alter the working environment, which another staff member highlighted as being critical to getting the staff group to support the activities.

> The best thing that has happened in regards to staff commitment, to taking a resident on an activity, was for that staff member to have sourced an activity for their key resident. Then you get the commitment. Once an activity was sourced for their key resident and they want the commitment from the other staff, then they know the commitment has to come from them in regards to the other activities. (I/DF/190907)

Certainly the change of house supervisor created a situation that was more conducive to the successful implementation of the Community Inclusion Framework. For the researchers and the CIO, who had been involved for at 64 Penny Lane for fourteen and seven months respectively, having to wait a further six months to see any outcomes for the residents seemed an interminable delay. Yet, the house supervisor faced some considerable constraints in implementing the Community Inclusion Framework, which have broader implications for implementing organisational change.

Issues that seemed to delay the change in practice

With limited prior experience of being a house supervisor, not only did the new incumbent have to gain knowledge of the role, but she also had to learn about the specific context in which she was managing, such as the personal characteristics of the residents and the staff, relationships with family members and available resources. A first-rate induction, both to a job and a setting, will assist good performance (Ford and Hargreaves, 1991). The house supervisor's view was that her induction could have been longer and better planned.

> I understand that they had constraints [because] they were going to be left with a house that didn't have a supervisor, so they had to move me here quickly. But in terms of my preparation and me getting a handover [I would have liked] better designed time-lines. Okay, the decision's made, give it a certain amount of time for the news to digest and for preparation, but then also have some follow-up after the changeover has occurred....After the

> changeover had occurred I think I probably could have done with a little bit more support….I suppose if I'd had a better handover given to me then I might not have been so idealistic and then felt so let down when what I tried didn't work. (I/DD/100107)

Our meeting to brief the house supervisor about the project might not have dampened her idealism, but it gave her the opportunity to hear our candid views about some of the issues that she needed to address in implementing the Community Inclusion Framework.

The house supervisor is an important channel between more senior managers, such as the CIO, and direct support staff. She therefore had to 'to face in more than one direction' (Reynolds, 2003, p.16) and experienced downward pressure from the CIO and upward pressure from the staff members she managed (see Elliott and Rose, 1997). Having taken on this 'leadership' role, the house supervisor had to find a way of dealing with the conflict between the different parties and find a way of implementing the Community Inclusion Framework.

> Walking into the project that is already up and running and the first I heard it was just like, 'Great, that sounds really good' but then getting into the house and hearing that there'd been a little bit of tension it made it a hard to be a voice for the staff, to be encouraging….I felt very torn in terms of what I was to do when I first got there because there was so much going on and having to catch up. That made it quite hard and the pressure did mount. A couple of times all of that sort of stuff needed to be aired for us as a team to go on. (I/DD/180907)

An initial early pressure was to develop Person Centred Plans for the five residents. Having to spend time thinking about PCPs helped to crystallize the residents' interests for the house supervisor and this informed the development of the individual activities. The list of activities given in Table 12 was given to us[35].

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[35] Basketball, cooking classes, football clubs, music, swimming, walking groups, and neighbourhood houses were all identified as activities and venues they would go away an explore at the half-day meeting 11 months previously (F/PL/030206).

Table 12. Activities identified for each resident (F/PL/240107)

Dan	Franco	Joseph	Milan	Wally
• Mosaic/pottery • Water aerobics • Basketball team	• Walking group • Music group • Pamphlet delivery	• Mosaic class • Social group • Cooking class	• Movie matinee • Music group • Yoga	• Dinner group • Music group • Community bus trips • Cooking class

With the exception of basketball and pamphlet delivery all of these activities were taken from programs at two neighbourhood houses. There is a point to note about this list. The first is that the mosaic and music classes appear for more than one resident. As part of our role in being more directive, we 'suggested' that only one resident should be enrolled in a class. This advice was consistent with our experience that having more than one person with intellectual disabilities in a class would negatively impact on the possibilities for making relationships.

It is also worth noting that one of the casual staff commented in an extract from an Activity Learning Log given earlier, 'Wally really enjoys these music lessons. I think they are fantastic and Wally should continue going - perhaps others too?' (D/PL/010807). It may be tempting to want to enrol another resident in a class that is successful, but we think it is important to resist the temptation. Not only does an individual activity become a 'group' activity, but in other settings larger numbers of people with intellectual disabilities impact on the possibilities for making relationships with non-disabled people.

The house supervisor's view reinforces our earlier suggestion that information in the documents such as IPPs and GSPs was of limited value in generating a useful starting list of activities.

> I still stick by the fact that PCPs would have been a very good tool to identify activities for the residents, if that was done before the project began. I think that getting all of that information would have identified these activities, so then we could have tied them in a little bit better and I think that would have helped the staffs' understanding. But that wasn't there at the start so I can't really criticise how it all began. (I/DD/180907)

Time will tell if adopting Person Centred Planning on a large scale in Victoria contributes to building inclusive communities. The largest formal outcome evaluation of PCP to date showed no impact on ‘inclusive social networks’, although there were benefits in other ‘quality of life’ domains (Robertson et al., 2005, 2006).

Stability: Team manager, house supervisor and staff group

Whilst she was developing the PCPs the house supervisor reported that she received some useful guidance and support from her team manager, which reflected our efforts to involve the team manager more positively.

> [The team manager] was quite proactive and was happy to chat to staff and put in effort to make sure it sort of tied in with the [project], making sure that staff understood exactly what goes into a PCP. (I/DD/180907)

However, 64 Penny Lane was one of the houses in the Making Life Good in the Community project where we observed a significant turnover at the team manager level. We have written at length elsewhere of the importance of creating stability in both the house supervisor and team manager positions (Clement and Bigby, 2007). During her 12 months at 64 Penny Lane the house supervisor had four different team managers over five different periods, that is, she had the same team manager but on two different occasions. The house supervisor commented:

> I suppose not having that continuity was really hard because you’re dealing with different people and perspectives. (I/DD/180907)

Stability at the team manager level improves the chances of giving better support and developing a relationship with the house supervisor, the staff team, the residents and their families. An enduring relationship increases the likelihood of good supervision, provides a platform for consistent messages, and means that both parties are aware of important issues, such as building inclusive communities, which are more likely to be followed through.

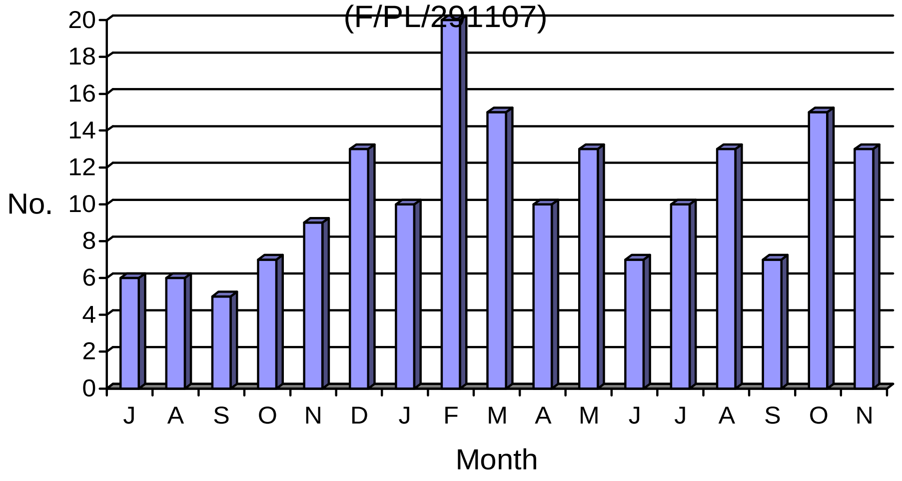
Providing people with intellectual disabilities with a stable, skilled workforce is integral to providing quality services (Lakin et al., 2005). One month after we were told to ‘leave it with me’ we returned to the house to find little progress had been made.

> Deidre’s first comment was that she had ‘stepped back’ from the inclusion work and the impression she gave was that nothing had really happened. She explained that there had been ‘no continuity of staff’ and ‘she had not been able to do the extras’. A number of staff had been sick or on annual leave, which had increased the number of casual staff in the house. The two

> active night staff had had one month annual leave each. Martin [a full-time day staff] had moved to nights and was now on annual leave for two months. (F/PL/291107)

As well as having to obtain casual staff to fill-in for sickness and annual leave, there had been some part-time vacant lines on the roster since the house opened. Figure 20 shows the number of shifts that were filled by casual staff each month since the house opened.

Figure 20. Number of shifts filled by casual staff at 64 Penny Lane from July 2005 to November 2006 (F/PL/291107)



The number of shifts filled by casual staff in October and November 2007 (28) is the highest two-month aggregate in any period apart from February and March of the same year (35). In such circumstances it was not surprising to hear that the house supervisor had ‘stepped back’ from the inclusion work.

Although some casual staff are excellent and may become regular workers at a house, planning and supporting the goal of building inclusive communities is less likely to de done when there are high numbers of casual staff. The focus becomes one of ‘keeping things going’ and ‘avoiding major incidents’, whereas building inclusive communities requires the staff team to ‘do new things’[36]. At the same meeting the house supervisor made some remarks about having so many casual staff.

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[36] ‘Keeping things going, putting things right, and doing new things’ are a way of thinking about management, which was learnt at Roffey Park Management College.

> There were some casual staff that they didn't have confidence in. It was not a good idea to go out with one resident and leave the casual in the house with four residents. The service doesn't flow when you use a lot of casual staff. Deidre said that she had prioritised the quality of care within the home. (F/PL/291107)

In one of the final interviews a member of the direct support staff echoed these sentiments.

> We still we still have the same issues as we did a while back, which is staffing. I can't always go orienteering with Franco and leave a casual here, because the casual might not know the house, they might not know the residents and if we've been having issues with a resident I don't feel comfortable with my duty of care to leave that casual here in case an incident occurs. (I/DF/190907)

Residents are likely to miss out on activities when a staff group is unstable. Rather than become a 'regular', a person's membership and interactions becomes fragmented. Complex issues, such as building inclusive communities, are unlikely to be effectively progressed when they move in and out of focus.

Stability in the house supervisor position also creates a better environment in which to exercise consistent practice leadership. Turnover at this level is not only caused by people leaving the organisation or being promoted, it is also related to the practice of removing incumbents to act-up or be seconded elsewhere, as at 64 Penny Lane. In the two-month period where there was the highest use of casual staff the house supervisor was acting-up as team manager, another staff member had been removed to act-up as a house supervisor elsewhere, and a full-time member of the day staff was covering an active-night staff's position, who was on one month's holiday.

As well as alluding to the personal toll that the job had on her, which was likely to have been exacerbated by the lack of a stable line-manger, she indicated that the house supervisor 'merry-go-round' impacts on motivation.

> Once I did find out that [the former house supervisor] was coming back, I wouldn't say I slackened off, but I stepped back a little and let things run their course a bit more. I probably had a little bit of burnout and probably had had enough for a bit. To know that [the previous house supervisor] was coming back was like, 'Oh well, do I really put in two months of a lot of effort and make sure that everything's up and running?', [only] to have the understanding that when he comes back that things might fall back a few

> steps, or do we just keep things going and then let the house sort the rest of the stuff out? There were times where I had had my fill of trying to motivate some staff. I'd just sort of had enough. (I/DD/180907)

Although the intention had been to find another venue for Milan to pursue yoga, this did not happen. When staffing resembles a 'revolving door', with changes of team managers, house supervisors and direct support staff, there will be constraints on enabling community participation.

Football: Joseph

The planning that had been done for Joseph is instructive of what can happen when the staff team lacks continuity. In her outgoing summary statement the house supervisor wrote:

> Nothing has happened for Joseph to date, but we have had encouraging phone conversations with Henry from Box Hill Hawks in terms of a membership for Joseph. I explained to him that we would be hoping for Joseph to form connections with people from within the club, etc. He suggested getting Joseph to help out in the Social Club section on game days, meaning he will be seeing the thirty-odd regulars that watch the game from indoors. I have sent a letter to Henry outlining what we have discussed. The next step is to get Joseph a membership in 2008 and start the conversation again with Henry before the start of the season in April. Paul and our student will be working together to source an activity for Joseph in the interim. (D/PL/300807)

The Activity Learning Logs describe Joseph's first visit to watch another football team.

> Went to watch a quarter of a local football match. Joseph thoroughly enjoyed watching a quarter of football. He was very observant of people walking by and waving hello. He was also very happy when people were walking by with their pets, wanting to pat them but couldn't get close enough. It was difficult for Joseph to follow the game the first time but I tried to show him where the ball was when it came closer to us. But he still found it difficult to follow. I think in time he might get used to it. (D/PL/150707)

Joseph's keyworker explained that changing the house supervisor had resulted in a change of focus.

> When Deidre was here, she wanted him to be more involved with the club, rather than just going to watch it. So he'll be hanging around the social club and seeing other people. They were saying that he could clean the place up while he was in there. Simon is not really for that. (I/PO/180907)

Rather than help out in the social club, Paul outlines an alternative plan.

> My idea was when you go, to sit in a certain spot. Everyone has their spot, you sit around with the same people, week-in week-out, and you start to get to know them. That's more of a social interaction. He doesn't have to go, clean things up, but he can still interact with people. That was my plan, but I have to wait and see how we go. (I/PO/180907)

There is merit in both strategies, which would benefit from being interrogated by the new staff group at 64 Penny Lane. A place to start might be to reflect on the information that is already available to them.

> We took Joseph to the local game; he was sociable, waving to people. He's very friendly in that way, and they waved back. They acknowledged that he was waving to them and that sort of thing and he seemed like he really enjoyed it. I don't know how many football matches he's watched in his life but each time the ball come down I'd try and point it out, 'Right, here's the ball now, this is where the action is, right here'. And then when the ball went up the other end he'd start focussing on the people around him again. When the ball came down again I'd say, 'Look, there's the ball again'. (I/PO/180907)

As well as the information in the quotations we have used, there is also the social network assessment to draw up, which reinforces messages in what people have written and said.

> Joseph is a very social person. He initiates interactions with people, even complete strangers. He enjoys the company of others…. Joseph is also able to offer reciprocal support to some of the staff in the house. In particular, he is able to offer concrete support, by helping out with jobs around the house. (D/PL/110507)

Our reading of the evidence suggests that Joseph is likely to get more out of interacting with the people at the Box Hill Hawks rather than understanding and reacting to the ebb and flow of the football itself. The same is true of Franco's involvement in orienteering. It is unlikely that he understands the aims of urban orienteering, but it provides him with an opportunity to walk in a context where he has the possibility of building natural supports.

We see nothing intrinsically devaluing doing some voluntary work in the social club. Members of staff at 64 Penny Lane may have different views. Given that Joseph offers concrete help in the house, and is the easiest resident to engage in household tasks, collecting empty glasses, for example, may provide a reason for engaging with regular members. These are issues to be debated by the staff team now that we have withdrawn from the ‘field’.

The skill mix of the staff group revisited

An important factor in the management of group homes is the skill mix of the staff working in a particular setting (Clement and Bigby, 2007). There may be just as much variability within a group home as there is between group homes. When 64 Penny Lane opened the majority of the staff group moved from KRS. Although some staff can make a comfortable transition to a group home, the first house supervisor suggested that a number of the staff at 64 Penny Lane did not easily adjust to the more demanding role in a community-based service. This view was echoed by the outgoing house supervisor:

> I’ve worked in completely different environments compared to some of the other staff at 64 Penny Lane. I think that amounted to being a little bit more flexible in thought patterns and processes. I think that’s just the differences of people working in an institution. What are your experiences for the last ten years compared to the experiences that I’ve had for the last ten years? They’re completely different. (I/DD/180907)

We have suggested in this report that building inclusive communities requires direct support staff to understand that their role is to facilitate society’s responses to individual support needs, which is a move away from service-centred thinking. The ease with which staff adopt this role and develop the accompanying skills places demands and constraints on a house supervisor’s management of the home. The house supervisor hinted at this:

> It depended on the role that the staff saw themselves as [having]. Did they see themselves as somebody that is responsible for going and sourcing an activity, sourcing the money and making sure that it doesn’t clash with anything else? [Or did they see themselves] as somebody that walks into the house and supports the residents in completing the housework and making the meals and all that sort of thing? (I/DD/180907)

As ‘outsiders’ our approach was to try use the tension between these opposing views as a basis for engaging with staff in order to generate a changed view of the direct support role and ultimately practice.

> [The different experiences were] also good because it got everyone thinking and talking, but then it also made it hard because of that mindset and that thinking. They're prepared to try and get themselves out of it but it's going to be a long process, compared to just going, 'This is what we can do, these are our options, we'll do that one, off we go'. (I/DD/180907)

Rather than an external challenge, staff with a more service-centred view need more internal direction, coaching, and support. Yet house supervisors often find themselves constrained by organisational structures and unable to provide the levels of support necessary for a directive leadership style (Clement and Bigby, 2007). Direct support staff can therefore find themselves left more or less to their own devices. We would suggest that this has contributed to the slow progress that has been made at the house.

> I think once we decided that this was something that we were going to do, and this was something we're going to do as a team, that's when we stepped over the line. I wouldn't say we ran with it, [we] started walking with it and activities started happening. People were more prepared to put in that forethought of what this all meant. I think that's why you were getting so frustrated because it took staff so long to actually get to the point where we're going, 'Alright, the reason that we're here is for them to participate in activities rather than getting them out and just being seen'. It took a long time to get to that, but I hopefully everyone's a lot more 'au fait' with what it's all about. (I/DD/180907)

Changes in knowledge and beliefs?

So, two years and two months after the house opened, eighteen months after the CIO's first visit to the house, are the staff team at 64 Penny Lane 'au fait' with the difference between community presence and community participation? Have they bought into the goal of building inclusive communities, and more specifically the research goal of expanding the social networks of people with intellectual disabilities to include relationships with non-disabled people?

Asking people to explain the difference between community presence and community participation is a reasonable way of testing their knowledge. The four direct support staff who gave a final interview could all make a distinction between these two terms.

> I know what community participation is. Whether it be staff or residents together going out into the community, whether it be shopping or going to the park, it's merely a presence, it's not actually interacting and

> communicating and forming your social networks. We had many, many, many arguments about this, not that they were arguments, but maybe I've come a long way, maybe I've shifted in the way I think. I don't know if that makes sense to you but I think because I came from an institution and I worked there for a very long time, I think it was a big leap to go into the community with these guys and perhaps I didn't see it. I saw community participation as merely being a presence in the community, I believed it was saying 'Hi' to the cashier, the guys putting food in the trolley, but I understand it'd be more to form a social network, to bond and make friends and see the same people from a group where you attend. It either grows or it doesn't, it's like us. (I/LW/180907)

Interviews are, however, not a reliable source of data about what people think about an issue. Nor are they a reliable source of information about what people actually do (Edgerton, 1984). So, although the quotations below are indicative of a shift in attitude, we cannot claim that that the quotations reflect an actual change in the respondents' attitudes. Nor can we be certain that efforts to build inclusive communities through individualised activities will continue now that we have 'withdrawn from the field'.

People stated that supplementing group activities with individualised activities was a positive change in practice.

> Having the individualised things was great. It gave them one-on-one, it gave them a sense of feeling valued in that staff are actually putting in the effort to do this for them, which they wouldn't have got otherwise. (I/DD/180907)

Another respondent ascribed positive psychological changes for individual residents. As we have suggested before, we do not know Wally's inner mental states.

> I guess [Wally] feels like, 'Oh, this is about me, and it's only me'. I'm not sure, I think he likes that. Whereas in the beginning it was like a chore to get him to the door….It must do something to the self-esteem, confidence, and a lot of other things, 'I'm important', you know….We tend to think that we always have to go out together all the time, but I think it's good to have a bit of time on your own. It's good to work with staff, but it's good to be by yourself too. It's a bit like that for the residents, instead of always being in each others' pockets and seeing the same thing and doing the same old thing all the time. (I/LW/180907)

Views expressed in the final interviews about the possibility of forming 'friendships' with non-disabled people were a million miles away from opinions articulated at the half-day meeting. Two staff members who had been present at the half-day meeting, where it was stated, 'You can't expect the guys to participate with non-disabled people' (F/PL/030206), said:

> [Friendships are] going to take some time, but it's definitely something that will happen. I can see it in orienteering already. Sometimes someone that walks on their own will come up and have a chat and you end up walking the course together. Although Franco doesn't talk verbally talk, he's still there and he's still part of the conversation, even if he is just listening. I'll introduce Franco and you see them the next week and you say 'Hi'. (I/DF/190907)
>
> You'd be surprised who we can [form] friendships with, people from different races, different beliefs, different everything. I know we're just taking a baby-step and I think we've got a long way to go. I'm not sure if Franco's going to form a friend with someone, we really can't say. I can't say to you that you're going to form a friend with someone tomorrow from a group you've never attended before but I think if we continue with these one-on-one activities I can see someone spending time with Wally and I can even see someone spending time with Franco, believe it or not, and saying, 'Come on mate, we'll go for a walk and then go for a Coca-Cola or a milkshake at McDonalds'. It's not farfetched, it can come real, but I don't know if it's going to happen or not because I'm not psychic. I think anything's possible. (I/LW/180907)

The statement, 'I think anything is possible' is an upbeat way of ending our discussion of the final research phase. It reflects a type of belief about which there does not have to be consensus (Rokeach, 1968). As it happens, we also believe that 'anything is possible', which we have tried to make clear throughout this report. People who hold this view probably believe in the transformative potential of people, for good and bad. The world and the people who inhabit it are not fixed. It is possible that someone from the orienteering group will want to spend time with Franco. It is possible that over time that person may call Franco a friend. It is possible to facilitate such interactions on a large scale. It is possible to reach a consensus on the meaning of building inclusive communities and work towards its realisation.

12. Discussion: Conclusions, lessons, future research, and unresolved issues

The data that we have presented in this report is primarily related to our efforts to encourage community participation at one house over a two-year period. In this final section we summarise the major claims about 64 Penny Lane, make some empirical generalisations about building inclusive communities in other settings, and raise issues that have relevance for policy-makers, mid-level managers and practitioners.

Revisiting the primary research goal: Beliefs, outcomes and findings

Given that our primary research goal at 64 Penny Lane was to expand the residents' social networks so that making friends with non-disabled people was a possibility, any reader must conclude, as we did, that our efforts were unsuccessful. None-the-less, we have learnt a number of lessons, especially in relation to the barriers that need to be overcome in realising this goal.

During the course of the research we also tried to critically examine the premises that underpin the research goal. Nothing that we have discussed in this report has made us change our belief that building inclusive communities is a worthwhile goal. It seems to express something about the kind of society we would like to live in, which is relevant for all people with intellectual disabilities. This is not to say that building inclusive communities for people with severe intellectual disabilities is not a challenge. The fact is, you only need to establish one relationship to demonstrate the possibilities; but as the experience of the last 30 years has shown, achieving this on a large scale is a different proposition.

Even though there were no positive outcomes in relation to the primary research goal, we have described a number of other encouraging outcomes in the main body of the report. Yet we think that we should be cautious about over-celebrating all of the positive outcomes. Caution is due because building inclusive communities is a complex term comprised of interrelated sub-terms. Progress in one area may have a negative consequence in another.

The staff at 64 Penny Lane put a lot of effort into increasing the number and variety of ordinary places that the residents know and access, and we would claim that the residents have greater community presence in their new home than they did in Kew Residential Services. However, the types of activities that people did, and the way in which they were supported, meant that there was little potential for facilitating community participation. As we shall argue later, because organisations have a finite capacity for pursuing their goals, overly focussing on community presence may leave limited or no time for facilitating community participation.

Planning and supporting individualised activities on weekday evenings was a significant change in practice at the house, which seemed to be accompanied by changed thinking about the goal of building inclusive communities and improved reflective practice. This may have represented the beginnings of 'cultural change' at the house. Yet this represented a small 'cultural shift', over a relatively long period of time. It was also associated with a significant injection of resources in the form of the CIO and the researchers. Although this report contains some lessons about implementing change it also points to both the length of time and the investment of resources that might be required to produce changes in practice on a large scale. We were cautious about claiming a real shift in attitude or certainty that this practice would be sustained in the long-term. This is because the original impetus came from external change agents and the house supervisor credited with shifting practice has left the house.

The findings support the proposition that house supervisor's have an important role in influencing practice. Both house supervisors gave a 'lead' to the staff group, the first privileging community presence, the second expanding the range of activities to enable community participation.

We put forward the proposition that the beliefs of direct support staff have an impact on their practice. In this regard, we see 64 Penny Lane as being a 'politically important case' (Miles and Huberman, 1994). The labels of severe and profound intellectual disability given to the five residents draw attention to the level of intellectual disability in relation to the goal of building inclusive communities. We have highlighted the obvious fact, though it is not always acknowledged in policy documents, that people with intellectual disabilities are not a homogenous 'population'. Variation in the level of impairment has important implications for staff practice, family members' views, and the reaction of the general public.

The goal of building inclusive communities: Issues for policy makers

It should be apparent that building inclusive communities is a complex and multifaceted goal. We have used it as an overarching phrase that embraces a number of related terms. As there is not an accepted definition of building inclusive communities, or even an acceptance that this is an overarching expression, these related terms are often used interchangeably in everyday interactions. This creates a 'contested arena' for discussing and implementing it.

It is beyond the scope of this report to provide a working definition of building inclusive communities, although we have outlined a number of concepts and made clear our thinking about certain contentious issues that might inform the development of a working definition. A major success at 64 Penny Lane was the creation of a common language that also provides a framework for action.

A definition needs to embrace many, if not all, of the ideas that we have introduced during the report. It needs to be a nuanced concept that allows both bonding and bridging relationships. This acknowledges that there is nothing wrong with people with intellectual disabilities choosing to be together or being friends with one another. However, our own thinking is such that any working definition or guidance about building an inclusive Victorian or Australian community must explicitly include the need to facilitate relationships between people with intellectual disabilities and non-disabled people. We are clear that doing so does not devalue people with intellectual disabilities, nor does it attempt to privilege relationships with non-disabled people. It arises from an understanding that most people with intellectual disabilities occupy a 'distinct social space', a situation that is not of their own making. Our argument is that direct support staff must supplement the work they are doing to support community presence, relationships with families and other people with intellectual disabilities with efforts to support community participation.

We have pointed out that participants have come away from training on building inclusive communities without understanding that part of their role is to facilitate relationships with non-disabled people. It is also possible to read the Department's current policy documents and have a similar understanding. Older policy documents and service ideologies were much more explicit about the goal of facilitating relationships with non-disabled people. We seem to have become overly cautious in stating that building inclusive communities will require these bridging relationships. This may be because in the field of intellectual disability, ideologies such as normalisation (Wolfensberger, 1972) and social role valorisation (Wolfensberger, 1983) came under some sustained critiques that have diminished their influence. At the same time, and more generally, intense community-building that has been done in the name of 'difference', 'identity politics', 'multiculturalism' and 'the politics of recognition', seems to have resulted in the strengthening of boundaries (Fraser, 1996). Friedman (1999, quoted in Bauman, 2001) writes:

> One of the things that is not happening is that boundaries are disappearing. Rather, they seem to be erected on every street corner of every declining neighbourhood of our world. (p.76).

We have made the point that the outcome of building inclusive communities is still an imagined society. Neither the assimilatory policies of the past nor the form of the current ‘multiculturalist’ program seem to offer much hope in realising this ‘community of our dreams’ (Bauman, 2001). It is here where we come up against the limits of a modest research project such as this one. Building inclusive communities is a social policy goal that reflects social values, which are embedded in the values of Australian ‘society’ (see Emerson and Pretty, 1987). This is a goal about what society and its people ought to be like (Peile and McCouat, 1997). Research can tell us something about implementing this goal, but it can tell us nothing about whether it is the right goal. We support the goal of building inclusive communities based on our non-scientific belief that is promises a ‘better’ society.

Since we started this project the Victorian Department of Human Services has published a number of documents related to a Quality Framework for Disability Services in Victoria (Victorian Department of Human Services, 2007). We think that you can read related documents, such as the Outcome Standards for Disability Services; the Industry Standards for Disability Services, the Essential Evidence Indicators of the Industry Standards, and the Disability Services Self Assessment System, and not understand that participation (an outcome standard) and participation and integration (an industry standard) will require relationships with non-disabled people[37].

It is also interesting to note that in one publication, another Government department, the Department for Victorian Communities, shied away from recommending the type of intervention that we have tried to encourage at 64 Penny Lane. Pope (2006) distinguished between three types of social networks; close personal networks; associational and community networks; and governance networks. Whereas a focus on community participation seeks to expand people’s close personal networks, Pope wrote:

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[37] These documents can be accessed through the Department of Human Services’ website http://hnp.dhs.vic.gov.au/wps/portal . The most explicit reference we found was in the defunct Direct Care Staff Handbook (Department Of Human Services, Victoria, 2002a).

> As a staff member, you should encourage residents to: Develop leisure and social skills that will lead to them participating in recreational activities alongside people without disabilities (p.18, bold added).

> It is difficult…to create policies that build, or increase the numbers of, networks of close family and friends….For this reason, the focus of the DVC's indicators is on the broader associational and community networks….These are amenable to public policy intervention and…can provide significant support to individuals, alleviating social problems such as social isolation in older people (p.8).

Such a view is incongruent with the practice that has been encouraged in services for people with intellectual disabilities over the last 30 years.

We suggest that the absence of a common vocabulary and shared understanding of what building inclusive communities means is a major obstacle to realising it. Without an accepted definition it makes it hard to describe an inclusive community, measure one, or intervene to build one. As a consequence a significant number of employees may not know what they are supposed to do or they think they are doing what they are supposed to be doing. Spending further time developing a clearer understanding of what building inclusive communities means would seem to be necessary.

'Social space': A useful concept?

We have made the point that ways need to be found of translating the goal of building inclusive communities and the values that underpin it into 'practical guides for action' for individuals supporting people with intellectual disabilities. This is even more pertinent when considering how to support people with severe intellectual disabilities. We have used Todd et al.'s (1990) concept of a 'distinct social space' throughout this report, not only to refer to a generalised pattern of social relationships typical of many people with intellectual disabilities, but also as an analytic concept that allows us to plan and take action. Rather than understanding this 'distinct social space' as fixed or permanent, we have developed the concept in a way that posits the boundaries around a specific individual as being in a state of flux.

By drawing boundaries we create an inside and an outside. As we keep emphasising, what makes the space surrounding people with intellectual disabilities 'distinct' is that inside the boundaries are typically only other people with intellectual disabilities, relatives and staff members. Outside the boundaries, or on the border, are non-disabled members of the public, engaging in mundane and fleeting contact. If we think about these boundaries as being in a state of flux then the actions of human service organisations and their employees can influence them. If the boundaries are fluctuating they can be strengthened or weakened, enlarged or contracted. If the boundaries are permeable then people can be helped to cross them.

This way of thinking also helps to explain why community presence is the most common outcome for people with intellectual disabilities. Most of the activities that are supported by staff establish those boundaries, with very few activities being pursued in a way that tries to bridge or break through the boundaries. Only certain activities have the potential to result in community participation, and so in most cases community presence is the final outcome.

It is important for human service workers to understand that their actions can significantly contribute to the creation and maintenance of this ‘distinct social space’. It seems to us that staff practice has a ‘default position’ that helps to achieve this. By ‘default position’ we mean the automatic practices adopted by staff when no alternative is specified. They focus on relationships with other people with intellectual disabilities, relatives, and staff members, or engage in service-centred practice. It is likely that too many staff primarily understand their role as being to ‘care’ for people with intellectual disabilities or support people to undertake activities, such as a trip to the beach or a restaurant. This may be one reason why after more than 30 years of initiatives to build inclusive communities, people with intellectual disabilities are still said to be present in ‘the community’ but not part of it.

Although some parts of ‘the community’ can be ‘hostile’ and ‘indifferent’, a variable that employees have some control of is their own behaviour. A good question to ask is: What effect does what I am doing, or what we are doing, have on a person’s ‘social space’?

As a concept, ‘distinct social space’ retains the complexity and multifaceted nature of building inclusive communities. Rather than state as an absolute position that human services segregate and isolate people with intellectual disabilities, we can understand that the actions of human service employees can both strengthen or weaken the boundaries, contract or enlarge them, make them less or more permeable. Rather than describing people’s lives in absolute terms, as being ‘included’ or ‘excluded’, we can understand people’s lives as they really are, as a complex web of ‘inclusionary’ and ‘exclusionary’ situations and experiences. If we understand boundaries in this way it is easier to see that we need to move beyond service-based supports, and discover how we can make use of ‘natural supports’.

However, we must acknowledge that making use of natural supports is hard and 'problematic'. This is because it means that supporting people with intellectual disabilities is not simply negotiating the balance between 'private' families and state 'welfare', but it also means enhancing the role played by members of the general public.

The goal of building inclusive communities is an attempt to shape and control public attitudes towards people with disabilities. In this regard, Furedi (2004) makes the important point that the policies of social inclusion have not been a response to popular demand. If we exclude employees working for human service organisations, then non-disabled people have not demanded that people with disabilities have access to sports centres, cinemas, cafés or supermarkets. Nor have they lobbied for close relationships with people with intellectual disabilities.

As we have made clear, the aspiration of building inclusive communities goes beyond community presence to include the expansion of service-users' informal personal relationships. This is a social engineering project that will require the penetration of official institutions into people's private lives. Furedi (2004) terms this 'the colonization of people's informal lives'. As things currently stand there is unlikely to be a public outcry from non-disabled citizens if they do not have a close relationship with a person with intellectual disabilities (Clement, 2006).

The project to build inclusive communities unfortunately comes up against both individual assumptions about impairment and the surrounding world's dominant social norms and values. The worst stories that are told by staff after they have stepped outside the front door of a group home are experiences of isolation, rejection, hostility, and avoidance. Unless staff possess a certain tenacity and resilience, and the work environment is designed to identify and work with the emotional distress or negative feelings that arise, then these negative experiences may make them less, rather than more likely to act as facilitators (see Clegg and Lansdall-Welfare, 2003).

Building inclusive communities: Keeping a systemic approach

In our writing we have always made the point that we need to examine the behaviour of staff in the context of the employing organisation. In the first part of this final section we have gone beyond this and located human service organisations in a broader social context. This reflects our systemic approach: that 'everything affects everything else, everything is part of something bigger and nothing can stand on its own or be understood on its own' (Handy, 1993, p.22-23). Although the preceding discussion should be of use to people with an interest in social policy, it may be of less value to mid-level managers and direct support staff. In the sections that follow we dwell on more practical issues for building inclusive communities.

Organisational capacity

Organisations only have so much capacity to achieve their goals. Building inclusive communities is only one goal and we have described community participation as but one facet of that 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 at 64 Penny Lane 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 haircut, 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.

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, and other places. With the latter, you ask, 'What shall we do this today?' The more time people spend in group homes — at day programs, using segregated leisure facilities, in a minibus, participating in group trips, or engaging in activities that lead to community presence — then the less chance there is to change the pattern of activities to include community participation.

Given that organisational capacity is limited, and that community participation is not a day-to-day priority for many staff, ways need to be found of bringing it into focus and making sure that time is allocated to work at it. Person Centred

Planning may help in this regard. We have given some concrete suggestions for enhancing planning and assessment tools.

As well as expecting direct support staff to put focused effort into community participation, there are also other ways of doing this. This includes specific schemes to link people with intellectual disabilities with volunteers (Gaskell, 1985; Walsh, 1984); the creation of specific positions to work with a small number of residents, called a ‘Ties and Connections Worker’ in one organisation (Whittington, 1993); and the creation of ‘circles of support’ (Wertheimer, 1995).

Organisation of resources

High-quality services need adequate resources and those resources need to be well organised (Emerson and Hatton, 1994). How staff are deployed will impact on the success of the goal of building inclusive communities. At 64 Penny Lane the five men are usually supported by two staff members. The staffing levels are adequate enough to allow residents to be supported inside and outside the home simultaneously.

However, a fixed roster is more likely to be staff-centred rather than service-user centred. Not only does a fixed roster determine the activities that can be supported on a particular day, but it also determines which member of staff supports an activity. How activities are supported is likely to have an impact on whether an outcome is community participation, and in particular whether the move from acquaintance to friendships has any likelihood of happening. There needs to be greater flexibility in the deployment of staff.

More flexibility at 64 Penny Lane would have allowed three staff to support the residents on Wednesday evenings. This would have allowed Franco to go orienteering, Wally to go to the music group, and the other residents to be supported at home. More flexibility might have allowed the same staff member to support Milan at yoga, rather than there being a different member of staff on each occasion. A direct support staff has a much better chance of acting like a facilitator when they support the same person in the same setting over a period of time. He or she gets to know a setting, the people who go there, and how the person behaves and interacts with the people in that setting.

Organisational stability

We have written at length elsewhere of the importance of creating stability in both the house supervisor and team manager positions (Clement and Bigby, 2007). Both the continuity and quality of service was affected at 64 Penny Lane by a degree of instability at the team manager, house supervisor and direct support levels. Community participation requires medium to long-term planning and continuity of support, neither of which are enhanced by a staffing pattern that resembles a 'revolving door'.

Building inclusive communities also requires leadership at the team manager and house supervisor levels. Stability in these positions improves the chances of giving better support and developing strong working relationships with each other, the staff team, the residents and their families. Consistency increases the likelihood of good supervision, and provides a platform for consistent messages. Important issues, such as building inclusive communities, are more likely to be followed through in such circumstances.

When a house supervisor has to contend with high numbers of casual staff the focus moves way from issues that require longer-term planning to 'keeping things going' and 'avoiding major incidents'.

The importance of 'internal' leadership

There needs to be commitment to the goal of building inclusive communities throughout an organisation if there is to be any significant progress in realising it. Having said that, the findings from this research lend support to the proposition that a house supervisor can have a big influence on the practice of direct support staff in a particular house.

The findings also reveal the limitations of 'outsiders' as change agents in group homes, which are relatively isolated and semi-autonomous settings. Although 'outsiders', such as the CIO and the researchers, can offer an external challenge, they are limited in the amount of monitoring and support that they can offer. Day-to-day practice in group homes can therefore become insulated from the Department's aspirations.

The notion of 'organisational readiness' (Table 8) may help both external change agents like the CIO and team manager to determine whether a particular staff group are ready to implement a program like the Community Inclusion Framework. It may also help in identifying strategies that will allow a program to be implemented more successfully.

House supervisors ought to be better placed to provide support to those staff who need a lot of direction or coaching to implement the goal of building inclusive communities. This is because, in most organisations, how a person actually behaves is related to the 'leadership' of the person's immediate supervisor (Georgiades and Phillimore, 1975). House supervisors should understand that they are practice leaders who have a key role in supporting the effective performance of the direct support staff they manage. In this specific instance, a prerequisite is being clear about what building inclusive communities actually means. Until we made our interventions at 64 Penny Lane, the staff group, including the house supervisor, did not know that they were meant to be supporting community participation, and they had not received any feedback on the practices they were supporting.

Yet house supervisors often find themselves constrained by organisational structures and unable to provide the levels of support necessary, especially when a directive leadership style is required (Clement and Bigby, 2007). Therefore some direct support staff can find themselves left more or less to their own devices. We would suggest that this has contributed to the slow progress that has been made at this specific house.

Issues for house supervisors: Knowledge, skills, and abilities

Although house supervisors should adopt a style of management that is appropriate to the context in which they are managing (Tannenbaum and Schmidt, 1958), a number of findings from this study suggest that house supervisors and team managers should not shy away from more ‘directive behaviour’ (Blanchard et al., 1986) where the goal of community participation is concerned.

It may be the case that many direct support staff do not have the knowledge, skills or abilities to competently tackle community participation and may be lacking in commitment to the goal. In such circumstances telling people what to do, how to do it, where to do it, and when to do it, and then supervising their performance might be appropriate. This may help to avoid disjointed, endless cycles of experiential learning, where the same mistakes are played out again and again. This also underscores the need to have competent house supervisors who can give direction to the direct support staff they manage.

The findings of this research suggest that building inclusive communities requires a theoretical framework and that ‘lay’ understandings of terms like inclusion and participation are inadequate. Given that individuals may hold a number of ‘objections’ to community participation, having well thought-out counter arguments may help managers to persuade front-line staff of the benefits of facilitating relationships with non-disabled people. A number of these counter-arguments have been outlined in this report.

As challenges to some beliefs are resisted strongly we think that house supervisors also need skills in managing conflict. Conflict is not something to be shied away from. We have attempted to use conflict as a creative force that can be used to generate change.

The direct support role: Role clarity and developing reflective skills

Our initial encounters with the staff at 64 Penny Lane revealed that they did not see themselves as having an active role in educating the Victorian community. This had to be done by other unspecified people.

Shifting from a service-centred way of thinking about the direct support role to a supports model requires a different mindset. Contemporary thinking about the direct support role emphasises both a strong educational and facilitative role. The job description needs to reflect this. The ease with which staff adopt this role and develop the accompanying skills places demands and constraints on a house supervisor's management of the home.

We also suggest that a clear message needs to be given to staff about the 'type' of relationship that they should have with service-users. Community participation can be enhanced if staff act as conduits, linking people with intellectual disabilities to their own social networks.

The limited amount of reflective space that exists for staff groups to discuss practice issues has been a recurrent finding in the Making Life Good in the Community research project. We have suggested throughout this report that better outcomes for service-users are more likely if people can critically engage with the ideas behind the goal of building inclusive communities and their own actions in relation to it.

If employees are to act in informed and conscious ways they need to be able to actively engage with the tensions within the complex ideas and perspectives that we have addressed. This is especially true for those in supervisory positions. When community participation is a specific goal we urge people to critique their ideas strongly at the beginning of the planning process, not when they have invested at lot of energy and taken a number of steps down a particular path. When making a judgement about the type of community they are engaging with or facilitating the following issues seem to be important.

- Is the activity that has been selected one where community participation has a greater likelihood of happening?
- Does it involve a place where the same people can meet routinely so that they can make a judgment about whether they want to spend time with one another?

- Does it allow non-disabled people to have direct experience of with people with intellectual disabilities so that they can gain familiarity?
- Is it an activity where social interaction is high?

The impact of severe intellectual disability

We suggested that the research at 64 penny Lane is a ‘politically important case’ because the five residents have been assessed as having either severe or profound intellectual disabilities. In this section we want to focus on issues related to the practicalities of realising the goal of building inclusive communities for people with severe intellectual disabilities.

We have highlighted the fact that the assumptions which staff, family members, and the non-disabled public hold about people with intellectual disabilities are important, because they have an impact on how people relate to one other. Many of the concepts embedded in the Department of Human Services’ policy documents are not easy to apply to with people with severe intellectual disabilities. Terms, such as engagement, inclusion, involvement, and participation are often poorly understood and implemented by front-line staff. Although the terms may be harder to apply, our approach is to focus on how to realise the related outcomes for people with severe intellectual disabilities.

We believe that it is necessary to acknowledge the personal restrictions of severe impairment. Doing so will help us think about how to make the concepts relevant. This does not mean overly focusing on severe intellectual disability to the exclusion of all other characteristics, but having the ability to attend to this particular characteristic, and other individual and universal qualities.

It seems helpful to acknowledge that people with severe intellectual disabilities:

- do not understand what abstract concepts, such as building inclusive communities or community participation means
- are at risk of not having these concepts applied to them
- live in a world where non-disabled people can, at times, be hostile or indifferent towards them
- may have more difficulty providing the reciprocity that is needed to maintain relationships
- may participate atypically in ordinary settings
- rely on other people to plan and organise their lives.

As a consequence of severe intellectual disability the individuals supporting them exercise a great deal of control over their lives. Some of these supporters:

- do not see the goal of building inclusive communities as being relevant to people with severe intellectual disabilities
- struggle to apply them to the people they are supporting
- are more or less willing and capable of identifying potential activities that support community participation.

We offered some possible explanations for this:

- some people disagree with the goal of community participation
- for others, different issues are seen as being of greater importance than building inclusive communities
- a significant number of people hold a world view that is based on practicality rather than universal rights
- the power of the 'intellectual disability' label to determine people's perceptions is so strong it makes it hard for them to see an individual in any other way.
- direct support staff may not have the knowledge, skills, and abilities to engender community participation for people with severe intellectual disabilities.

In addition to the ideas that have been suggested throughout this report it may be helpful to focus on the following in any training or coaching:

- the difficulties non-disabled people experience when they first encounter somebody with severe intellectual disabilities
- strategies related to what staff might do after introductions had been made.
- preparing people for atypical behaviours
- modelling ways of engaging with people with severe intellectual disabilities.

We reached a point at 64 Penny Lane where we had addressed all of the aforementioned barriers to community participation and the staff group had begun to support individual activities where expanding people's social networks had become a possibility. The length of time that it took to do this precluded the possibility of learning about these training and coaching issues — those related to what staff might do when people have said 'hello'. This seems to be an important area where future research might help to reveal some practical guidance.

The question still remains: Is building inclusive communities a possibility?

In the Introduction we framed the story of building inclusive communities at 64 Penny Lane as being about conflict; where arguments, disagreements, and misunderstandings were an integral part of the narrative. We think that our findings reveal a great deal about a goal that is a key component of most industrialised countries' social policy 'vision' for people with intellectual disabilities. The issues in this report help to illuminate why only modest progress has been made in enabling community participation in the last 30 years. More than 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** [bold added]' (p.232).

Thirty years later this question still remains. It seems to us that unless more time and focused effort is put into discovering whether we can build inclusive communities on a large scale then the question is likely to remain unanswered.

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Appendix 1: Steering committee membership – March 2008

Mr John Leatherland	Chair Regional Director, Eastern Metropolitan Region Department of Human Services
Ms Alma Adams	Manager Kew Residential Services Redevelopment
Mr Anthony Brown	Family member
Mrs Nancy Brown	Family member
Mr Peter Downie	Family member
Ms Heather Forsyth	Self-advocate
Mr Alan Robertson	Self-advocate
Mr John Gray	Manager, Well Being and Practice Improvement Quality Branch, Department of Human Services
Ms Christine Owen	Manager, Disability Services, Eastern Metropolitan Region Department of Human Services
Ms Kerrie Soraghan	Executive Officer, Steering Committee
Mr Kevin Stone	Executive Officer, VALID (Victorian Advocacy League for Individuals with a Disability)
Ms Joanne Matchado	Co-ordinator – Lifestyle Approaches, Eastern Metropolitan Region Department of Human Services
Ms Dorothy Wee	Manager, Disability Services North and West Metropolitan Region Department of Human Services
Ms Noble Tabe	Manager, Disability Accommodation Services North and West Metropolitan Region Department of Human Services

Ex-officio members

Dr Christine Bigby	Associate Professor School of Social Work and Social Policy La Trobe University
Dr Tim Clement	Research fellow School of Social Work and Social Policy La Trobe University

The contribution of former members of the Steering Committee since the beginning of the research in 2005 is also gratefully acknowledged.

Appendix 2: The Five Accomplishments - Adapted from O'Brien (1987, p.177-178)

Accomplishment	Definition and rationale
Community presence	Community presence is the sharing of ordinary places that define community life. Without focused effort, people with severe [intellectual disabilities] will be separated from everyday settings by segregated facilities, 'special activities', and different schedules. Valued activities will increase the number and variety of ordinary places that a person knows and can access.
Choice	Choice is the experience of autonomy both in small, everyday matters (e.g., what to eat or what to wear) and in large, life defining matters (e.g., with whom to live or what sort of work to do). Personal choice defines and expresses individual identity. Without focused effort to increase available options and provide support for decision making, people with severe [intellectual disabilities] will be passive and without voice or the ability to escape undesirable situations. People with severe [intellectual disabilities] can challenge other's ability to detect personal preferences; some may depend on a guardian to chose their interests. Valued activities will increase the variety and significance of the choices that a person makes.
Competence	Competence is the opportunity to perform functional and meaningful activities with whatever level or type of assistance is required. Without focused effort, people with severe [intellectual disabilities] will be deprived of the expectations, opportunities, instruction, and assistance necessary for increased competence. Valued activities will increase a person's power to define and pursue objectives that are personally and socially important.
Respect	Respect is having a valued place among a network of people and valued roles in community life. Without focussed effort, people with severe [intellectual disabilities] will be confined to a range of stereotyped, low-status community roles that will restrict their opportunities to be seen as valued individuals. Valued activities will challenge limiting, negative stereotypes about a person and provide access to valued roles.
Community participation	Community participation is the experience of being part of a growing network of personal relationships that includes close friends. Without focused effort, people with severe [intellectual disabilities] will have unusually small social networks whose membership is restricted to clients and staff of the services they use, and perhaps immediate family members. Many of these contacts will be impersonal and temporary. As a means to increased community participation, it is important to provide opportunities for [non-disabled] community members to meet people with severe [intellectual disabilities] as individuals. Necessary assistance should be provided in ways that support existing and developing relationships. Too many crucial services cut ordinary people off from the chance to know individuals with severe [intellectual disabilities]. Valued activities will provide opportunities for a person to meet and develop a variety of types of relationships with an increasing number of people.

Appendix 3: Process to connect people with disabilities to their local community (2)

1. What is the person interested in?
2. Research options in the community.
3. How is it going to work?
4. Provide necessary support.
5. Ongoing evaluation and reflection.

Appendix 4: Activity Learning Log

This Learning Log has been developed as a way to document activities and gather person centred information at the same time. It can be used to tract action plan steps or activities that occur outside of the PCP meetings. The Learning Log is one way to gather information for the Personal Focus Worksheet over time. The Learning Log asks staff to share information specific to what worked and what didn't work for each activity, allowing support providers to continually fine tune their information and plan differently.

DATE/TIME	ACTION	OTHERS INVOLVED?	WHAT WORKED WELL?	WHAT DIDN'T WORK WELL?
	What did the person do? What, where, when, duration	Who was there? Name staff/ Residents /others	What did you learn about what worked well? What did the person like about the activity? What needs to stay the same?	What did you learn about what didn't work well? What did the person not like about the activity: What needs to be different?

Appendix 5: Examples of how to summarise Activity Learning Logs

I started thinking about what I might do with the information collected in the Activity Learning Logs if I was a keyworker, where the focus is on an individual resident. I thought I would like to know the types of activities each person had done in a month and how often they had done them. I also want to know whether these activities had been a success or not and what we had learnt from supporting the residents in the activities.

On the next pages are two examples for Franco. I would suggest that you take some time to look at them.

Given that two goals of the service are developing individual lifestyles and building an inclusive community for the residents you might ask yourselves whether, and to what degree, each resident's data reflects an individualised lifestyle and how well these activities would lead to an inclusive community.

For each person you might ask: Is the resident happy with the range, frequency, timing and type of activities that he partakes in? Are you happy?

Activity	Frequency			
Franco	May	June	July	August
Eating out	1	1	1	2
House Shopping	1			
Personal shopping				
Cinema				
DHS office (Box Hill)				
Bus trip		2	8	4
Visit another CRU				
Walk			4	
Library				
Basketball				
Total	2	3	13	6

- You have commented that shopping in a large supermarket for a large number of items does not suit Franco. How else might you organise this activity so that he does participate?
- Given that walking is a preferred activity for Franco is the data accurate? (Walking probably means local walks along Arthur's Creek.)

Appendix 5

A keyworker could summarise a month’s worth of data for discussion at the house meeting and/or in supervision.

Franco: Summary of community activities - July 2006

Activity	Frequency
Franco	July
Eating out	1
House Shopping	
Personal shopping	
Cinema	
DHS office (Box Hill)	
Bus trip	8
Visit another CRU	
Walk	4
Library	
Basketball	
Total	13

Summary:

Franco went on bus trips to Eltham, Templestowe, Doncaster (2), Port Melbourne (3) and Frankston. On five occasions a walk in a park or food/drink was recorded. Franco had four walks along Arthur’s Creek. Seven of the activities were on a 1:1 basis (4 walks, 2 bus trips, and eating out).

Appendix 6: External activities categorised as community presence, participation or segregated activities

Appendix 5 contains the raw data that is shown in graph form in Figure 12. The activities in Table 6 were re-categorised as either community presence, community participation or segregated activities to create Table 13.

Table 13

External activities categorised as community presence, participation or segregated activities

Type of activity	Frequency
Community presence	17
Community participation	3
Segregated activities	4

Table 14 comes from information recorded on the Activity Learning Logs. They were re-categorised as either community presence, community participation or segregated activities to create Table 14. We used the shading to highlight when new activities were introduced. E.g. the library in July; bowling in August.

Table 14

Number of external activities at 64 Penny Lane by month

Activity	Frequency[38]				
	May	June	July	August	Total by activity
Eating out	2	2	2	3	9
House Shopping	3	4	4	2	13
Personal shopping			1	1	2
Cinema		1			1
DHS office (Box Hill)		2			2
Bus trip		1	8	5	14
Visit another CRU		1			1
Walk		1	4		5
Library			1	1	2
Basketball			1		1
Bowling				1	1
Buying take-away food				1	1
Total for month	5	12	21	14	52

---

[38] In May data was kept for 11 days.

Table 15

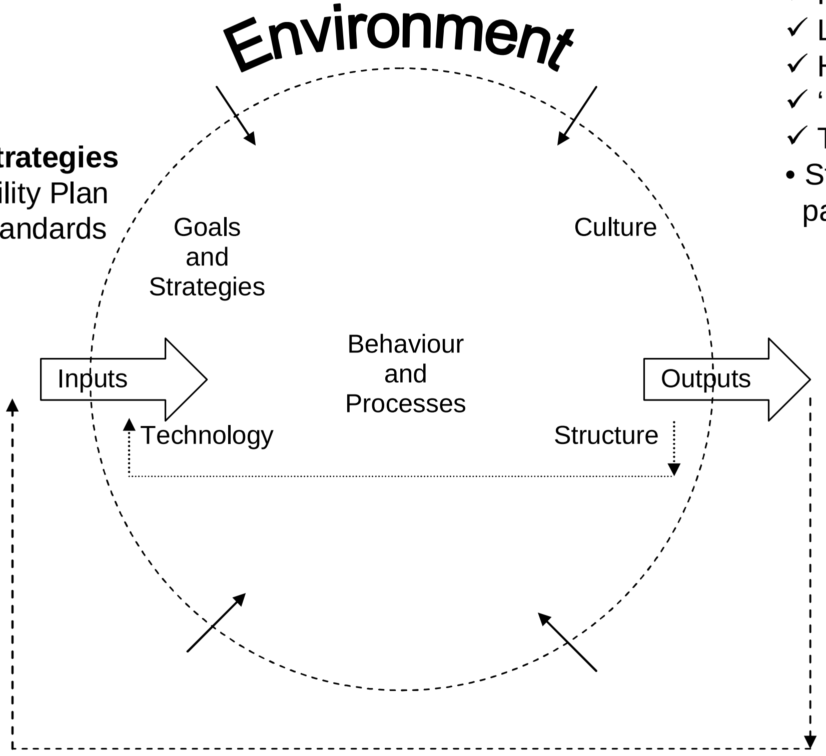
External activities categorised as community presence, participation or segregated activities

Type of activity	Frequency				
	May	June	July	August	Total
Community presence	5	10	20	14	49
Community participation					0
Segregated activities		3			3

Appendix 7: Analysis for Phase 3

Harrison (1994) proposes a model that can be used to diagnose an organisation or any sub-division. This model was used to understand how the Community Inclusion Framework was being implemented at 64 Penny Lane. The model is useful because it directs one to take account of the major elements of a system, rather than oversimplify the picture. The eight main elements of the model were used as a ‘provisional ‘start-list’ of analytic codes’ (Miles and Huberman, 1994, p.58). Initial analytic choices were therefore structured deductively in advance by the model, but new codes we re developed inductively (LeCompte and Schensul, 1999). Qualitative data analysis (QDA) software, Atlas.ti (Muhr, 2005), was used to facilitate data analysis.

A simplified description of the findings that emerged from applying Harrison’s (1994) model is given in Figure 21, which shows the eight main elements of the model and the new codes that were developed inductively.



The task environment
- Residents
- Other human services
- Neighbours
- Family members

The general environment
- Neighbourhood
- Attitudes towards people with (severe) intellectual disabilities

Goals and strategies
- State Disability Plan
- Disability Standards

Inputs
- House staff
- House supervisor
- Community Inclusion Officer
- Researchers
- Knowledge, skills, abilities and orientations that people bring about 'building inclusive communities'
- Specific training

Technology
- Planning tools
- Data collection tools
- Heuristics

Culture
- Beliefs, attitudes, and values related to:
  - ✓ People with intellectual disabilities
  - ✓ Residents
  - ✓ Leisure activities
  - ✓ Human services
  - ✓ 'Building inclusive communities'
  - ✓ Their role
- Stories about community participation

Outputs
- External activities
- Community participation

Structure
- Vacant lines
- Inadequate position descriptions
- De facto staff team of three
- Hands-off team manager

Behaviour and Processes
- Habitual actions of staff group
- Doing things for rather than with residents
- Low levels of critical reflection
- Thin formal supervision in house
- Negative leadership
- Spontaneous planning
- Conflict between staff team and CIO/researcher

Appendix 8: Actions to develop individual lifestyles and build an inclusive community for a person with a disability

What is the specific activity that the person wants to participate in? Draw the activity or cut-and-paste a symbol or picture that represents the activity.	How did you identify the activity that the person would like to participate in? Tick the documents you looked at and/or people you talked to. Write in any extra information that you think is useful. Ask the person ☐ Asked day services staff ☐ Asked family members ☐ Communication Dictionary ☐ Goal outlined in the person's IPP ☐ Essential Lifestyle Plan ☐ Likes / Dislikes list ☐ Strengths List ☐ Other ☐

Community presence

- The sharing of ordinary places that define community life (O'Brien, 1987).

Community participation

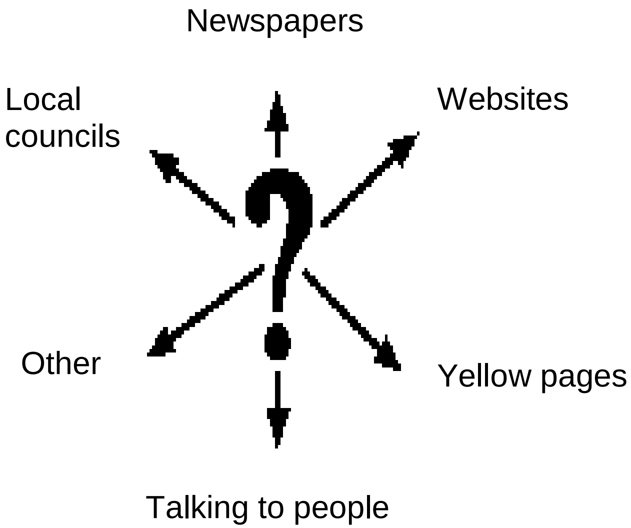
- The experience of being part of a growing network of personal relationships that includes close friends. This should include people other than other clients, paid staff and immediate family.

Refer to the definitions, then tick one or both of the boxes

Will this activity lead to:

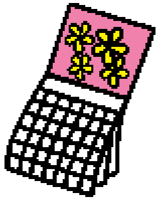
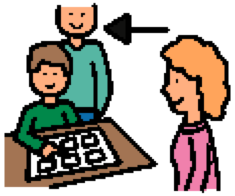
Community participation? ☐ Community presence? ☐

Explain how this activity will lead to community participation and/or community presence. If the activity does not lead to either community participation or community presence then what is your justification for it?



Where does this activity take place? Try to find at least two venues. List the relevant information, e.g. address, telephone numbers, opening hours, etc..

List the pros and cons of these venues.

  	How do you plan to organise this activity so that it happens, the person gets the right support, and it is successful?

Ideally this form should be completed with the identified person and individual communication strategies should be referred to.

Once the activity has been undertaken complete the Activity Learning Log

Appendix 9: Competency areas for DHS house supervisors

Table 16

Competency areas for DHS house supervisors

Competency Area	Definition
1. Enhancing staff relations	House supervisors enhance staff relations by using effective communication skills, encouraging growth and self-development, facilitating teamwork, employing conflict resolution skills, and providing adequate supports to staff.
2. Providing direct support	House supervisors provide direct supports to residents and role model such supports to direct support personnel by assisting with living skills, communicating and interacting with residents, facilitating community inclusion, maintaining an appropriate physical environment, providing transportation, maintaining finances, developing behaviour support plans and demonstrating the importance of residents becoming active citizens in their neighbourhoods and local communities.
3. Building inclusive communities and supporting residents' networks	House supervisors facilitate and support the development and maintenance of resident support networks through outreach to family members, community members, and professionals and through coordination of personal planning sessions in collaboration with the individual served.
4. Support planning and monitoring	House supervisors oversee support planning and monitoring by planning and developing individual goals and outcomes with residents, coordinating and participating in support network meetings, monitoring, documenting, and reporting progress toward meeting outcomes, and communicating with other service organisations.
5. Managing personnel	House supervisors participate in processes to hire new staff, provide professional development and supervision, facilitate team work and staff meetings, delegate tasks and responsibilities, encourage effective communication, defuse crises/conflicts between staff, and in conjunction with his/her manager respond to grievances and offer, monitor, and review fixed-term contracts.
6. Leading training and staff development activities	House supervisors coordinate and participate in direct support staff training by orienting new staff, ensure that staff to attend training sessions, document staff participation in training events, and support on-going staff development.
7. Promoting public relations	House supervisors promote public relations by educating community members about people with intellectual disabilities, advocate for the rights and responsibilities of people with intellectual disabilities, contribute to in-service promotional materials and accept students on educational placements.
8. Maintaining homes, vehicles, and property	House supervisors coordinate and participate in maintaining homes, vehicles, and personal property in proper order.

9. Protecting health and safety	House supervisors ensure that residents are safe and living healthy lives by monitoring safety issues, coordinating, monitoring and documenting medical supports, practicing appropriate emergency procedures, responding to emergencies, and promoting residents' rights regarding health and safety issues. As the home is also a workplace, house supervisors ensure that the house is a safe and healthy workplace for staff, contractors and visitors.
10. Managing financial activities	House supervisors ensure financial responsibility by managing the Client Expenditure Recording System (CERS), supporting residents in the management of their finances; reviewing, managing, and implementing household budgets; arranging payment for specific bills, and completing audits of household and resident finances.
11. Rostering and payroll	House supervisors ensure direct support professionals are rostered, paid, and receive time off when requested.
12. Coordinating Weekday Daytime Supports	House supervisors monitor residents' involvement in external activities (e.g. day programs) and/or ensure that schedules are created for residents who are 'at home' on weekdays that are based on their individual preferences and needs.
13. Coordinating policies, procedures, and rule compliance	House supervisors understand and implement current state rules and regulations, Department of Human Services' policies and practices, and the protection of individual rights.
14. Office work	House supervisors communicate effectively in writing and via the telephone; complete various office tasks; and utilise the computer effectively for word processing, developing spread sheets, and managing data bases.

Appendix 10: Social Network Assessment (Tracy and Abell, 1994)

Consider who, over the past month, has been important in this person's life and who has had active contact with them. This can include people who have provided concrete or emotional support or have given them information or advice.

Please do not include casual acquaintances.

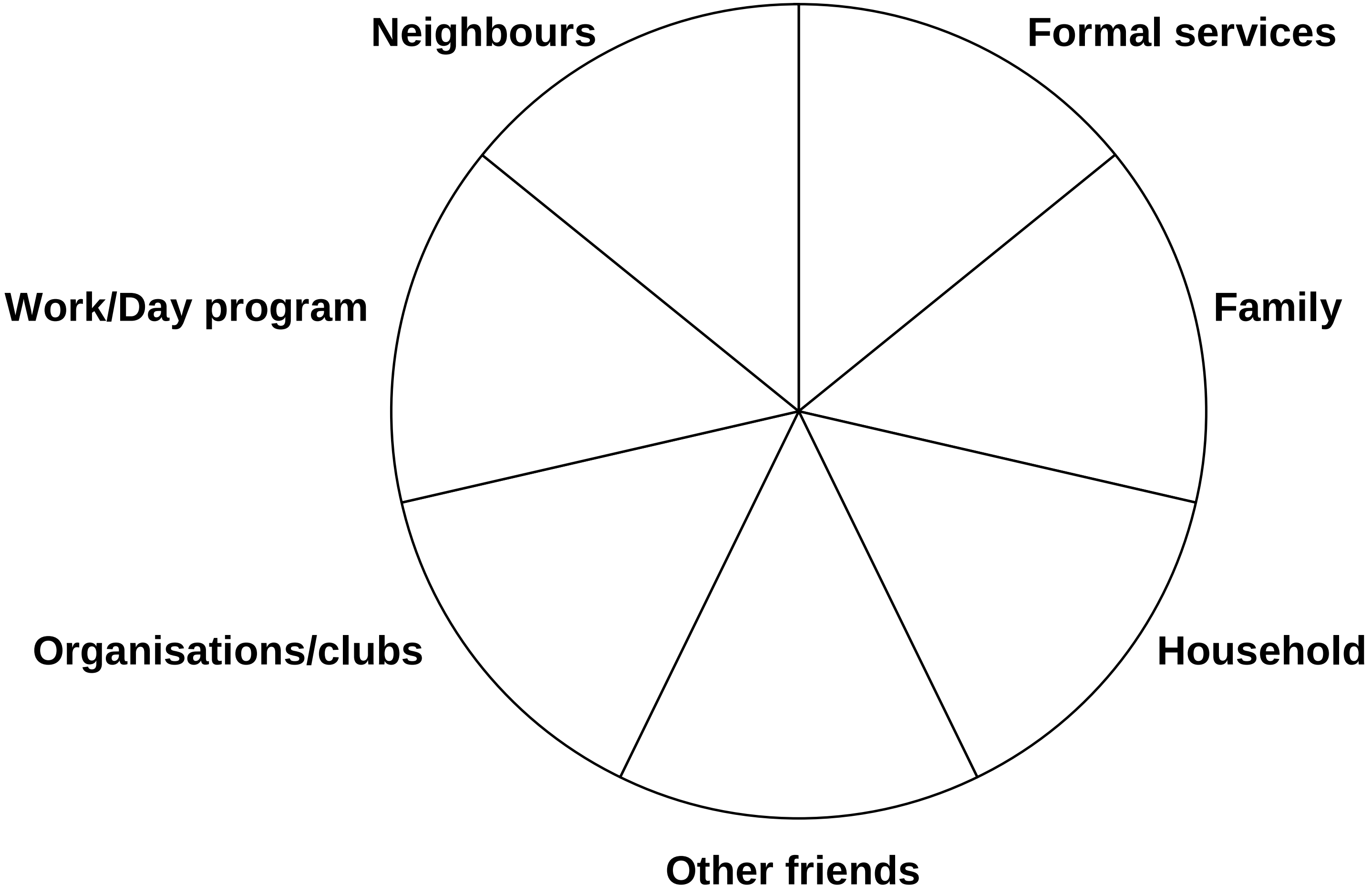
In the circle below, put the initials for each person you think of in the appropriate segment (we do not need to know who the initials stand for):

1. Formal services: People who come into contact with the person as part of their job
2. Household: People living with the person
3. Family: Family members with whom the person has contact
4. Work/Day service: People the person knows from attending work or day service
5. Organisations/Clubs: People the person knows from organisations and clubs or church
6. Neighbours: People living close by
7. Other friends: Any other friends that the person has who are not included in any of the above.

If the person identified has an intellectual disability please place a circle around their initials. If the person identified is a member of staff please place a square around their initials.

After you have completed the 'wagonwheel' the second step is to ask questions about the types of support available; the extent to which members are critical of the individual; the direction of help; the closeness of relationships; the frequency of contact; and the length of relationships.

If there are more than 15 people in the network, then ask the questions about only those active network members.


Neighbours
Formal services
Work/Day program
Family
Organisations/clubs
Household
Other friends

Appendix 10

		Area of life 1. Household 2. Other family 3. Work/Day program 4. Organisations 5. Other friends 6. Neighbours 7. Professionals 8. Other	Concrete support 1. Hardly ever 2. Sometimes 3. Always	Emotional support 1. Hardly ever 2. Sometimes 3. Always	Information/ advice 1. Hardly ever 2. Sometimes 3. Always	Critical 1. Hardly ever 2. Sometimes 3. Always	Direction of help 1. Goes both ways 2. You to them 3. Them to you	Closeness 1. Not very close 2. Sort of close 3. Very close	How often seen 1. Does not see 2. Few times year 3. Monthly 4. Weekly 5. Daily	How long known 1. Less than 1 year 2. 1-5 years 3. More than 5 years
	1									
	2									
	3									
	4									
	5									
	6									
	7									
	8									
	9									
	10									
	11									
	12									
	13									
	14									
	15									
1-6		7	8	9	10	11	12	13	14	15

Appendix 11: Jim's Social Network Assessment

Jim will be 53 in 2007. He was born on April 17 1954. He went to live at Kew Cottages (KRS) when he was about nine years old. He lived at KRS until 2005, when he moved to 96 High Street. He lives with five other people with intellectual disabilities, Brian (B), Alberto (A), Rose (R), Sarah (S) and Aphrodite (A).

Jim was interviewed by Andrew (A), a member of the support staff at 96 High Street. Andrew used photographs that were available in the house to discuss Simon's 'friends'. Although Simon can talk, he finds it hard to recall information and answer direct questions. He finds naming people difficult. Simon did not list any of the people in the social network map (Figure 17) as friends. He did not list any of the people that he lives with as his friends, nor did he recall the names of any friends from House Hostel, where he used to live at KRS. He did not list any people at the day program as friends.

The following comments are based on the information given by staff who work at the day program and at 96 High Street.

Simon is probably not that close to any of the people that he lives with. He used to live with Aphrodite and Brian at House Hostel (KRS) and likes them more than his other housemates. Jim will sit by Brian on the couch and will sometimes rub Brian's back. Jim may dislike Alberto and gets annoyed with Rose. He gives little support to the other residents and receives little in return.

Jim is said to prefer 'peace and quiet'. This may be why he does not like some of the louder residents. However Jim likes company and he will sit with staff watching the television.

Staff at the day program suggested that Jim does not like to be associated with other people with disabilities. This may be another reason why he is not close to the people he lives with, who have obvious visible impairments. Jim goes bowling with Rodney and Brett from another house, but he does not show an interest in their company.

In contrast Jim was said to get on well with three service-users at [the day program] (F, S, and K), which is a day program for people with Acquired Brain Injury. [The day program] is a community-based leisure group. The group choose their own activities and have participated in trips to places such as a museum, a bowling alley, and typically they eat their lunch out. His closest relationship was said to be with F. These men have no visible impairment and all have speech. None of the residents that Jim lives with have speech. As Jim likes to talk to people, he must converse with staff at his home.

Jim has been observed talking to other service-users, Luke (L) and Henry (H), but at the moment they can best be described as acquaintances. It may be possible that Jim liked some of the other residents who lived with him at House Hostel. Two women were mentioned as being people whom Jim seemed to get on with, but staff did not know their names. There has been no contact with Jim since he moved to 96 High Street.

Jim gets most of his support from paid staff. At the house this is a core of six staff, most of whom knew him at KRS. Andrew and Julie (J) possibly have closer relationships with Jim than other staff members. Jim is also able to offer reciprocal support to some of the staff in the house. In particular, he is able to offer concrete support, helping out with jobs around the house.

Jim goes to a variety of activities during the day. Three paid staff were mentioned as individual's that Jim likes, Harry (H), Gordon (G), and William (W). Gordon works with the community-based leisure group service-users.

As well as being able to offer support to Jim, he perceives staff as being ‘in charge’. In addition to getting information, concrete and emotional support from paid staff, they are also the people that are most likely to offer occasional criticism of him.

At his home Jim does not come and tell staff what activities he wants to do. Staff have to offer Jim a small number of choices. Not surprisingly, it was suggested that Jim sticks with activities that he is interested in.

Over time staff can read his body language. He may not tell staff what he wants, or how he is feeling, until he has got angry. Staff who have built up the best relationships with Jim have probably built up a degree of trust and delivered on ‘promises’ they have made to him, i.e. if they have said they will do something for Jim they have.

A recent success has been the reestablishment of contact with certain members of his family. Since his move to 96 Street, his sister and her family have had contact a few times each year. This has expanded to include another sister and Jim’s father. This has to be managed discretely as his father has not told his wife (Jim’s mother) that he has visited their son. It was suggested that Jim is very close to one sister and his father.

Conclusions

Jim’s social network could be said to be relatively small. It is comprised of people with disabilities, paid staff, and a small number of family members. It should be noted that the family members have recently rejoined his network and have seen him a few times each year. It could be said that Jim’s social network is typical of many people with intellectual disabilities, and reflects a form of ‘social exclusion’. He is not living with people that he is particularly close to or with whom he communicates with very effectively. The people that he is probably closest to are paid to support him.

There is an obvious gap in the social network, in that there are no ‘ordinary’ members of the community. Filling this gap will build a more socially inclusive network for Jim.

Possibilities to strengthen Jim’s network:

There are people in the network that might strengthen his network: service-users at the day program and other acquaintances. It would be worth talking more with Jim to find out whether there are people from the past that he would like to get back in touch with. These relationships would be with other people with disabilities.

Given the delicacy of his family relationships, it is not possible to say what opportunities there are for more frequent contact or expanding the number of relatives that Jim has contact with. This should be considered.

At present the key people in Jim’s life are paid staff. Staff are therefore likely to be the people who are best placed to exploit available opportunities for Jim, but they could also consider possibilities for making links within their own social networks.

Jim does rely on other people, particularly staff people, for concrete, emotional, and informational support, but he is capable of returning the favour, especially with concrete help. Is this an area for development?

The assessment suggests the following strategies may be helpful:

- Being with people who have verbal communication.
- Smaller groups of people.
- Activities of interest.

- Places that are not overwhelming with regard to noise.
- Consider concrete tasks or activities.
- Prepare people for the need to build a relationship with Jim over time.

This assessment was completed and written by Tim Clement and Silvia Warren. People who were consulted in putting this information together:

Jim
Five Day program staff
Two Residential staff