Community Living Indicators Project

Facilitating community inclusion
for people with disabilities:
Where do we go from here?

Community inclusion is having a range of opportunities to explore different interests and pursue interactions and relationships with others. These opportunities shape the choices people have about how they participate and experience life.

A project for the Coalition Against Segregated Living to explore how they can actively contribute to facilitating community inclusion in Victoria

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- The numerous individuals we spoke to along the way who provided ideas, resources and inspiration.

1. Introduction

This report is based on the findings of a scoping study to explore ways to facilitate community inclusion for people with disabilities, with a focus on people moving from institutional care into the community. The project was known as the *Community Living Indicators Project* or *CLIP*. The key aim for this enquiry was to resource a small Victorian advocacy network to think about possible ways they can contribute to facilitating community inclusion in Victoria. This is therefore the start of an ongoing process.

Background

The *Community Living Indicators Project* was an initiative of the Coalition Against Segregated Living. The Coalition Against Segregated Living (CASL) consists of a collective of advocacy groups that believe everyone should have the right to live and participate in the community. Originally formed to lobby for the closure of institutions for people with disabilities, CASL obtained trust funding to support the cause of 163 residents of Kew Residential Services in Melbourne who had identified an interest to move into the community.

In 2001 the Minister for Community Services, Christine Campbell, announced the decision to close Kew Residential Services. CASL decided to use the remaining trust funding to explore guidelines for creating sustainable and successful opportunities for people with disabilities moving out of institutions to be included in their new communities.

The advocacy services that comprise CASL were keen to develop a platform for advocacy to promote community inclusion from a well-informed basis and identify areas in which they could make a difference. To this end, two project workers were engaged to work with CASL to explore how to best develop an action plan to play a strategic role in facilitating community inclusion for people with disabilities moving into the community.

Context

This project:

- Purposely engaged a diverse range of stakeholders across the disability service system to think about the key research questions
- Heard many people across the service system report the need for greater collaboration on this issue. The Victorian disability sector is generally fragmented and people felt that community building within the sector would be energising
- Acknowledged that the sheer enormity of the service system, the number of services, contexts, and people involved has implications for how one approaches any solutions or proposes any changes.
- Is only the tip of the ice-berg of developing knowledge of community inclusion for people with a disability. Feedback suggests that it is a useful resource for advocates and practitioners who are addressing the challenges associated with making community inclusion a reality for people with disabilities.

Underlying assumptions of this project

In designing this project it was important to acknowledge the diverse range of perspectives that different stakeholders have, and to identify the principles or common ground that most people approaching the questions posed by this project would agree to. The underlying assumptions that this project made were identified early on in the project and circulated broadly with the research brief to key stakeholders. These included:

- That community connectedness and inclusion is important to all people (critical to health and well-being and there are consequences if this doesn't happen)
- That planning for people with disabilities is on an individual/person centred basis
- Individuals have "rights" as outlined under disability legislation and standards (etc. stemming from universal declaration of human rights)
- That many people with disabilities being moved out of institutional care settings have the need to be supported to effectively find "community" and integrate into "community".
- That many people with disabilities being moved out of institutional settings need support to find, access and have opportunities to explore their interests, meet a range of people, maintain relationships
- That many people living in CRUs, and people being moved from institutions out into the community are not effectively becoming connected, included or integrated into "community" life.
- That community integration/inclusion/connectedness is a complex process to facilitate and this is not well understood
- That community inclusion should not be viewed as a secondary or Rolls Royce level of service provision – rather it is paramount to a person's health, well-being and fundamental quality of life
- That it is important to focus on what is potentially improvable and to think about ways to maximise the possibility of making a sustainable difference.

Outline of the Report

The following summarises each of the ten chapters in the report:

- **Chapter One** provides the background and context to the project and articulates the underlying assumptions
- **Chapter Two** describes the methodology used to collect and analyse information gathered
- **Chapter Three** presents a discussion paper which collates the range of thinking on community inclusion and summarises the key elements
- **Chapter Four** provides an overview of community inclusion in Victoria, including the current policy context and a range of initiatives
- **Chapter Five** presents the key barriers and issues regarding community inclusion that were gleaned from conversations with key contacts
- **Chapter Six** summarises the learnings from previous deinstitutionalisation processes
- **Chapter Seven** describes the solutions offered by key contacts
- **Chapter Ei**ght forms the conclusions of the report and considers questions to help develop solutions and plans for action.
- **Chapter Nine** reflects on the implications of these findings for the deinstitutionalisation process at Kew Residential Services
- **Chapter Ten** is a discussion paper offering suggestions and an approach for possible action by the advocacy services and others
- **Appendices:** Appendix A provides an annotated reference/resource list; Appendix B is a list of the key contacts we engaged and others we recommend be approached and Appendix C is a summary of key terms of advocacy, recreation and natural supports.

2. Methodology

The following aims were established by CASL prior to the commencement of the project and steered the initial approach:

- To highlight major learnings in previous deinstitutionalisation processes in Victoria
- To liaise with key individuals in the advocacy sector, research, government and service delivery sectors to identify approaches to maximise community inclusion for people moving out of institutions.
- To establish recommendations/guidelines for creating successful community living situations and sustaining opportunities for community inclusion for people with disabilities moving out of institutions. i.e. To create a resource that will be instrumental in creating benchmarks for successful community living arrangements for people moving from institutions.
- This project will have a particular focus on enhancing the de-institutionalisation process at Kew Residential Services.

While these aims were an important starting place, the project moved on from these to develop specific research questions and a primary purpose, which was: to provide a resource for CASL to develop an action plan to facilitate community inclusion for people with a disability in Victoria.

The CASL Working Group

The CASL Working Group met with the project workers several times throughout the project to assist in:

- Conceptualising the project's approach
- Setting the objectives and outcomes
- Identifying key contacts
- Providing resources and references
- Commenting on the draft project outputs
- Considering each phase of the project
- Developing ideas for an action plan

At the beginning of the project the coalition of advocacy services decided the project should involve a range of stakeholders as key contacts to refine the research questions and the methodology for the project. A Reference Group representing a diverse range of stakeholders was established to determine the directions for the project and two Focus Groups were subsequently held.

Action for Community Living, a CASL organisation, auspiced the project, and two CASL members participated on the Reference Group as well as on the Focus Groups. While the aim of the project was to provide a useful resource to CASL, the CASL Working Group acknowledged the value of consciously engaging a range of people to promote dialogue on the issues of community inclusion, develop ownership and adopt a collaborative approach to thinking through solutions and action

Key Contacts

The CASL Working Group initially identified a list of key contacts for the project whose opinions were sought about how and where this project could best contribute and who else to involve. These key contacts included practitioners from across the disability sector, people who had experienced deinstitutionalisation, family members, advocates, researchers and government officers from both disability in head office, regional offices, Kew Residential Services and from the Office of the Public Advocate.

Discussions were held in several ways; either one-on-one with individuals, within the Reference Group meetings or within one of the two Focus Groups. The key contacts were initially asked what they felt were the issues and barriers to community inclusion and their ideas for approaching solutions. They provided personal and professional insights, assisted in identifying resources for the project and actively participated in problem identification and problem solving around the primary research questions.

Throughout the project the list of key contacts grew beyond the capacity of this project to pursue, as most contacts identified other people we should also speak to. Outlined in Appendix B is a list of many of the people we approached and those we propose might be contacted in the next phase of this work. From these early discussions and further consultation with the CASL Working Group the key research questions listed below emerged.

Key Research Questions

The questions that emerged from this process as most important were:
- What is community inclusion?
- What facilitates community inclusion?
- What are the barriers to improving community inclusion for people with disabilities?
- What are some of the potential opportunities for change?
- What action is required to facilitate that change?

In the early stages of planning for this project various CASL members had envisaged a range of different tangible outputs the project might develop, such as a tool-box for community inclusion that would assist support staff and/or a resource outlining alternative housing and support models for people with support needs. After the early conversations with key contacts and the commencement of the literature review, it was agreed that there was already substantial work addressing housing and support models for people with disabilities (see Reference List). In fact, it became clear that the issues were more complex than developing a single “checklist” on community inclusion or a “position” on housing models.

It was commonly agreed that the issues and therefore the possible solutions, are numerous and multi-faceted, and there are important foundations that need to be established before the most effective solutions can be identified. What emerged was the need for a scoping study that would produce a report for CASL that ‘unpacks’ what community inclusion is, frames the key elements that contribute to a lack of sustainable community inclusion for people with disabilities, and most importantly identifies the potential opportunities for change and action that the CASL group can work toward.

Identifying key references and resources

One aspect of the project was to locate existing reports on the closure of institutions in Victoria. These references were examined for any clues about the success or lack of success of deinstitutionalisation, in terms of the extent of integration of people with disabilities into their new communities. The project sought to identify key learnings from these reports about the processes required to support community inclusion.

Other references and resources identified were on deinstitutionalisation in general; deinstitutionalisation processes overseas; the Victorian disability context; good initiatives in community inclusion in Victoria; ways to facilitate community inclusion; quality of life measures; CASL reports; housing and support; person-centred planning and active support; concept of social capital and information specifically on Kew Residential Services (see Appendix A).

Reference Group

The Reference Group was formed once a range of key contacts had been approached and the issues, references and resources had been identified. The group met at two points of the project:

1. For the first meeting participants were provided with draft material about learnings from previous deinstitutionalisations and a discussion paper describing community inclusion for critical comment. The aim of this session was to review this material and identify an approach for the Focus Groups. The following points were made that informed the project:
    - There was general consensus that community inclusion is important and possible and that a number of things need to be in place to facilitate community inclusion.
    - Clearer evidence of what is working, why it is working and consideration of what that means for influencing wider practice is required.
    - It is useful to focus on good practice initiatives that facilitate community inclusion rather than focus on the barriers.
    - The model in itself of community inclusion or housing or support is not necessarily the answer, but the way of working with people with a disability is important, as are the foundations for facilitating that approach.
    - It is important to look outside of disability, government constraints and political imperatives at the issue of community inclusion with “fresh eyes”.
    - There is a need to think about the sustainability of solutions through time.
    - How “successful community inclusion” is measured is an issue.
    - The key is to develop and explore opportunities and possibilities to enable individuals to have choices, as people are different, rather than forcing some degree or check-list for inclusion on all.

2. The second Reference Group meeting considered the themes and conclusions which emerged from the Focus Groups. The aims of the meeting were to:
    - Receive feedback about key project outputs
    - Further develop ideas for action
    - Allow the advocacy services to hear from a broad range of stakeholders about their role in facilitating community inclusion.

Focus Groups

The two Focus Groups were held once the Reference Group established that a useful approach was to highlight any initiatives in community inclusion and explore what practitioners consider are the good practice elements that facilitate community inclusion. These groups aimed to:

- Invite various stakeholders to present examples of where initiatives were occurring, or had occurred in the past, including beyond ID services
- Collectively explore the elements of those approaches, including who was involved and what they did
- Understand the range of factors that have contributed to good outcomes for individuals
- Think through the role of the advocacy services in bringing about a more inclusive community for people with disabilities and highlighting potential action that needs to occur for change to happen.

3. What is Community Inclusion?

What is community?

Phrases such as "community inclusion", "community integration" and "connectedness with community" are often used, without a shared definition of what they mean. Before proceeding further, it is important to firstly define what "community" means. Community may be different for different people – one can be a member of one community or many communities and this may change over time.

McLeod (2000) notes that community in urban Australia is defined more in terms of shared interests than location, and no longer tends to be based on local neighbourhoods. This can present a problem for people with a disability who can be less mobile, and therefore more reliant on developing ways of interacting with others at the local neighbourhood level.

Dr Joe Patterson in *Personal Futures Planning*, says of community:

> Community life includes all aspects of living in the community that most of us just assume to be normal routines and may never think about. Such things as shopping, going to visit friends, going to church, going to a movie, eating in a restaurant or joining the local health club are just a few of the ways that most of us participate in our communities. (Patterson, undated)

O'Brien defined community membership as "the intentional creation of relationships and social structures that extend the possibilities for shared identity and common action among people" (p. 153 in Kultgen 2000)

Hutchinson and McGill (1992) offer four categories to understand the notion of community, as follows:

- Psychological sense of community – i.e. feeling of belonging
- Community as a spatial or geographical concept
- Community as social networks
- Communities of interest (common interest)

The concept of "social capital" is used to refer to the level of social networks and acts of citizenship that facilitate cooperation in community. One can measure social capital in a range of ways and at a range of levels, such as the amount of volunteering that exists in a community, how well one knows one's neighbours, the number of people who belong to service organisations (such as Lions or Rotary), or attendance at public meetings (Putnam 1995). Putnam argues that where there is high social capital in a community there is likely to be a higher connectedness, leading to outcomes such as a lower crime rate and more effective government. If this is so, then communities with a high social capital might be more accepting of diversity or prepared to seek ways to engage full participation by all members of the community.

Putnam suggests that social capital is declining and that the connections with one's "local" (i.e. geographic) community or indeed other kinds of community (such as a church, service club) have become more tenuous, as people become more engrossed in work and their own family unit. Finding ways to facilitate the rebuilding of communities has been an increasing focus for governments, as the previously intangible benefits of community engagement to the broader society have become more tangible in their absence.

For those who have lived most of their life in an institution, the level of participation in a local community or communities other than the immediate community of co-residents (and staff) has often been limited. Living in the broad community, rather than in a segregated environment, can provide increased options for participation at a range of levels. For those people with family connections, family are a key community from whom a person can create a range of relationships.

Within the disability sector there is an increasing emphasis on exploring ways to actively assist people with a disability to develop community connections. Many such people have not experienced being part of communities other than those exclusively with other people with a disability.

What is community inclusion/integration?

The literature refers to terms such as community inclusion, connectedness or integration; we have chosen to use the term community inclusion. Whatever the term used, this project was interested in how to maximise the potential for people with a disability moving out of an institution to experience being an integral part of their new community(ies), by developing relationships, taking on new roles and participating in meaningful activities, rather than just being physically located outside of an institution "in the community".

Community inclusion is providing opportunities for individuals to experience different activities, explore different interests and pursue interactions with others so that they have a wider range of possibilities to then make choices about how they wish to shape their life. The level of a person's disability should not be a barrier to assisting that person to explore ways of being connected with community. Rather the fundamental principle behind the promotion of community inclusion is that it is possible for all, whatever the level of disability. Some people with a disability, either through lack of experience, communication difficulties or particularly complex needs may need to be actively assisted to find ways to participate in community. Many such people have not experienced being part of communities other than those exclusively with other people with a disability.

In the evaluation of the Kew Residential Services Hirondelle move (Radler, Laurie and Gavidia-Payne 1999), community inclusion is defined as "Being *of* the community", including the concepts of "citizenship, fraternity, acquaintanceship and neighbourliness". They assert that:

> ... Being of the community is marked by the existence of a myriad of relationships that vary along the dimensions of intimacy, frequency, duration and type of contact (p.15).

Broadly speaking, being *of* the community includes experiencing:

- People who know you – being recognised as a "regular"
- Reciprocity in relationships, whereby one gets and also gives
- Sense of familiarity and safety
- Belonging/identification to a group with whom one has something in common
- Having a valued role/contributing
- Feeling of self-worth
- A shared history with others
- Participation/working together
- Connections
- Interdependence

Community inclusion in the form of robust social networks contributes to happier, healthier lives (McLeod 2000). One of the three key mental health determinants acknowledged in the National Mental Health Promotion Plan is "social connectedness". An individual's level of social integration and social support – which includes having someone to talk to, trust, depend on and who knows you well – is a powerful predictor not only of mental health status but also of morbidity and mortality.

Research shows that socially isolated people die at two or three times the rate of people with a network of social relationships and sources of emotional support (VicHealth 1999).

The Victorian Department of Human Services recently released State Disability Plan describes inclusive communities as places where:

- people have a sense of belonging
- people can contribute to the community with a shared sense of the responsibilities of citizenship
- people can participate in all aspects of community life
- people are valued for the contributions they make to the community
- people have their rights respected and can take action if they are discriminated against
- people have strong social, cultural and volunteer networks
- people are listened to for their views on local issues
- supports and services respond to the needs of the local community
- families are valued and supported (DHS 2002, p.35)

The progressive closure of institutions and relocation of people with disabilities to the community is part of a paradigm shift in the disability sector, with the following features, some of which are in practice, and some of which are still concepts under discussion. Moving:

- From institutional care settings, to individually tailored packages in the community
- From block funding of organisations, to consumer-focussed funding
- From charitable, paternal values of care, to professional, standards-based, rights-focussed services with quality improvement accountability systems in place
- From community ignorance and limited information and exposure to disability, to greater awareness, understanding and experience encountering people with disabilities
- From a position of total dependence, to empowerment of individual consumers with rights and choices
- From ‘carers’, to disability support workers

In terms of ‘community inclusion’, these changes are moves:

- From people being only physically located in a community, to being active participants and community members
- From a focus on health and safety, to a focus on a diverse range of services which support a person’s quality of life
- From a focus on placements in programs, to a focus on people as individuals, with lifestyle choices, interests, aspirations and desires
- From a focus on skills development as a end in itself, to developing the skills required to achieve social inclusion and connectedness with the communities in which people live
- From focus on service goals, tied to the service provider, to life goals, tied to the individual
- From people with a disability needing to change to fit in to the community, to a position recognising that the community also needs to adapt to accept people with a disability

(adapted from Ecumenical Housing 2000, McLeod 2000, DHS 2002)

Considerable energy and thought is now being devoted to ways to assist individuals with a disability who have moved to the community to develop their own personal relations and a sense of membership and belonging in places important to them. A critical component is being equipped to experience choice, take risks, meet people and try new things. Community capacity building is seen as an investment in social capital.

The development of connections to community requires:

- A belief that community inclusion is possible and high expectations for individuals
- A consciousness of what individuals are doing in good practice to achieve positive outcomes

- A stick-to-it-ness – with the ability to reflect on what is working and not working – i.e. questioning, lateral thinking, ability and preparedness to question one's role and review approaches (i.e. reflective practice)

Who do we connect with? In contemplating our own experience of the communities of which we are a part, the following encapsulated who we might choose to develop a relationship with.

- People who respond to us
- People who encourage us
- People who give us positive feedback
- People we communicate with
- People who understand us
- People like us
- People who are different from us
- People who feel comfortable with us
- People we feel safe with; that is accepted, respected, listened to, valued, important to

McLeod (2000) offers a model for social inclusion concentrating on the different levels of social interaction. He conceives of social inclusion as a series of concentric circles with the individual in the centre, and the inner circles representing smaller number of contacts but more intimate relationships, to the larger outer circles representing the larger number of acquaintances with whom the individual has contact.

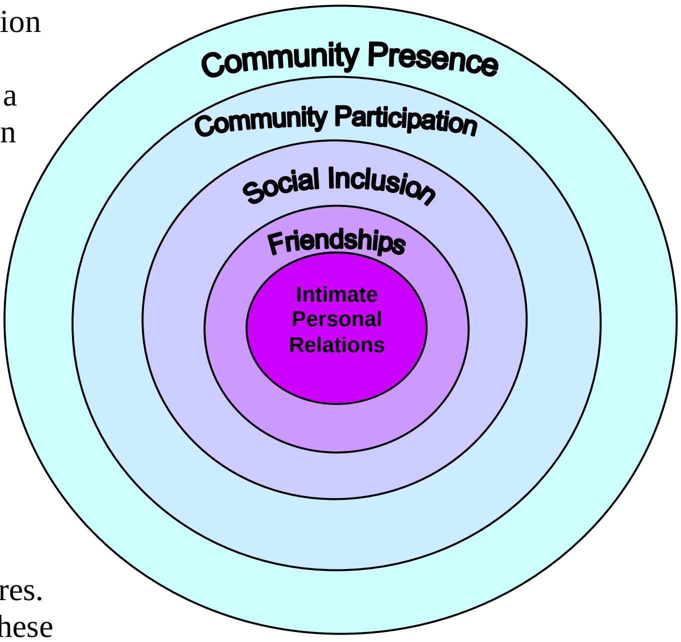


Figure 3.1: Levels of social interaction adapted from McLeod

The basis for community inclusion is maximizing compatibility with those in communities, and as such requires information, training, exposure and skill development about community rules, taboos, norms, and social mores. We usually learn through our childhood years these "rules" for engaging with others, which we continue to refine in adult life. For those who have not been part of a wider community, this learning may not have occurred. Facilitating community inclusion therefore requires:

- Evaluating the person's capacity to engage with others, and coaching them to understand the rules of engagement
- Creating opportunities to engage
- Actively sustaining important relationships and connections over time

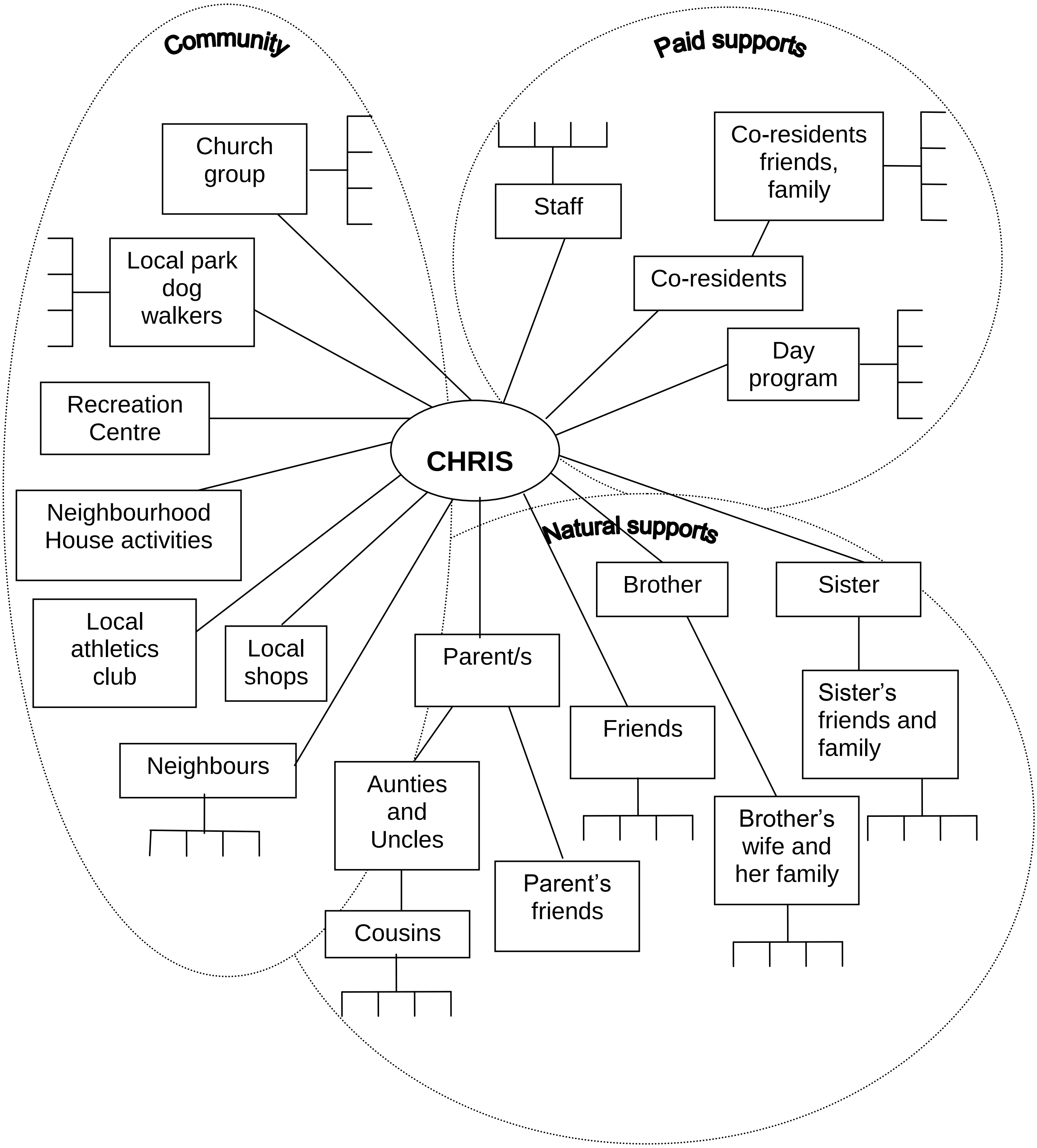
Cummins noted that Nirje developed six levels of integration (1993), however suggested that only the first three had been achieved as a result of deinstitutionalisation:

- Physical integration; moving physically into community
- Functional integration; living in community
- Organisational integration; using community organisations
- Social integration; mixing socially with members of the community
- Personal: developing friendships with members of the community
- Societal: full integration into society

Cummins stated that the outstanding goal was to assist others moving into the community "to obtain the greatest degree of happiness and life-fulfilment that our resources can bestow" (p.71), through monitoring social integration plus the whole construct of subjective quality of life for individuals.

In considering the range of connections a person can have, we developed Diagram 3.2 to map out what might be possible for an individual who requires support to facilitate community inclusion.

Diagram 3.2: Every individual has different connections – maximising community inclusion is based on natural supports, paid workers or community members understanding their role as facilitators. This shows the links that "Chris" has with the assistance of existing networks who actively seek ways to explore Chris' interests and then assist to make connections.



Following on from Diagram 3.2 we developed Diagram 3.3, which portrays the importance of the *interconnectedness* of community, formal and natural supports in facilitating community inclusion for a person with a disability dependent on supports. This diagram proposes that if all are aligned toward facilitating inclusion for an individual, the opportunities are likely to be maximised.

If, on the other hand, one sphere, say family, is risk averse and lacks understanding of the possibility of community inclusion, they may unwittingly sabotage efforts in other spheres to enhance inclusion. Similarly, there can be efforts made by family members to include a person in community activities, but the community or support services response may well inhibit their efforts. A shared vision and commitment to support a person to explore their interests and engage with others is required for community inclusion to succeed.

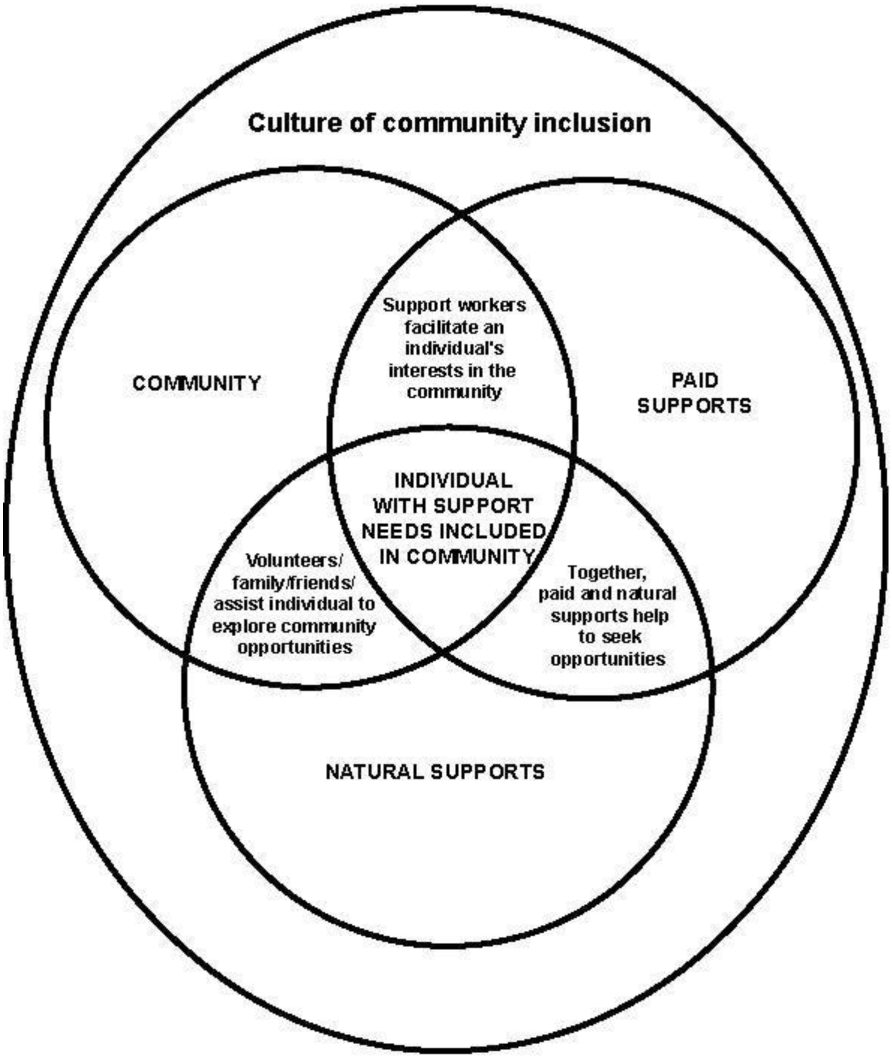


Diagram 3.3 Three spheres of influence and how they connect

What community inclusion isn't

It is also useful to consider what community inclusion is not, as this helps to create a fuller picture of the goals we are aiming toward by describing what we are moving from. So, some summary points about what community inclusion is not include:

- People with a disability being segregated from the community and therefore excluded from the day-to-day experiences most of us take for granted, such as having choices about how one spends one's time, exposure to a range of social opportunities, being in control and making decisions
- Support organised where staff work 'one to many' rather than focussing on particular individuals
- Services designed to achieve economies of scale above individualised responses and planning
- People grouped according to labels assigned to assist service provision rather than expressed wishes or individual needs
- Regimented and centrally managed routines which disallow innovation and flexibility

- Staff approaches which encourage consumer obedience, conformity and dependence on the service and its regime
- Living in a service-driven world with day-to-day interactions primarily with paid staff and other people with disabilities
- No access to the local community to experience casual/spontanaeous relationships

Other key terms

Advocacy, recreation and natural supports are useful sources of support to consider when exploring ways to facilitate community inclusion. For example, advocacy is work that is intended to support people in asserting their rights and interests, or asserts their rights and interests with them. These terms are defined in detail in Appendix C.

What would good practice in community inclusion look like?

We asked the two focus groups to describe what would be in place for a person with a disability who is actively part of the community, in the sense that he/she feels included, has a role to play, is being supported to maximise opportunities to be part of the community. The following emerged as the behaviours, values, skills, processes, knowledge and activities one would see, from the perspective of the range of stakeholders involved. The elements each group developed were not dissimilar, so have been ordered and combined to present a picture of 'successful' community inclusion.

Questions posed to the focus groups: What key elements would you expect to have enabled a person dependent upon supports to experience community inclusion? How did this happen? What sort of things might you find are in place?

Philosophy guiding action <u>at all levels</u> – including paid and unpaid people with whom an individual interacts, the service system and the wider community:

- People are clear about what good practice in community inclusion looks like, therefore have a vision of what to work towards.
- Risk management strategies are in place that creatively allow for reasonable risks – that is, a balance between risk and adventure is allowed and recognised as part of ordinary living.
- There is an understanding that relationship building is central to community inclusion and therefore relationship development skills are critical and need to be facilitated.
- Individuals are not overly protected from experiencing the downsides of relationships, such as failure, rejection and hurt, rather these are acknowledged as part of 'ordinary' living.
- A culture of learning from mistakes, reflective practice and continuous improvement is promoted.
- Unpaid relationships in a person's life are seen as valuable and are actively promoted.
- People are comfortable with organic/dynamic processes, recognising that community inclusion will look different for different individuals and that "one size fits all" solutions won't work, nor will plans that are fixed in place, as a person's interests, needs, situation will change and develop over time.
- There is recognition that community inclusion requires planning and time to build, therefore resources are committed with a long-term timeframe in mind and perseverance in identifying ways a person can engage with others and/or develop their own interests.

- Space and freedom for spontaneity and serendipity is created, as occasions for social interaction and understanding of a person's interests often emerge from unplanned encounters. Paradoxically, the opportunity for spontaneity needs to be created and requires commitment/investment and a long-term stick-to-it-ness.
- An environment is created that allows the individual to make decisions and have choices about what is important to them. Where it is difficult to understand an individual's desires, intense effort is made to identify from their behaviours and actions what they like and dislike, with mechanisms put in place to translate that information into providing choices.
- Inclusion starts with where the individual lives – staff/families model inclusive practices and ensure an individual is fully engaged in the 'home community' by the way they are included in activities, conversations and decision-making.
- All key contacts with whom the individual interacts, such as family, friends, paid support workers, proactively think and look for opportunities for them to be engaged in community.
- There is a more holistic approach and process for understanding the individual and their preferences, interests and lifestyle choices across services and supports.
- Government funding is flexible and encourages, rather than prohibits, community inclusion.

Characteristics of communities:

- There is a range of places to go where people with a disability can feel welcome and valued.
- Communities accept and appreciate diversity.
- The geographic community where a person moves feels safe to move to.
- Communities are accessible.
- There is a high disability awareness and education about disability issues.
- There are opportunities to enjoy reciprocal relationships with people with disabilities.

The individual:

- Has experienced intimate relationships as a basis to build other relationships – i.e. has supportive families or good friends who know them well and love them
- Has been coached in how to make the first move to develop relationships
- Is allowed and enabled to develop a community of interest – i.e. people with similar interests with whom they can do things
- Is allowed and enabled to make conscious choices – i.e. can decide how they want to spend their leisure or work time
- Is allowed and enabled to have reciprocal relationships – i.e. relationships that are of equal value to the individual and to the other person/s
- Has resources to do things – i.e. access to transport, adequate personal income
- Has one or two unpaid strong reciprocated relationships at any one time

Support staff:

- Are skilled facilitators of community inclusion
- Have the freedom and ability to support people across the spectrum of building casual relationships to intimate relationships

- Are committed to community inclusion, have a good knowledge of local community resources and have ideas on how to engage others with communities of interest
- Have integrity and are excited and engaged in their work
- Have a balanced role – i.e. balance of community inclusion with duty of care, risk taking and house maintenance
- Understand that their job role is to be warm and respectful toward the individual with the disability
- Value, encourage and actively support the development and maintenance of important friendships and family connections and welcome others' interaction with the person with the disability.
- See their role as understanding and supporting the individual's needs, preferences, unique interests and have a high level of commitment and perseverance
- Are empowered by their management to have a say, exercise reasonable control and make decisions, focussing on the individual
- Management explicitly value community inclusion in the way staff are performance-managed and give "permission" to staff to try new ways of engaging individuals with others, rewarding them for their attempts to facilitate community inclusion. This includes actively involving individuals and their families in planning activities.
- Formal transition support has been provided to people moving from an institution into the community.

Family:

- Are involved in the individual's life
- Understand and are supportive of the goal to actively include their family member in the community/ies of interest
- Allow their family member the freedom to develop relationships

Together these descriptors, collated from a range of stakeholders, build up a picture of the elements that need to be in place for community inclusion to become a reality for individuals with a disability dependent on day-to-day support to find and actively contribute as valued community members.

4. Community Inclusion in Victoria in 2002

There has been considerable activity in recent years in Victoria in describing, implementing and integrating programs, processes, approaches and philosophies that promote the concept of community inclusion and community building. A range of these activities are outlined below.

In 2000, the Victorian Government commissioned the report ***The Aspirations of People with a Disability Within an Inclusive Victorian Community*** (2000) which involved interviewing people with a disability about their hopes, needs, concerns and aspirations. This report started to highlight the desire for closer community connections. Barriers identified included:

- motivation and confidence of people with disabilities
- community attitudes towards disability
- availability of family and outside support
- accessibility to the wider world – e.g. public transport
- information being "hit and miss"
- limited opportunities, isolation and limited finances

(see report online: http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/research#aspir)

In that same year the government released a report ***Community Inclusion – Enhancing Friendship Networks among People with a Cognitive Impairment*** (McLeod 2000), with an emphasis on how to facilitate social inclusion and friendships for people with an Aquired Brain Injury or Intellectual Disability. This report identified the specific barriers that existed and considered ways of addressing those at a range of levels, including policy development, program responses and skills of individuals. McLeod described the changes, or paradigm shift needed in the sector as:

- A shift from skills development to social inclusion
- Workers now disability support workers, not carers
- Increased focus on individual choice interests and preferences
- Specialised disability supports plus natural community supports and unpaid supports
- Clear distinction between life goals, tied to the individual and service goals, tied to service provider
- Move from people with disability needing to change to fit in, to more balanced position that the community also needs to adapt to be more accepting of people with a disability

(see report online: http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/research?Open#friends).

Actively finding ways to build community has been a recent government focus in Victoria, with the development of programs such as the ***Community Support Fund*** designed to explicitly encourage people to engage with others at a range of levels, whether it be assisting disadvantaged people in the local community, developing initiatives in the arts, sport and recreation, or just creating opportunities for individuals with common interests to come together. (see http://www.dpc.vic.gov.au/csf).

The ***Disability Advisory Council of Victoria*** was launched by the Victorian Minister for Community Services in 2001, with the Council's vision the achievement of an inclusive and accessible Victorian community (Disability Advisory Council of Victoria 2002).
(see website: http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/council).

The Victorian Government's Vision outlined in the ***2002 State Disability Plan***, launched in September, is:

> 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 (DHS 2002 p.7)

The Plan identifies the desired progression from 2002 to 2012 as a movement from:
- people living in the community to people being included and participating in the community
- creating lives of dependence to enabling lives of connectedness with the communities in which people live
- focus on health and community services to focus on full range of services which support people's quality of life
- focus on programs to focus on people as individuals
- making placements in programs to enabling people to have lifestyle choices

(see plan online: http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/plan).

Most recently, the ***13th World Congress of Inclusion International*** was held in Melbourne in September with papers exploring ways to promote inclusive education, self-determination, social inclusion and support building community.
(see website: http://www.icms.com.au/inclusion)

In addition, regarding Kew Residential Services (KRS) specifically, a Community Inclusion Package is being developed for those moving into the community and the City of Boroondara have engaged Josie Prioletti to facilitate two community forums to inform locals about the deinstitutionalisation process with the aim of developing a broader understanding of people with a disability moving into the community. SCOPE are providing training to KRS staff in community inclusion.

There is no doubt that community inclusion is a central theme within the disability sector and reflects a striving toward greater integration of people with a disability in the wider community. In discussing the concept with practitioners, researchers, government officers, people with disabilities, families and advocates actively engaged in the sector it appears that there is still a gap between the philosophy of integration/inclusion/connectedness and embedding the practice in real terms for individuals (who require support to achieve these goals).

However, there were a number of examples of what individuals describe as good initiatives that enable community inclusion that were highlighted throughout the project, some of which were discussed in the focus groups. A brief description of each of these programs follows, with an analysis of why they work and the barriers that still need to be overcome to create even more successful outcomes.

Current initiatives in community inclusion in Victoria

In discussions with key contacts and at the focus groups we were able to gain insight into some existing initiatives that report to be actively working towards good outcomes in community inclusion. A selection of these programs is described below and brief summaries are provided for a range of other initiatives that were not explored in depth.

RuralAccess

Established in September 2000 the RuralAccess initiative aims to support "rural and regional communities to plan and develop strategies which will increase community membership and participation opportunities for people with disabilities." RuralAccess is part of Disability Services' broader vision which aims for an inclusive Victorian community that reflects the needs and aspirations of all people with disabilities. The program currently has a two-million dollar budget.

RuralAccess is a partnership between the Department of Human Services, Disability Services Branch and Local Government Authorities and Community Health Services. There are now 27 full time RuralAccess workers based in local government and community health services throughout rural Victoria who work with others to plan and develop initiatives across the full range of community infrastructure, including education and training, transport, health, accommodation and housing, physical access planning, communication and information, and sport, recreation and the arts.

Each RuralAccess worker has a brief to develop a range of projects which will engage people with a disability in the broader community, often piggybacking on existing planning processes, such as transport planning or small business initiatives, so that disability issues are integrated and explored as part of the wider processes of building a better community. Workers come to the role with a knowledge of disability issues and established relationships with the local community and hence provide a bridge for those people with a disability seeking to be more involved in the community and for those who have little experience or understanding of disability issues.

Workers help to question and make links between existing initiatives and how they might impact on people with a disability. Often by exploring these links they are able to create better outcomes for the community at large, as often the issues raised are not isolated to effecting people with a disability, but to others in the community, whether it be physical access issues which can be equally relevant for older people or parents with prams, access to communities, planning inclusive events or employment initiatives.

Being placed in local government means workers are well-placed to hear of programs which may impact on people with a disability, network with others in the service system, influence colleagues to include disability issues in their planning processes and in evaluating services and access resources.

Projects arise from local consultative processes and a community mapping process to ascertain the existing gaps in the community. Workers report monthly to share progress and are encouraged to focus on outcomes. Management encourages reflective practice, lateral thinking, solution creation rather than a focus on problems, taking a big picture view rather than thinking only of the impacts on people with a disability. Key to this work is building strategic partnerships with others who may be looking at similar issues but perhaps with a different target group in mind (e.g teaming with the Road Safety Council to investigate safe, accessible footpaths and public transport).

There is an acknowledgement that community inclusion initiatives can take time and be complex to build. Getting ‘runs on the board’, however small, is actively encouraged to build momentum and enthusiasm. In addition, knowing that the program has limited resources and may even have a limited lifespan, there are active attempts to mobilise support for positive initiatives from those in power, so that they are embedded in practice, rather than seen as an add-on.

Although the RuralAccess initiative has not been independently evaluated, they report that important outcomes to date have included:

- Approximately 15 rural councils have started to develop Disability Action Plans since the inception of RuralAccess.
- Discourse around disability is being infiltrated in a range of existing planning forums, breaking the nexus between disability-specific forums and mainstream planning. Spin-off benefits are being realised as disability issues are seen to apply more broadly to others in the community, for example through involvement in Municipal Health Plans, issues such as social isolation are being identified and addressed.
- There are more and more stories being created and many more storytellers providing examples of people with disabilities engaging in communities, reinforcing the expectation that it is possible for people with disabilities to engage in mainstream activities. These stories and expectations are being disseminated through projects such as a community video

showing people with a disability engaging in a range of ordinary activities and talking about what needs to happen for them to be able to do so.
- By providing bridge builders in the form of RuralAccess workers, more and more community members are being supported to understand and have relationships with people with a disability, through clubs, interest groups, social interactions and committees.
- Stronger partnerships are being developed in local communities, providing options for individuals that are outside the disability service system.

The government recently announced at the launch of the State Disability Plan their intention to commence a MetropolitanAccess program in Melbourne. (see website for more information: http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/prog_rural).

Activate.com

This DHS-funded program, auspiced and initiated by Leisure Action, who are part of SCOPE, has been developed in response to a need for day programs to be assisted to be more outward thinking and flexible in how they include people with a disability in community. Activate.com has been in place in the western suburbs since July 2000 and stands for 'Activate communities: creating capacity, inclusion and change'.

The goals are to work with both the community sector and the nineteen DHS funded day programs in the region to increase their capacity to support community inclusion for people with a disability. A budget of $80,000, which includes a full time worker, with some additional support, provide training, advice, support, and engage community organisations to build relationships with day programs – eg in local government, leisure centres and neighbourhood houses. Involvement with Activiate.com is built into the funding agreement. Currently the program is funded to Feb 2003 with no commitment beyond that point.

Activate.com is currently actively engaged with eight of the nineteen programs, who are committed to exploring ways to change their activities to be more community-based and individually tailored to people's needs and interests. Day program staff often don't have the skills or time for capacity building and Activate.com helps to overcome these potential barriers, apply for funding and helping them find ways to engage individuals through pragmatic problem-solving to address resource constraints as well as innovative thinking about new possibilities.

It is recognised that time and perseverance is required to realise the vision, so that if a new initiative doesn't work staff don't give up but engage in reflective practice, learning from that and trying again armed with a new perspective. The program has strong leadership and management support and is staffed by individuals with a background in working with people with a disability and skills in client advocacy, rights, and education. Communicating information to residents in Community Residential Units so they and staff are aware of the myriad of options available is an ongoing challenge.

Some of the reported outcomes from Activate.com are as follows:
- There are now 10 formal partnerships in place with community organisations such as RecWest, Footscray Leisure Centre and the Ascot Vale Leisure Centre who are actively seeking ways to include people with a disability in their programs. For example, for a small outlay, Activate.com engaged an Occupational Therapist to help an aerobics teacher learn how to develop exercises for people with a disability, so that the gym is now committed to providing this activity.
- Training sessions on "Developing Community Connections at a Local Level " are offered to day program staff, with Activate.com paying for backfill and training and/or conducting training after hours so staff can attend.

- Alternative sessions outside the normal 9am to 3pm Monday to Friday day program session times have been established, as a way of increasing flexibility to meet individual needs. An example is Club Wild a Friday 4-10pm disability friendly disco funded by DHS. This has involved working with staff from the accommodation sector to devise creative rosters within existing budgets. A Timetable Working Group is developing more flexible holiday arrangements so that individuals have more choices about when to attend day programs.
- A partnership project with VALID has been established whereby there are 25 clients representing all the day programs who meet monthly with day program staff to talk about issues ad evaluate what is working well and what can be improved.
- SCOPE "Come and try" days are held at the start of the year covering a range of activities such as Belly Dancing, Women's Day, exercise options as a way of exposing people with a disability to different activities and exploring what they might enjoy pursuing further. Similarly, there are evaluation processes at the end of every term to explore what else a person might like to try
- Day program staff have become more aware of the resource available to them in the local community and this information is being brought to the Individual Planning Process so that a wide range of options are offered.

(see website: http://www.scopevic.org.au/everyday_activate.html)

Interact Learning Centre

Interact Learning Centre is a community-based organisation based in Fairfield which is part of Interact Australia. Established in 1992, the Centre provides educational, training and community inclusion programs for approximately 85 residents of Kew Residential Services. This includes skill development, recreational activities and personal care and transport assistance.

Interact has been focussing on shifting their emphasis from community access to community inclusion, recognising that whilst people who participate are often placed in the community, such as going to a community swimming pool to actively creating opportunities for people to make friends with others, and engage at a more meaningful level. Many of the clients are unable to communicate, may be difficult to judge whether they are engaged and what they might enjoy and/or have poor social skills. Hence a range of strategies is required to prepare individuals to be able to interact with others more effectively. A focus is to help staff consider how to communicate and involve these individuals in the community, from a basis that they have a right to participate.

Mechanisms to assist people with a disability to be included were:

- The 'book about me', which helps people with whom individuals interact when they are out in the community understand more about them, allaying potential fears and serving as a point of focus. It helps to overcome the problem of initiating small talk, acknowledging that a lot of people would like to communicate with people with a disability but don't know how to.
- A monitoring sheet, with a part on community inclusion, which provides both a weekly process and direction for staff to engage in reflective practice, questioning themselves on whether in their daily activities they have taken opportunities to assist individuals to relate to others. For example this might include taking the opportunity to educate the community about some a person with a disability, presenting clients in the most positive way to ensure they are well positioned to be accepted (e.g. appropriate dress) and providing a role model when in the community of how to interact with individuals, by treating them with respect and dignity.
- Seizing spontaneous opportunities that arise when in the community to pursue an individual's interest. For example whilst a group was at the gym one of the clients noticed a tap dancing class and was fascinated. The staff member noticed and accompanied him to see

them close up. The tap dancers were happy to have him observe and now he gets invited each week and enjoys this more than staying with the group. Such serendipitous events require staff to be vigilant in observing what a person enjoys, prepared and resourced to follow the individual’s interests, and able to facilitate connections and follow through at every opportunity.

- Staff are encouraged to constantly review the experiences offered to clients and ensure there are opportunities for new experiences, making conscious decisions to assist a person to find a community of interest, rather than relying on repeating experiences they one enjoyed and ‘doing them to death’.

(see website: http://www.interactaust.com.au/learn/int_australia4.htm)

Scope Lifestyles

In 2001, Scope (Vic) Ltd, formerly the Spastic Society of Victoria, acknowledged that there was a need to review their day services to ensure the outcomes they were achieving with individuals were aligned to the organisation’s mission. Scope’s mission is to enable people to achieve their potential in welcoming and inclusive communities. It was clearly evident there was a gap between what was espoused and what was being offered in day services in terms of the ability to achieve community inclusion. As a result, for the past 12 months the organisation has been planning an improved approach to supporting individuals called Scope Lifestyles. This is now a demonstration project that has been implemented across the northern half of the DHS Southern Metropolitan Region. If it proves to be effective, Lifestyles can then be implemented for individuals in Scope day services across Victoria.

The intention is to implement Lifestyles within existing recurrent funding, with some additional trust funding required for transitional costs and evaluation. Twenty-seven people have either nominated to participate, or were nominated by family/advocates where unable to make an informed decision. Participants have a diverse range of needs and abilities, and include people with high support needs.

Lifestyles was designed to provide an alternative to a program-driven approach, and to break the nexus between the traditional Monday to Friday pathway from home to the day centre by enabling participants to take different paths traversing other parts of the community.

There are three major elements to this approach:

1. Start with the Person
   Support the individual to plan and think “from home” about possibilities that might interest them and then give them some experiences to test their enjoyment/interests. Rather than undertaking separate planning processes in the home and in the day service, a whole-of-life approach is taken. Techniques such as MAPS, Lifestyles Planning and other person-centred planning frameworks are adapted to suit the individual. The focus is aspirational, but also acknowledges support needs in achieving goals. The use of circles of support is a key component of the planning process.

2. Community
   Work with the community that exists around individuals. An important element of Scope Lifestyles is enabling communities (eg. services, clubs, local government) to build capacity to support and/or engage with people with disabilities. This work is considered essential if real alternatives to day centres are to be created and sustained. The focus of this community capacity building work is on such things as infrastructure, skills and attitudes, policy and procedure, and community leadership.

3. Services
   Configure resources currently tied to day services around individuals by adopting a person-centred rather than program and building-driven approach. This is based on a recognition that you can’t plan services until you know what people want.

Staffing consists of a pool of direct support workers, funded according to the Service Needs Assessment allocation for each person. In addition, there is a full-time “lifestyles facilitator”, a half-time position focussed on person-centred planning and a half-time community capacity building role. This latter role, in addition to enhancing community capacity, also supports participants and staff to extend their skills in connecting with community.

Scope Lifestyles is exploratory in orientation, which is necessary for any new initiative. The aim is to learn, move on and adapt. The management team are driving the approach, providing permission for participants and staff to try new things and reinforcing innovation. The program is being independently evaluated. The evaluation will test assumptions that Lifestyles leads to:

- Improved quality of life for participants
- Increased ability of participants to make decisions
- Participants being better able to identify what is important to them, and achieving these things
- Increased expectations by day and accommodation staff about what is possible for participants to do and to achieve
- A rethink on the purpose of day services
- Increased number and improved quality of relationships between participants and people who are not paid to be in their lives
- Greater levels of community participation, and enhanced community capacity.

Volunteer Initiatives in the Community:

Leisure Buddies

The aim of this program is to pair a volunteer with a person with a disability on the basis of shared interest to form a friendship and way for the person with the disability to engage in broader community activities. This might mean going shopping together, going to the football, having coffee or spending time in the gym together.

As an extension of this program, in two places there are groups of pairs who come together, again based on a shared interest, to spend time in a group-learning environment. One group is based at Bridge Community Garden Centre in Kilsyth (which is part of Japara Neighbourhood House), and focuses on craft, with 4 or 5 pairs working on different projects at any one time, facilitated b a group coordinator. Another is a literacy group based at Deakin University. The groups meet weekly and share lunch. This form of activity reduces the focus on the one-on-one, creating a broader social network.

Neighbourhood House Models

Neighbourhood Houses are places where locals can come together to learn, with subsidised courses and activities arranged to appeal to a broad cross-section of the community. Some Neighbourhood Houses consciously have made attempts to be physically accessible to people with a disability, including ensuring there is a welcoming façade, with signs showing where to go and people to greet newcomers at the door, appropriate programs offered, a centrally designed kitchen to facilitate meeting others and places to engage with others or just “be”. For example, the Bridge Community

Garden Centre has an active garden where individuals can garden, as well as a passive scented garden.

Whilst not all Neighbourhood Houses have achieved the same degree of participation by people with a disability, those that are actively seeking ways to engage others are characterised by one or all of the following: a transparent commitment to welcoming a diverse range of people, inclusive processes, management and policies, firm linkages with disability agencies and local government to explore ways to further inclusion and/or coordinators who are actively engaged in promoting their place as a centre for all community.

(see website for more on neighbourhood houses and community centres http://www.netc.net.au/neighbour or contact the Association of Neighbourhood Houses and Learning Centres website: http://www.anhlc.asn.au)

Community Learning Partners Project

The Community Learning Partners Project aims to create a learning package for adult partners learning together when one partner has an intellectual disability. Such learning can take place in paid employment, community settings or recreation settings. The aims are to develop connections between partners, more inclusive practices in the community and help both partners develop skills, confidence and pathways to gaining education or work.

Funded by a trust and led by a project worker, the project is auspiced by a range of community groups, including Reinforce, AMIDA, Gawith Villa Inc., Borderlands Co-operative, The Association of Neighbourhood Houses and Learning Centres, Deakin University and Kew Neighbourhood House.

(for further information contact Judy Buckinham at jmb@deakin.edu.au)

An Evaluation of Trust in a Primary Health Care System

This is a study funded by the National Health and Medical Research Council and being undertaken by Dr Rae Walker of La Trobe University. The aim is to describe and analyse how people within the primary health care system create and maintain relationships of trust between individuals, and between organizations. It will do so by investigating the processes by which:

- Individuals in organizations interact in trustworthy ways with each other
- Organizational systems facilitate or present barriers to creating trust
- Institutional environment impact on inter-organisational requirements

The project is being undertaken over a two-year timeframe. It is acknowledged that trust is a very important issue in primary health care collaborations yet is rarely discussed and explored. The outcomes the project hopes to achieve include ways of understanding how to achieve the following objectives:

- Negotiated protocols and procedures across related organisations to strengthen integrated action
- Greater exchange of information about client needs and service issues to support more integrated services
- More constructive ways of managing and overcoming differences between organizations to achieve greater coordination
- Deeper understanding of relationships between primary care organizations to help people and organisations create trust and collaborate.

(for more information contact Dr Rae Walker at La Trobe University)

Access for All Abilities

This government program aims to "encourage the sport and recreation industry to respond to issues such as physical access, attitudes of the people who work in the industry, and the appropriateness of existing services for people with disabilities". (see http://www.sport.vic.gov.au/dir017/srvsite.nsf/pages/services_activecomms_disserv?OpenDocument#introduction).

Previous Initiatives - Focus on Recreation: David Craig

One of the challenges put by some family members of people with disabilities who have significant and complex support needs is that the community will not accept their family members due to unacceptable behaviour in public. As a manager of a team of community recreation workers employed at the Spastic Society in the 1980s, we were confronted with this situation in relation to our community based recreation programs.

At the time the service, known as Leisure Action, sought to respond to this challenge by taking affirmative action to ensure that people with the most challenging support needs would be included and supported. One particular initiative in the Southern Metropolitan area allocated five hours per week of recreation support worker time to each of five people with disabilities who were identified as among those who presented the most significant challenges for inclusion in community recreation options. It was also planned that if the initiative were successful, volunteers would be trained and introduced by the Leisure Access Workers to take up the support role so that the program could be offered to more than the initial participants.

The project followed a participative action research model, demonstrating an outcome focus for recreation support that emphasised the importance of choice, voluntary relationships and friendship development, enjoyment and fun, control over free time, adventure, belonging and participating in community life and capacity to be spontaneous.

Workers were expected to get to know the individual in their own environment and establish some sense of the kinds of leisure experiences that would most likely be meaningful and enjoyable. Observing the way family or primary carers interacted and interpreted needs and wants was a starting point for workers and gradually built up through increased direct interaction through such activities as massage, playing music or going for walk around the block. As the relationship grew in confidence it was clear that trust was a key to extending the range and length of the recreation experience.

Workers reported that individuals they were supporting began to connect and respond more readily as the relationship continued. As part of the commitment to continuous development and extension of the program, a volunteer was introduced to the individual by the worker with the view to extending the support network and eventually freeing up paid worker to commence with a new individual. In some instances, transferral of trust and the capacity to develop an introduced relationship was surprisingly easier than it was to establish the first relationship.

Further into the program, it became clear that the one-to-one support relationship was lacking something. It was decided to try linking into a program at the local pool that was adapted for people with disabilities. When the workers supported the individuals to link into a community recreation program with other people, the group dynamics proved to be an important factor in maintaining a sense of enjoyment and extension of skills and level of community engagement.

Continued participation in the swimming program and having a coffee afterwards built social connections that were another critical part of the development of the individual's recreation. Finding the balance between individual and group interests and between maintaining a familiar routine and continuing to try new interests or extend the existing interest was important.

Outcomes for the individual were that when they received support that was tuned in to maximising their control over where they went, what they did, when it was done and who it was done with, they began to respond and develop in ways that made them seem less impaired. What may have been mistaken for inability to act and initiate choice and control initially, came to be seen as conditioned withdrawal from being offered little chance to exercise choice. Through this process the individual was able to trust their support worker, gain confidence in going out into the community and begin to establish social links and relationships with others.

For the parent/s or family members the delight in seeing a contented and more socially active and engaged son or daughter was important. In particular, meeting people who chose voluntarily to befriend and support their son or daughter was regularly reported as a very moving experience. Families were able to experience respite in a natural way, knowing that they didn't have to feel the guilt often associated with some of the more formal respite programs.

Key things we learned through this process were:

1. People with complex and significant support needs could benefit from support that was patient, persistent and facilitated control and choice.
2. That the principles of good recreation practice employed are a valuable guide to supporting the process of community living.
3. That building trust in relationships between a participant and worker and good process is a critical element in successful growth and development. Relationships and friendships are the key to success in community participation.
4. Starting from a familiar environment (home) and gradually moving into new settings in the local community in a phased way seemed to give an individual more sense of control.
5. Volunteers have a much greater capacity to accept and befriend people with high support needs than is often credited by either families or paid staff. Well-supported and trained volunteers can achieve some things that are not possible in a paid relation ship.

There was nothing startling about this initiative and there are many other small isolated examples of this kind of activity in other organisations and services. Unfortunately, documentation is often not done or difficult to find. Further, significant changes in funding and disability services priorities and staff turnover have led to disruption and discontinuation of many of these types of programs. The devalued status of community-based recreation may also be a key factor in limiting the continuity and development of work like this undertaken in the late 1980's.

Common elements of these initiatives

In reflecting on what makes these initiatives work, the following elements appear to be common to many programs which focus on assisting people with a disability to be more broadly included in a range of community activities and interests. These are summarised as follows:

- Strong belief that community inclusion is achievable for all
- Management who are committed and support staff to develop innovative practices which encourage community inclusion
- Staff who are skilled at working with people with a disability and who motivate others through their positive and enthusiastic approach
- Climate of lateral thinking and risk taking, acknowledging that not everything will work but that the only way you progress is to try new things and try again

- Focus on developing partnerships to maximise potential possibilities and increase efficiencies of effort
- Processes in place to reflect on practice, with a heightened awareness and ability to evaluate what works and what doesn't work and learn from that experience
- Strong influencing skills to work with others to shift their thinking by demonstrating what is possible
- Making small steps and building on those
- Pragmatic yet high expectations – ie understanding that there is often a need to work around resource constraints, existing systems, but with an expectation that this is doable rather than too hard
- Presence of a bridge builder who can facilitate between the community and the individual or service provider, building understanding
- Robustness about what is possible
- Acknowledgement of the level of skills required to facilitate community inclusion by appropriate remuneration of key workers
- Allowance of adequate time to plan, develop and implement programs, understanding that change takes time.

5. Key Barriers and Issues Regarding Community Inclusion

The following perceived barriers to people with a disability achieving community inclusion were gathered during the data collection phases of this project from conversations with individuals, discussions at the Reference Group and Focus Group meetings and supporting information from the literature. The strong message received from these discussions was that it is important to progress from focussing on barriers, to considering what is possible to achieve. However, it is still important to acknowledge that real and perceived barriers exist.

The following is a summary of the factors currently at work in Victoria that others see are actively working against community inclusion. Many of these barriers are based on perceptions of what people with a disability can/should/could do, which can be addressed by education and an acknowledgement of the limitations imposed by the current service system. Throughout the course of this project there was a shared belief that many of the following barriers can be addressed, provided there is a strong vision and will to facilitate community inclusion for all:

Lack of understanding of what community inclusion is and then how to do it

- The prevailing narrow view of the kinds of involvement with community people with a disability can achieve limits the opportunities they have. This view is often based on a limited experience of including people with a disability. There aren't enough stories documented to convince community, workers and families of what is possible.
- The way in which people make choices about friendships, how they spend their leisure time, what interests they pursue, or groups they join, is not consciously analysed. Therefore when confronted with the task of assisting another person to engage in community, people find it hard to know where to start and what to do, as they often haven't thought about how they have developed their own range of interests and connections with others.
- There aren't clear measures of what "successful" community inclusion looks like, so it is hard to know when it is working. Attempts to measure community inclusion have been quantitative – i.e. number of relationships a person has, the number of activities a person engages in, rather than workers measuring how the individual feels their life has improved as a result of greater connections with others and with their interests.
- There are professionals in the community who are skilled at community inclusion, such as leisure, recreation and community development workers, however their expertise is under-utilised and not well understood.
- There needs to be a conscious way of reviewing activities that a person is engaged in. Some activities "we hang onto for years", "doing them to death" and the other extreme is allowing people to "constantly taste things and never fully enjoy them". Assumptions are made about a person's interests or what is working within a program and these are not revisited. "Staff get the original high from the innovation then they forget to continue to innovate."
- Whilst information on good practices in community inclusion might be available, it is often not documented, widely known or accessible – there isn't a single source of information or simple ways of exchanging information to promote good practice.
- It is hard to get information to individuals who live in CRUs – DHS can act as a barrier to sending out information to CRUs, using privacy legislation as a reason. As a result, individuals may not be informed of all the possibilities and resources for engagement available.

It's too hard or impossible for some people with a disability to be included

- There is a lack of a vision that community inclusion is possible for all people with a disability.
- The person's degree of disability is often viewed as a limitation by staff, families and the broader community who can have low expectations of what is possible. They may be focussed on what the person is unable to do, rather than challenge themselves to find ways to interact and achieve a higher quality of life for the individual.
- People feel uncomfortable with disability – both workers and others – this is a barrier to looking beyond the disability to the individual.
- The inability to communicate verbally is used as a reason for not attempting to discover a person's interests and gifts, as they may be harder and take longer to discern.
- It requires hard work to develop relationships if a person is unlovely or hard to engage with.
- The service system defines people in clinical terms, focussing on deficits, and does not always have high expectations for what is possible.
- Disposition in disability toward "care", "containment" and "protection" affect the service system response and can work against community inclusion.

Facilitating community inclusion is currently no-one's role

- Disability workers aren't recruited to facilitate community inclusion.
- Some disability workers are not connected with community themselves; they may be "fringe dwellers", therefore how can they be expected to be good at facilitating community inclusion if they aren't connected themselves?
- Disability workers aren't trained to understand how to connect people with a disability to others and to identify and facilitate their interests.
- Disability workers aren't appraised on the basis of how they have connected individuals to community – their performance is based on different measures, therefore community inclusion is not rewarded and barriers they construct which prevent inclusion are not addressed.
- Many disability workers in houses have either 1) not been oriented to the new paradigm of focussing on the quality of life of each individual, rather seeing their primary role as looking after the house, attending to administration and working to a program, or 2) have found it difficult to make this shift in thinking.
- The presence of friendships in a person's life is acknowledged as critical to wellbeing, however developing and supporting people with a disability to achieve friendships is not a priority.
- Facilitating community inclusion is seen as a "big ask" for any one individual to do - there is a need for a range of people to support individuals to achieve community inclusion. If this mission is reliant only on disability workers it is unlikely to occur as current staff don't have the time.
- Facilitating community inclusion requires skills, knowledge and an appropriate attitude, so who *is* positioned to do it? Do we need to employ another layer of people to take on this task? Who is responsible? Who has the right mix of skills?
- Disability workers may not view their role as advocating for the best quality of life for the person with the disability, seeing themselves as responsible to their employer first rather than to the client.

Community aren't equipped or interested in engaging with people with a disability

- The level of acceptance of people with a disability in the community varies. Fears are often based on a lack of living in a community with people with disability. A lot of people would like "to do the right thing" and don't know how.

- Some neighbourhoods feel unsafe to people with a disability.
- The "eternal child" view of people with a disability positions them as having a limited capacity for independence and allows others to assume a nurture and protect approach.
- "Us and them" view – some see people with a disability as fundamentally different.
- A critical foundation for developing relationships with people with a disability is finding communities who are accepting of the person with the disability.
- It isn't a commonly held view that one can have a reciprocally satisfying relationship with a person with a disability.
- Declining social capital and exclusive behaviours of some groups makes it difficult for anyone to engage in community, let alone people with a disability.
- There is a lack of understanding of the power and importance of voluntary relationships. We overly value what a paid person can do and diminish what a person who isn't paid can do. We think that paid people are safe and skilled and unpaid people are unsafe and unskilled and therefore miss out on tapping into valuable connections that individuals could make.

There are too many risks – people with a disability need to be protected

- The political climate is one of risk aversion – this is translated in the disability sector to ensuring staff minimise risks at all costs, whereas developing connections with community is about adventures and taking risks.
- Where staff have choices on how to work with individuals, they are likely to choose the most risk averse option, as if anything goes wrong it will be on their head. This often works against efforts to include people and expose them to having new experiences.
- Parents tend to want to protect their children, particularly as they age and are frightened others will take advantage of them.
- The growing emphasis on protection of privacy means individuals often have to give up opportunities to engage with community for privacy and vice-versa.
- The lack of encouragement to take risks stifles creativity and opportunities for individuals.
- There is an idea that the first attempt at developing relationships has got to be perfect, whereas it is inherent that relationships fail. Allowing people to be hurt or rejected is part of developing relationships and this needs to be permitted. The average person often learns most from mistakes and relationships that don't work.
- Exposing individuals to different people and experiences requires trust, particularly if they have had negative experiences in the past. Often there isn't an acknowledgement that people need to mend before they can build trust again and that developing relationships takes time and skill.

The service system is not structured or resourced to promote community inclusion

- The provision of housing linked with support for many people with a disability means CRUs are viewed primarily as workplaces rather than homes for individuals. Whereas attendant care workers who go to a person's home often have a more respectful view that their role is to work to satisfy the individual's needs.
- In ID the system has traditionally meant that others are 100% responsible for everything that happens to a person's life. We need to work out what the disability service system needs to be accountable for, and realise what can be done elsewhere.
- The limitations in the disability sector, such as staff shortages and funding constraints, make it difficult to promote community inclusion.
- The service system is fragmented, partly as a result of the competitive environment fostered by the previous Liberal State Government, hence it is harder to develop networks and trust to work with others for the benefit of the individual.

- There is an inability for those in the disability service system to think outside the disability system, in terms of ways to link in with others, as for a long time the needs of people with a disability have been provided for within a closed sector.
- Services have been planned without knowing what people want.
- Day program staff don’t have skills or time for community capacity building.
- People with a disability often have activities prescribed based on program boundaries – i.e. 9am -3pm day program Monday to Friday - but no activities outside that. There is the expectation that these programs suffice, whereas these fixed schedules and group-focussed activities are artificial constraints that act as a barrier to creating an ordinary life.
- The weakness of service delivery staff controlling programs for clients is that they may interpret clients’ interests in ways that fit with their own service delivery needs or understanding.
- There is a lack of direct service measures that relate to community inclusion. Although in the State Plan community inclusion hasn’t been translated through policy and procedures to work on the ground.
- Government services often “average things out”, working to a low common denominator.
- Effort is put into regulation and monitoring which creates a deadening rather than a creative culture.
- Access issues, such as steps, inaccessible buses, absence of disabled toilets, footpaths, kerbs, and inappropriate seating, are still a preventative barrier to community participation.

Absence of leadership around community inclusion in the disability sector

- Whilst there are practitioners who are successfully promoting community inclusion, they are often not supported or rewarded for their good practice, and are often working against prevailing norms of containment and protection of individuals, which means it is hard work to sustain efforts over time.
- Poor practices that work against promoting individual client needs are not addressed or punished.
- Whilst the State Disability Plan reinforces the importance of community inclusion, the translation of this paradigm shift to practice is painfully slow, is often sabotaged, not understood and lost along the way.
- Staff working in the sector often feel the effects of a fragmented system – there needs to be leadership in facilitating ways for individuals on the ground to come together in a positive and safe environment for exchanging ideas and empowering each other to try new ways of working.
- Managers have enormous power and control in allowing what workers can and can’t do, whether explicitly or implicitly by their responses. They have a responsibility to develop strategies for individuals to assess risks and make judgements that do not limit opportunities for individuals.
- There is a need for leadership for staff to try new things and fail and learn from that, as that is the only way to evolve good practice.

6. Learnings from Previous Deinstitutionalisations

In reviewing the reports on the following deinstitutionalisation processes in Victoria, the questions we asked focussed on evidence of community inclusion planning, outcomes and learnings. As community inclusion was not the prime focus of these evaluations, where there was evidence of integration it is not always clear whether this was systemically planned or due to efforts of particular individuals. A number of barriers were identified and comments offered on how to assist individuals to participate more fully in their new locations. The institutions for which written information was available were:

- Aradale, Ararat
- Colanda, Colac
- Caloola, Sunbury
- Janefield, Kingsbury
- Hirondelle, Kew
- Mayday Hills, Beechworth
- Pleasant Creek, Stawell
- St. Nicholas, Melbourne

The themes that emerged as summarised below:

Importance of accurate information about the individual, their needs, desires, interests as a base from which to effectively provide services

- Pleasant Creek evaluation (French, Prioletti and Associates 1996) recommended that staff need training in the writing of GSPs and IPPs so that they accurately reflect client's skills, developmental needs, are not judgemental or contain 'old' information. Plus they suggested adding an "Outcomes/Progress" section to GSPs and IPPs.
- Pleasant Creek evaluation (Burnet and Sykes 2000) stated that information regarding clients was often based on perceived rather than actual events – e.g. that they wouldn't participate in activities and needed intensive support to do so, which sometimes wasn't the case. In addition,

  > …assumptions were made about a client's capacity to cope in the community, often based upon information that was at best misleading or at worst wrong". (p.41).
- Aradale and Mayday evaluation (Picton et al 1997) reported that staff needed to take into account clients' personal preferences.

Key role of staff approaches and management style in improving quality of life outcomes for individuals

- Hirondelle evaluation (Radler et. al. 1999) emphasised that staff attitudes and management style were both critical in the way they influenced interactions with clients and provided them with greater opportunities. Some of the key elements they reported to be crucial in facilitating opportunities were:
  - direct support staff involved in decision-making which has resulted in a greater level of commitment, motivation and enthusiasm for the job and a team spirit
  - leadership by example
  - respect for individual workers and consumers
  - focus on the wellbeing of the consumers
  - concern for the staff, positive feedback, being listened to (i.e. reflective, supportive practice)
  - greater range and level of responsibility offered to staff and embraced by them

  - retention of staff

- Aradale/Mayday evaluation (OPA 1994) recommended the need for greater staff development to assist consumers to develop social networks and noted that a potential barrier to integration was the attitudes of ex-Aradale staff who were subsequently employed in accommodation and support services for these clients.

- Caloola evaluation (Owen et. al. 1994) measured quality of life outcomes and stated that for those with "much improved" quality of life who had moved to CRUs the features were higher staff-client ratios, coupled with low staff turnover and high expectations of consumers' potential. It was noted that:

  > Appropriate provision for individual needs appears, however, to require substantial input of skilled staff time in a developmental culture which respects individual choice and responsiveness to personal concerns and capacities. (Owen et al 1994 p.ix)

- Pleasant Creek (French, Prioletti and Associates 1996) recommended staff training in:
  - principles of social role valorisation
  - provision of 'insitu' training, especially regarding program development and activity options
  - understanding advocacy and the implications for clients of conflict of interest

- Colanda evaluation (French, Prioletti & Assoc 1997) recommendations included the need:
  - To foster meaningful interactions between clients and staff, as most communication occurs in response to routines and regimes
  - For increased direction, support and training of staff to enable them to take up their roles with "innovation, creativity and compassion" (p.3)
  - For more collaboration and open communication between unit managers and senior managers
  - Increased staff training and development – to develop knowledge, understanding of clients disability and encourage team work.

- Pleasant Creek evaluation (Burnett and Sykes 1999) noted the following:
  - The issue of staff feeling a sense of client ownership, that is, some direct care staff or day program staff felt that they were the only people who could best meet the needs of particular clients, which had a restrictive effect
  - For day programs some staff "hung on" to clients so they wouldn't lose funding
  - The importance of staff retention, noting that the frequency of staff changes often affected smooth running and communication and therefore the ability to achieve individual outcomes
  - The importance of organizational culture, explaining the need for more work with staff so that the institutional culture was not replicated in houses.

- General (Fyffe 1999) Critical factors identified to date in determining the quality of residential services have included the nature of staff and their defined purpose, with implications for consumer interaction, organisational arrangements and service leadership.

  > Staff require expert skills to implement active support, promote individual decision making etc.…the intellectual disability field has accepted that low staff skills are all that is required to implement community support. The emerging evidence is contrary to that (Fyffe 1999, p.188)

Role of formal and informal support

- St Nicholas (Cummins 1993) – whilst there was a dramatic increase in life skill development once out of the institution, the level of social integration was still very low – the average rate of contact with relatives rose only to about six times a year and the average rate of contact with friends outside the CRU was less than once a week.

- Aradale and Mayday (Picton et al 1997) reported the need to strengthen family and social networks and recognise the value of, and extend, the concept of friendly visitors, that is, volunteers recruited to share skills and experiences with clients through home visits, with a focus on leisure and recreational pursuits, encouraging social integration and providing friendship and companionship.

- General (Fyffe 1999) The task is to understand the implementation of community living and assist communities, staff and families to understand the support role (Fyffe 1999 p.188)

  > Living in the community requires active and planned support from formal and informal supports to achieve the goals of community membership and participation. Without this support the degree of personal choice, social networks and level of community participation for each individual can resemble those of people living in traditional congregate care settings …(Fyffe 1999 p.188)

Resources/Funding

- Aradale and Mayday (OPA 1994) noted that there is a need for adequate resources for individuals to access opportunities to achieve community integration, including:
  - Transport to get to places
  - Staffing constraints
  - Fees to participate in day programs

  > One question not covered in this evaluation, but which with hindsight emerges as an important one, is the question of payment for day program activity…some clients are well resourced, while others suffer restriction of activity with a shortage of personal finance and an increased expectation to pay their way in areas such as accommodation, transport and recreation/leisure services. For future examination, there was some evidence to suggest that transport and personal finance are sometimes barriers in the area of recreation and leisure opportunities. (p.vi Picton et al 1997)

- General (Glennen 1999): In a climate of limited resources, funding arrangements can discourage community placements if not flexible and innovative. For example, the funding formula which provides funding for those in day programs does not provide funding to assist consumers to participate in other community settings, even though staff time is required to support those activities. In addition Fyffe (1999) noted that “Economic constraints are acting against the ideals of community support models of service unless a service minimum can be established…”(p.188)

Need for more individualised approaches

- Aradale and Mayday (Picton et al 1997) stressed a need for access to individualised recreation and leisure programs.

  > Although important to the social and emotional wellbeing of clients, participation in these (day) activities did not lead to the development of meaningful interpersonal relationships with other members of the community. Rarely were such activities conducted on an individual rather than group basis, and activities did not generally lead, at least according to staff, to interaction with others in the community. (Picton et al 1997 p.ix)

- Colanda (French, Prioletti & Assoc 1997) Stressed the need for a formalised and objective method of selecting and matching clients to day placements. Matches tended to be based on availability of hours in programs and staff perceptions of the consumer’s interests, which may not have been accurate.

Suggestions on increasing community integration and/or barriers identified

- Aradale/Mayday evaluation (Picton et al 1997) recommended that the Department:

    - extend its knowledge base in relation to family reunification processes in the disability field
    - explore strategies to achieve a better community integration outcome, such as community education, skill development strategies, brokerage, social network analysis and the utilisation of client communication abilities and preferences.
    - conduct further research into the quality of life and community integration experiences of people residing in community-based residential options.

- Caloola evaluation (Owen et al 1994) noted that despite individuals having increased engagement in activities, many of these were in formal day programs or inhouse. This kind of activity had not translated into the development of social support networks that reached into the community. It was recommended that attention be given to those factors which diminish quality of life, including

  > …limited contact with family, friends and community members, staff performance and some attitudinal shortcomings on the part of caregivers (e.g. limited knowledge of client needs and lower than appropriate expectations), the quality of the physical and material living environments, and the range of accessible community-based social and leisure activities (p.x)

- Colanda (French, Prioletti & Assoc 1997) noted that unit routines and regimes were the "biggest barrier to the development and implementation of flexible and responsive client programs in Colanda" (p. 5). (Note that Colanda is a cluster living setting).

- Hirondelle evaluation (Radler et al 1999) stated that the outstanding issues were the ability to make big choices – where to live and who with, with barriers perceived to be skill level, limited ability to communicate and inflexibility of the service system (e.g. day program hours).

- Pleasant Creek (French and Prioletti 1996)
    - Recommended that more independent advocates in the form of community visitors were needed, who had time to better understand true client needs, were able to verify information given, and were provided with additional training specific to the needs of these consumers.

- Pleasant Creek (Burnett and Sykes, p.43.) recommended "adequate consultation with the local community is required so as to assist the process of community acceptance and integration".

It is recognised that although the philosophy of community inclusion for people with disabilities in Australia has been in place for many years, practice has lagged. Therefore in these earlier deinstitutionalisation processes there were significant areas for improvement. Community integration is now explicitly part of the policy agenda and has become increasingly a focus for improving the quality of life for people with a disability. This discussion raises the question of how the learnings and recommendations from previous deinstitutionalisation processes are being integrated to ensure the best possible outcomes for residents of KRS in their new communities. A evaluation of Kew residents who have already left the institution is currently underway.

7. Solutions Arising from Discussions with Key Contacts

Below are the range of solutions and possible actions suggested by key contacts in the course of this project. We talked to all of the key contacts about the barriers and issues they saw surrounding community inclusion for people with disabilities, and also sought their input on potential solutions. Section 8, which follows this section, provides the conclusions and a proposal for the advocacy coalition to use as a basis for how they will further develop this project.

Analyse, document and share good practice

A key theme raised by people when addressing their ideas for solutions was the need for capturing the essence of good practice in community inclusion. People commented on the need to:

- Clarify what successful community inclusion looks like
- Find evidence of what is working, analyse why it is working, document what has worked and what could be done differently and find ways to influence wider practice
- Share success stories that demonstrate that even those people others think are least likely to succeed in the community CAN be supported to experience community inclusion, especially to direct support workers and families who may not be aware of what is possible e.g. on a community inclusion website, describe good services through newsletters, create videos
- Promote "good" services to balance the overly-critical nature of the disability service system, which can result in staff going into a bunker mentality, inhibiting them from being adventurous or innovative. When we report the good stuff people feel encouraged to try.
- Suggest services inform DHS of the good things that are happening and DHS keep a register of initiatives.

Maximise opportunities for community inclusion outside the disability sector

Comments were made about facilitating community inclusion by going beyond the disability sector to the community, such as:

- Identify influential citizens who are supporters of community inclusion – eg. Local mayor – and enlist their active support in promoting community inclusion
- Set up mechanisms for people with a disability to participate within mainstream community forums within local government to influence change, e.g. on public transport issues, access etc.
- Look beyond what is offered by the disability sector and find ways of engaging people with a disability in recreation, leisure and interest groups that exist in the community.

Support people in the industry

Other solutions that people discussed at length were ways to assist workers. Comments included:

- Facilitate opportunities, such as forums, for direct care workers to meet and share ideas in a positive and safe environment, perhaps using drinks/food as a way of brining people together. Management forums are common but there are not as many opportunities for direct care workers to share their experiences.
- Ensure service provider infrastructure and staff practices are aligned with policies, managing and supporting staff to be innovative and rewarding good practice, rather than focussing on mistakes.
- Skill staff to assist individuals to make decisions and choices, as this is a foundation for being included. For people with a disability who have lived for a long time in an institution, having choices is often a foreign concept.
- Bring about systemic change so that even if "good" staff leave the vision isn't lost and the system continues to build on community inclusion outcomes
- Change disability workers jobs to emphasise community inclusion, e.g.

- make “an interest in facilitating community inclusion” a prerequisite for the job
- train workers to engage their clients in the community
- develop direct service measures that relate to community inclusion
- change new workers expectations of the job so that it emphasises community inclusion

- Support awards to recognise good work– e.g. unions sponsor two awards
- Make IASSID conference affordable so that workers can attend
- Provide training on facilitation and networking for direct support workers e.g. SCOPE have a two-day course
- Better resource House Supervisors as they pay a critical role
- Review the content of training courses – Deakin has been defunded – only RMIT now. Is the new State Plan reflected in courses? Is there an emphasis on community inclusion?
- Undertake a PR campaign on the rewards of working in the disability field
- Five staff greater control to make changes – the opposite is the feeling that “nothing is your work” – so they feel a connection between positive results and their own effort

Create change - from a climate of minimising risk to maximising quality of life

Risk management was mentioned frequently, as was the need for cultural change in service provision. Comments included:

- For people dependent upon support, shift the family and/or workers views to thinking about what is possible, rather than a person’s limitations.
- Develop effective risk management strategies which enable particularly support workers and families of people with disabilities to take sensible risks therefore allowing individuals to take up new opportunities
- Change the emphasis from support workers primarily seeing themselves as accountable to DHS (big brother) to being accountable to the individuals they support
- Decentralise the control of service provision, allowing more control at local levels to enable innovation and counter over-regulation
- Acknowledge the primary duty of the service is to maximise participation and independence and choice by resourcing good decision making, whilst still taking into account duty of care

Encourage continuous quality improvement

A strong theme raised was the need for quality monitoring and continuous quality improvement. People made a range of comments including:

- QA needs to be more than just looking over the shoulder, rather promote service development
- QA needs a degree of independence, whereas it is usually done by those who have the power to reward and to punish
- Services need to be person-centred and designed to elicit feedback for continuous improvement from individuals or their representative e.g. participant-focussed feedback mechanisms such as forums or surveys whereby issues are raised and addressed in an ongoing way that promotes ownership and forward thinking.
- View problems as tools to bring about service improvement, e.g. the numbers of complaints could be seen as a sign that it is safe and people are encouraged to give feedback.
- Acknowledge that support workers make hundreds of good decisions each day and maybe a handful of bad decisions, yet the bad decisions are jumped upon - acknowledge good intentions of many services and support workers. Criticism needs to be constructive and positive with a view to finding ways to improve not punish
- Help staff to specify and monitor good practice, identify areas for improvement, set collective goals and encourage reflective practice.
- DHS send letters of congratulations to day programs who do innovative things

Change the service system

- Look beyond the model as this is usually not the answer – the way people work is often the key.
- Fund “community inclusion” workers to resource disability services to facilitate community inclusion for individuals.
- Address the lack of trust across the disability service system, e.g. CRU staff feel untrusted by parents, management, day programs, DHS, by good leadership enabling open communication and all parties taking responsibility
- Workers be encouraged to tap into volunteers and people’s informal networks and natural supports as this is a rich source of identifying opportunities for individuals
- Recognise that good community inclusion often happens in small, innovative, community-run organisations, which can be more flexible to individual needs, and support such organisations.
- Narrow down what ID services need to be accountable for - the traditional approach to service delivery is holding providers 100% responsible for everything that happens to a person’s life which can be a barrier to community inclusion.
- Create a case management function outside the department and connected to community to facilitate inclusion.
- Separate the functions of accommodation provider and the support provider, often both provided by DHS
- Develop tenancy rights for people with disabilities.
- Assist DHS and service providers to be more “thick skinned” re criticisms and confidant in supporting change and informed risk taking
- Acknowledge the interconnectedness of the service system – to serve clients well we all need each other to work toward the same goals
- Acknowledge the important role that unions can play and skill managers to more positively deal with unions who are a valuable resource for promoting better outcomes for individual workers and clients.
- Introduce values-based human resource management
- Promote partnerships between workers and individuals and families
- Identify and value skills and leadership and passion - middle managers are the key

8. Emerging Themes and Questions

> *There is nothing more difficult to take in hand, more perilous to conduct or more uncertain in it's success than to take the lead in the introduction of a new order of things. (Machiavelli)*

The following key themes arose when working through the issues for facilitating community inclusion through to the development of solutions and plans for action. The ten themes are:

1. ***A common understanding and strong vision of community inclusion***
2. ***Acknowledgement of the complex nature of community inclusion***
3. ***Development of good practice and continuous improvement across the service system to enable community inclusion***
4. ***Identification and measurement of good outcomes for individuals***
5. ***Sharing and promotion of good practice information and initiatives for community inclusion***
6. ***Protection of good practice initiatives***
7. ***An understanding of how to facilitate community inclusion for people with particularly complex needs***
8. ***A paradigm/cultural shift in service provision to focus on community inclusion***
9. ***Engagement with families***
10. ***Community capacity building and strategic partnerships outside of disability specific organisations and government departments***
11. ***Collaboration across the service system***

1. A common understanding and strong vision of community inclusion

There is a need for a commonly agreed foundation of community inclusion based upon a clear vision and values from which to move forward. This involves developing a common understanding about community inclusion and what is possible for individuals. This vision needs to:

- Be shared by families, services, workers, advocates, researchers, governments
- Acknowledge different perspectives and 'roles' for various stakeholders
- Be able to exist despite changes in government or social policy
- Be a long term vision
- Be inclusive of all stakeholders

Resource: See Chapter Three of this report 'What is Community Inclusion?'

Questions: *Is this paper useful? How do we usefully share ideas and thinking about community inclusion? Who do we involve in this thinking? How do you facilitate a common understanding of what is meant by community inclusion?*

2. *Acknowledgement of the complex nature of community inclusion*

There needs to be an acknowledgement that good practice in community inclusion isn't simple or straight forward. It is multi-layered, involves a commitment across the system to both evolve and sustain good practice and requires the development of explicit outcomes that focus on community inclusion within these various layers and with various stakeholders.

Resource: When considering solutions and actions there are activities that need to occur within all of the following layers and many solutions require action across many of these layers:

- Individual people with disabilities
- Family
- Other informal supports and networks
- Formal supports inc. income, housing etc.
- Support practice in working with consumers
- Program design and resourcing
- Management of support staff, including how they are recruited, appraised, supported, accountable
- Training support staff
- Organisational culture within disability and also more broadly in other organisations
- Governance
- Local community context/environment/facilities
- Community awareness, understanding and attitudes
- Collaboration and linkages and dialogue e.g. between services and advocacy
- Social policy

Questions: *When thinking about working towards solutions: How do we prioritise? What will have the greatest impact? What skills, resources and expertise do we have to draw on? Where to begin? Who to involve? Who could support this objective? How will we approach this? What are likely benefits? How important is this? How feasible is this?*

3. *Development of good practice and ongoing continuous improvement across the service system to enable community inclusion*

There needs to be a commitment to both

- evolving good practice initiatives AND
- improving existing services

One approach to evolving good practice initiatives is by starting at the edges of the bigger service system at the individual person, program or organisation level. Initiatives need to be planned with continuous improvement processes in mind, acknowledging that there are likely to be important learnings for the bigger service system. In addition, a long time frame to allow success stories to emerge is important, acknowledging that there are no quick fix solutions and that these endeavours take time and perseverance.

A long-term, forward-thinking approach to continuous improvement is also required across the existing system that includes:

- working with each individual
- within each service
- building stronger co-ordination and more collaborative ways of working
  - across the service system, and
  - within local communities

It is important to work from where people, services and the service system are at and to consciously choose to work progressively and systematically to support individuals, to develop services and to build more collaborative relationships across the service system and within local communities. Brining about quality improvement requires a culture of learning from mistakes, reflective practice and continuous improvement, promoted through strong leadership.

Resource: Some Victorian initiatives in community inclusion have been documented (see Chapter Four in this Report).

Questions: *In what ways can good practice be facilitated? How do you ensure that the service system invests in developing good practice? How can the learnings from these initiatives be translated into information for the broader service system?*

4. Identification and measurement of good outcomes for individuals

Attention needs to be paid to how we identify and measure good practice. Currently attention is paid to counting "how many" and "how much", focussing on what goes wrong or isn't working and the "bottom line". The system needs to get better at measuring and focusing on effective community inclusion outcomes for individuals, such as concentrating on improving the use of quality of life measures and finding ways to ask individuals to express their feelings and attitudes and describe activities they enjoy.

Questions: *If "good practice" generally is the foundation for enabling community inclusion, do we need to identify what common good practice is? If we know this are we then better able to develop community inclusive practice?*

5. Sharing and promotion of good practice information and initiatives for community inclusion

Once good practice is identified, investing in ways to share and actively promote good practice, learn from initiatives and then develop services based on these learnings is important. There needs to be an ongoing commitment made to actively promote examples of good practice in community inclusion.

Resource: Attached is a list of Victorian initiatives that are actively striving to tackle a number of the known barriers for community inclusion in the way they approach service delivery.

Questions: *If we want the initiatives that are underway to be recorded and tracked and learnings from these shared, how do we make this happen? How do we share, highlight and promote good practice in community inclusion when we find it?*

6. Protection of good practice initiatives

Whilst a number of initiatives are in place to progress community inclusion for people with disabilities, many are in jeopardy from short term funding, changes in policy or changes in management.

Questions: *Are there ways to ensure sustainability of initiatives working to improve community inclusion outcomes? e.g. Rural Access, AAA, Interact, Activate.com, Lifestyles, Person-by-person, the Neighbourhood House tool box? How do we ensure and support effective time frames for these initiatives to fully explore their potential? How do we support and ensure good* *evaluation information of these initiatives is then available to establish what is good practice? Once we have information about good practice how do we sustain that which is effective?*

7. An understanding of how to facilitate community inclusion for people with particularly complex needs

Community inclusion requires different sets of things to happen effectively for different groups of people with different resources and abilities. There are many families and support workers who are not convinced that community inclusion is a realistic aim for people with complex support needs. Particular attention needs to be paid to evolving good practice for people with more complex and higher support needs.

Questions: *How do we resolve what is possible for people with complex support needs within the constraints of the system? How do we develop good information and practice for different groups supporting people with particularly complex support needs?*

8. A paradigm/cultural shift in service provision to focus on community inclusion

There needs to be a cultural shift in focus in mainstream service provision. It is important to describe what this shift means for service delivery. For example, community inclusion means friendships outside the paid and disability sectors and providing multiple opportunities for exploring interests and making connections within various communities.

To achieve this new focus on community inclusion, service managers need to actively talk about it, provide information, model approaches, seek evidence of instances where it is occurring, analyse and document successes. Providing risk management strategies to address barriers that arise is also important, to reinforce that community inclusion is a priority focus and needs to be at the forefront. Continually exposing workers to good practice examples of community inclusion, providing permission to innovate and follow through on ideas will assist to empower staff to try new approaches.

The provision of good leadership and management is critical in navigating the challenges and complexities of supporting people with disabilities to experience community inclusion. Strong leadership involves encouragement, recognition, appreciation and accountability for developing community inclusion opportunities for individuals. A key to supporting people with disabilities to experience community inclusion requires innovative risk management, shifting the emphasis from overly protective duty of care that may inhibit their exposure to new opportunities.

There is a need to acknowledge the reality of the hard things in facilitating community inclusion, such as:

- Balancing duty of care versus dignity of risk
- Managing occupational health and safety issues in service provision
- Assisting people (with complex needs) to make choices and develop preferences, and have meaningful opportunities
- Finding and building community capacity

Question: *What progress has been made in developing resources, training materials, solutions in tangible policy and procedure around these challenges for mainstream practice? How can services and organisations be supported to work to change deeply imbedded authoritarian or benevolent cultures of service delivery? E.g. How do you approach changing the prevalent risk minimisation approach in service delivery to people with intellectual disabilities?*

9. Engagement with families

A key theme emerging from this enquiry is the need for active engagement with families and natural supports and networks of individuals. When thinking about the continuum of “supports” there are many different ways of ensuring people with disabilities get the best balance of supports and opportunities possible. A suggestion is that “caring for” can be thought of as being a paid domain, and “caring about” the domain of non-paid family and friends. Thinking about what paid and non-paid carers can do most effectively to enhance the opportunities and possibilities in the lives of people with disabilities is a worthwhile exercise. For many people with disabilities their family and social networks include untapped potential opportunities for actively pursuing community inclusion. In many cases of institutionalisation families and natural supports have been excluded by the nature and context of the housing and support provided.

Questions: *Is there a role for advocacy to be developing and supporting the families and natural support networks of people with disabilities to promote an understanding of the potential for community inclusion?*

10. Community capacity building and strategic partnerships outside of disability specific organisations and government departments

Community capacity building is an important area to concentrate on to ensure effective community inclusion. One way of including people with disabilities is for disability services, organisations, departments and committees to consciously work within mainstream community organisations and processes rather than developing separate, segregated organisations and processes. The inclusion of disability issues in general community infrastructure forums often reinforces the similarities, rather than differences, that people with a disability may face compared to others in the community. For example, broadening access for people with a disability to places may also be helpful to older people who are less mobile or parents with prams. Strategic partnerships and involvement with resources outside of disability services can have broader community benefit as well as promoting education of disability issues. Partnerships with recreation providers, local government, community groups, local individuals, businesses and organisations can have dual benefit.

Questions: *How do we ensure we openly explore opportunities outside of the disability service system, working across community groups, and considering all local resources? How do we effectively develop the local community’s capacity to be welcoming and aware of people with disabilities?*

11. Collaboration across the disability system

While networking and collaboration across the service system is an important part of service system development, it requires trust, time, organisation, resourcing and commitment. Collaboration is an important way to facilitate cross-fertilization of ideas, create links across services that will enable quality outcomes for consumers, resolve system issues and promote good practice. Given the sheer enormity of the service system, one approach to effective co-ordination and collaboration is to start at a local level, such as local area co-ordination that feeds into sub-regional and regional processes.

> ***Questions:*** *How can this be facilitated? How do we ensure that this happens in an inclusive way – that is, not excluding the people working at the coalface, families, or people with disabilities? How do you bring people together to work through opportunities for people and solutions in service provision, such as people in day centres, recreation, employment and respite? There are high-level skills required to facilitate this kind of networking into collaborative practices and co-operative working agreements. Whose role is it to facilitate this? What happened to the plans for more integrated local area planning?*

In thinking through any actions that aim to facilitate community inclusion, the following questions provide a useful prompt for how to think through how to prioritise effort and resources:

- How do we prioritise?
- What will have the greatest impact?
- What skills, resources and expertise do we have to draw on?
- Where do we begin?
- Who could we involve?
- Who could support this objective?
- How will we approach this?
- What are likely benefits?
- How important is this?
- How feasible is this?

9. Deinstitutionalisation Process at Kew Residential Services

Community inclusion is not a simple concept. Facilitating community inclusion requires a level of commitment, understanding, energy, skills and resources. In light of the findings from this project when considering the opportunities for the residents at Kew Residential Services (KRS) moving into the community, the following questions arise:

Questions: *How might the deinstitutionalisation process at KRS be supported to maximize the possibility for community inclusion for residents moving into the community?*

We have learnt from previous deinstitutionalisation processes that when community inclusion isn't the focus it doesn't happen. Hence for the outcomes at Kew to most effectively maximise the possibilities for individuals to experience community inclusion KRS would need to approach this process with community inclusion as the conscious vision and focus for service delivery.

One opportunity arising at this time is for DHS to develop the deinsitutionalisation process at Kew Residential Services (KRS) as a community inclusion demonstration project.

A demonstration project would require the development of good practice initiatives within the planning for the redevelopment and a clear common vision. This includes staff training and support to be innovative, leadership and modelling of good practice in community inclusion, and effective and ongoing management of community inclusion barriers and outcomes. Collaboration across the service system, community capacity building and strategic partnerships would also be required.

A demonstration project of this nature would require planning and thinking through a number of questions, such as:

- Who are their strategic partners?
- What resources can KRS call on to support them with these aims?
- Would additional "expertise" in community capacity building be an important addition to support the transition phase from KRS into various local communities?
- Can KRS work within existing DHS procedures and policies and fulfil these aims?
- Can DHS policies be modified to reflect the learnings from such a demonstration project's reflective practice?
- What are the most important resources KRS need to equip their workers with a belief that community inclusion is possible?
- How could KRS utilise and learn from other community inclusion initiatives?
- How will they measure their success?
- How would they protect this initiative?
- How will they share their learnings?

10. Possible Action for Advocacy Services and Others

1. Ensuring the services have a good knowledge of community inclusion

To play any role, part of the core business of an advocacy service is to be well-informed about community inclusion, including knowing about:

- key resources
- good practice examples
- what has worked and where and under what circumstances
- who has been able to resolve practical issues and how
- what to do and who to involve to have influence

2. Contributing to developing and disseminating knowledge of community inclusion

To play any role, part of the core business of an advocacy service is to be well-informed about community inclusion, including knowing about:

- key resources
- good practice examples
- what has worked and where and under what circumstances
- who has been able to resolve practical issues and how
- what to do and who to involve to have influence

3. Contributing to developing and disseminating knowledge of community inclusion

What role can advocacy services play in resourcing key stakeholders about important aspects of community inclusion?

Is there a role for advocacy services to play in developing and disseminating *specific information/discussion* on:

- Privacy legislation?
- Dignity of risk versus duty of care?
- Effective risk management rather than risk aversion
- Who takes responsibility for thinking through risk management AND how this is resolved? (Note: risk management needs to be well researched and supported by thoughtful legal advice around these challenging issues e.g. Intellectual Disability Rights Service (IDRS) in Sydney and Villamanta in Victoria?)

Is there a role for advocacy services to play *at a broad level* in promoting:

- Community inclusion so that it is top of mind for support workers, families, community groups etc
- Lateral thinking about community inclusion
- The ethos of try, try and try again, helping to create an environment where some failures and negative consequences will occur but that this shouldn’t deter trying and congratulating others for having a go
- Sensible risk taking
- The development of good practice
- Connections between stakeholders

4. Building networks

Can the advocacy services actively build networks, a shared understanding and vision at each services/person’s local level and then bring back to CASL the experiences and developments in each local area to inform the bigger picture and agree on the outputs that advocacy could be developing?

Who could be collating information about initiatives in community inclusion practice and tracking their progress and learnings?

Trust and confidence building in relationships between services, families and government is important – is there a role for advocacy services in rebuilding and building these important links?

5. Engagement with Families

Can the advocacy sector actively work to inform, resource, educate and facilitate family involvement in community inclusion goals, particularly for people who can't make informed decisions?

6. Training

What are some of the logical links that need to be made in how training is conducted?

Who trains others in community inclusion and what is offered?

How does good practice knowledge link into current training?

How might good practice knowledge about community inclusion be formally incorporated into mainstream disability training?

How does advocacy duty of care versus dignity of risk link into current training?

7. System information

What information exists about disability resources, services and supports?

How do you ensure pertinent information is available across the sector and to the community?

Is there a role for advocacy to ensure pertinent information is more broadly available?

Who needs to do what?

Focus of advocacy effort

The struggle by advocacy groups to oppose ongoing institutionalization of people with a disability is carried out in the context of drawn out timelines and sharply contested thinking about what is best for people currently living in institutions. Through this struggle, it is possible that CASL becomes too, intent on what it is **standing against** and missing the opportunity to shape the kind of options and support systems that **stands for.**

The table below offers an inclusive way of thinking about how CASL might work with others:

How to openly involve other key stakeholders:	**Closed approach:**
Inclusive of all people (and their opinions)	Exclusive
Collaborative, with an intent to find common ground on an issue “We are for….”	Take a position and highlight and focus on difference. “We are against…”
Decision-making from an informed basis	Uninformed decision making
Actively listening and seeking to understand others perspectives and to actively communicate	Telling people, preaching to people, asserting positions
Proactive – Leading positive change/being open to change	Reactive
Broadly consult	Narrowly choose people who are already like minded
Work from the assumption that there is value in engaging and that everything is resolvable	Working defensively, critically, negatively, attacking, assuming the world is a battle ground
Engagement (with love) looking for the best in people	Engagement with angst
Create allies	Create enemies
Congratulate/promote/acknowledge good practice	Blinkered and focus only on the bad practice
Supportive of continuous improvement	Critical
Solutions focused and problem solving	Shallow problem identification only
Awareness raising and take an educative role	Not actively learning or sharing knowledge
Capacity building	Ego-centric

Appendix A: References and Resources

There were numerous references and resources collected during the eighteen weeks of the project. Those that were key to shaping the project's approach are annotated below. There were several other references that were useful and others that we did not have time to fully explore. This is viewed as the start of further explorations on community inclusion. To aid in finding relevant material we have included a list of references and grouped them according to subject areas.

Victorian Context

Commonwealth Department of Family and Community Services, *Stronger Families and Communities Strategy*, http://www.facs.gov.au

Department of Human Services, 2002. *State Disability Plan 2002-2012.* DisAbility Services Division, Department of Human Services.

Department of Human Services, 2000b. *The Aspirations of People with a Disability Within an Inclusive Victorian Community.* Prepared by Jeanette Johnson, Millward Brown for DisAbility Services Victoria, Department of Human Services. http://www.dhs.vic.gov.au/disability.

Articulates the hopes, needs, concerns and aspirations of 444 people with a disability interviewed face-to-face, 168 of who had an intellectual disability.

Department of Human Services Disability Services Division Research Projects Website – provides a useful overview of recent research, research underway and contact details.

http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/research

Department of Human Services Disability Services Division, 1999. *Towards Best Practice in Disability Services: Forum Report.* Forum held in September 1999. Prepared for the Quality Improvement Reference Committee by Chris Fyffe.

Disability Advisory Council, 2002. *Disability Advisory Council of Victoria Strategic Plan 2001-2003*, Disability Advisory Council of Victoria, Victorian Department of Human Services.

Ozdowski, S., 2002. 'Human rights for people with intellectual disabilities in Australia: Where to from here?', Paper presented at the *Inclusion International 13th Congress, Melbourne 24th September 2002*. http://www.hreoc.gov.au/disability_rights/speeeches/inclusion.htm, downloaded 1st October 2002.

VicHealth (Victorian Health Promotion Foundation), 1999. *Mental Health Promotion Plan 1999-2002*, VicHealth.

Yeatman, A., 1996. *Getting Real: The Final Report of the Review of the Commonwealth/State Disability Agreement*, Australian Government Publishing Service, Canberra.

Victorian Programs Facilitating Community Inclusion

Access for All Abilities http://www.sport.vic.gov.au/dir017/srvsite.nsf/pages/services_activecomms_disserv?OpenDocument#introduction

Activate.com

http://www.scopevic.org.au/everyday_activate.html)

Community Support Fund

http://www.dpc.vic.gov.au/csf

Neighbourhood Houses and Community Centres
http://www.netc.net.au/neighbour
or Association of Neighbourhood Houses and Learning Centres web site:
http:// www.anhlc.asn.au

RuralAccess Initiative

http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/prog_rural).

Evaluations of Previous Deinstitutionalisations - Victoria

Burnett, N. and Sykes, D., 1999. *The Pleasant Creek Advocacy Project; In the Context of the Victorian Experience of Deinstitutionalisation.* Paper presented at the 35th National Australian Society for the Study of Intellectual Disability, Sydney, September.

Department of Human Services, 1997. *Colanda Client Needs Consultancy, Barwon-South Western Region: The Next Step.*

French, Prioletti and Associates, 1996. *Pleasant Creek Consultancy Project: Findings, Issues and Options*. Presentation Notes 23/05/96.

French, Prioletti and Associates, 1997. *Colanda Client Needs Project – Report: Executive Summary*.

French, Prioletti and Associates, 1997. *Colanda Client Needs Project – Report*.

French, Prioletti and Associates, 1997. *Appendices: Colanda Client Needs Project*.

OPA 1994, *Report of the Aradale Closure and Relocation Project*

Owen, L., Cooper, B.K., Barber, J.G., Picton, C. and Frederico, M., 1994. *Relocation of People with Intellectual Disabilities in Victoria: Final Report*, The Human Resource Centre, Graduate School of Social Work, La Trobe University, Australia.

Picton, C., Cooper, B. and Owen, L., 1997. *Evaluation of the Relocation of Caloola Clients Project*, Human Resource Centre, La Trobe University.

Picton, C., Cooper, B. and Owen, L., 1997. *Evaluation of the Relocation of the Aradale and Mayday Hills Clients Project*, Human Resource Centre, La Trobe University.

Radler, G., Laurie, D. and Gavidia-Payne, S., 1999. KRS Hirondelle; Improved Lifestyle Project: A Description and Evaluation of the Move of Forty from Unit 30/31, Kew Residential Services to Group Houses in the Community. Kew Residential Services, Eastern Metropolitan Region, Department of Human Services, Victoria.

Evaluations of Previous Deinstitutionalisations - Overseas

Ericsson, K, Ahlstrom, J., Brusen, P. Ericsson, P. Jonsson, A., Kylsten, K. Lycknert, S., Rosdahl, T and Akerstrom, T., 1992. 'Community Participation: The life of persons after leaving the residential institution', *Contribution to IASSMD 9th World Congress*, Brisbane, Australia.

Lord, J. and Pedlar, A., 1990. *Life in the Community: Four years after the closure of an institution*. Centre for Research and Education in Human Services, Canada.

Lord, J. and Hearn, C., 1987. *Return to the Community: The Process of Closing an Institution*. Centre for Research and Education in Human Services, Canada.

Deinstitutionalisation References

Burden, J. and Uniacke, M. 1986. *Moving Out, Moving On*. Disability Resources Centre, Melbourne.

Emerson, E. and Hatton, C., 1996. 'Deinstitutionalisation in the UK and Ireland', *Journal of Intellectual and Developmental Disability*, 21, 17-38

Farlow, D., Lord, J. and Schwier, K.M, 1987. *Reuniting Families: A Resource Guide for Family Involvement in the Closing of Institutions*. Family Support Institute, Canada.

Johnson, K., 1998. *Deinstitutionalising women: An ethnographic study of institutional closure,* Cambridge University Press, UK.

Exploring Community Inclusion Opportunities

The Ability Australian Foundation, 2002. *Global Disability Reform – A Whole of Life Approach A Proposal for a Global, Community-based Disability Program and a Global Pilot implementation in the United States, the United Kingdom and Australia*. Prepared by The Ability Australian Foundation.

Brown, R.I. 'Learning from Quality-of-Life Models' Chapter 2 in *Community Supports for Aging Adults with Lifelong Disabilities*. Paul H. Brookes Publishing Co., Maryland, USA. pp. 19-40

Suggests that quality of life needs to focus on:

- The perceptions of the individual with a disability – ie how do individuals with an ID view their experiences? What needs do they say they have and what form of experiences do they seek?
- That person's views of interactions with the environment
- Concerns relating to the construct of the environment by people with a disability

Quality of life is defined as "a multidimensional concept involving personal well-being across life domains with the context of an individual's met and unmet needs and desires" and "the extent to which an individual increasingly controls his or her environment, regardless of initial baseline" (p.21 – based on Brown, Bayer and MacFarlane 1988). Brown's view is that the quality-of-life model "accents individual needs and perceptions, recognises the importance of personal power and requires recognition of choice…It argues that personal control enhances self-image and, therefore, motivation and growth, thus conflicting with the prevailing attitudes toward congregate or group settings, education, and training within and beyond the disabilities field." (p.21)

Cummins, R.A., 1993. 'On Being Returned to the Community: Imposed Ideology versus Quality of Life', *Australian Disability Review,* 2-93.

In looking at quality of life, the important reference point is "the optimum subjective quality of life that our resources can provide". Cummins suggests a need to focus on the subjective needs of individuals using a comprehensive quality of life scale to measure what is important to an individual and how satisfied they are.

> Typically researchers measure variables such as the type of accommodation, the number of accessed community resources, the number of life skills, etc. It is notable that these are all objective measures of life quality, and while they are undoubtedly important, they do not reflect how people fel about themselves and their lives. People's feelings lie in the subjective domain which involves quite a different set of variables such as self-esteem, having close friends and intimate relationships, feeling secure in understanding and controlling their immediate environment, and being happy. (Cummins p66)

Fyffe, C., 1999. 'Residential support for people with an intellectual disability' Chapter 5 in Ozanne, E., Bigby, C., Forbes, S., Glennan, C., Gordon, M. and Fyffe, C., 1999. *Reframing Opportunities for People with an Intellectual Disability*. A report by the Myer Foundation undertaken by School of Social Work, The University of Melbourne, pp171-192.

Beliefs about the ideal residential service are a consequence of many factors, such as:

- the rights of people with ID – rights-based models advocate for a range of options within typical community settings, whereas emphasis on care and protection leads to options where participation in the community is a lower priority
- the optimal outcomes from services
- different understanding of terms such as "community living" and "institution"
- limited evidence re outcomes – mostly from those leaving one kind of housing to another
- economic issues

Moving to the community out of an institution does not in itself ensure a better quality of life – there is still low engagement of clients in meaningful activities and people with high support needs receive less staff time. Skilled support is required to make community living a reality for many.

Three determinants of quality community services have been proposed:

- adequate level of human and financial resources is a necessary but not a sufficient condition – i.e. there is not a clear link between resources available and performance on quality indicators
- internal organisation structures must ensure efficient and appropriate use of resources and planning of staff and service user activity
- organisation leadership is required to acquire and sustain resources, establish appropriate internal structure and motivate staff to implement the procedures to ensure quality lifestyles for people with disabilities. Common difficulties are staffing (not enough, untrained, high turnover); funding; lack of continuum of available services and problems with interagency relationships.

New role of service providers in assisting those living in the community:

- "to identify and remove barriers to full participation" p179
- "to ensure that people make social connections and become fully integrated into the life of the community, and family-life is an integral component"
- "to assist people to make informed choices and to ensure meaningful choices are available"
- to use person-centred planning and design supports around the person
- the service supports the person wherever they choose to live, learn or work

Goals of community support are there but are often hard to achieve in practice – those outcomes that have been more difficult to achieve are:

- People choosing personal goals
- Where and with whom they live
- Where they work
- People live in integrated environments
- Participate in the life of the community
- Perform different social roles
- Choose services
- Exercise rights

Optimal model for residential services would be expected to incorporate:

- Separation of housing and support so the individual controls the housing

- No more than1-4 people living together, preferably following their choice
- Individualised planning which emphasises community membership and opportunities which parallel those of other community members
- Training and supervision for staff to maximise interactions with individuals
- Capacity for changing staffing support needs as individual circumstances change

> Living in the community requires active and planned support from formal and informal supports to achieve the goals of community membership and participation. Without this support the degree of personal choice, social networks and level of community participation for each individual can resemble those of people living in traditional congregate care settings …
>
> Staff require expert skills to implement active support, promote individual decision making
>
> Economic constraints are acting against the ideals of community support models of service unless a service minimum can be established…

Ericsson, K. and Ericsson, P. 1994. 'Development and dissolution during the normalization process', paper presented at the *AAMR Conference, Virginia, USA*.

Glennen, 1999. 'Positive Practices' Chapter 4 in Ozanne, E., Bigby, C., Forbes, S., Glennan, C., Gordon, M. and Fyffe, C., 1999. *Reframing Opportunities for People with an Intellectual Disability*. A report by the Myer Foundation undertaken by School of Social Work, The University of Melbourne.

Henry, D.B., Keys, C.B. and Factor, A.R. 'Value-Based Human Resources Management' chapter 16 in *Community Supports for Aging Adults with Lifelong Disabilities*. Paul H. Brookes Publishing Co., Maryland, USA, pp.271-286.

Looks at the benefits of articulating the organisation's values and then institutionalizing these values in the selection, training, and evaluation of staff. This approach, which focuses on achieving the organisation's core values, fosters team spirit and a sense of mission in work, and helps managers, staff and consumers of service to work together to link positive ideals to daily reality.

Hutchinson, P. and McGill, J., 1992. *Leisure, integration and community*. Leisurability Publications, Inc., Ottawa, Canada.

Jackson, S., 2000. *Development in services for people with intellectual disabilities with a particular focus on community inclusion and on issues related to ageing and disability.* Churchill Fellow Report funded by the Winston Churchill Memorial Trust of Australia.

Janicki, M.P. and Ansello, E.F., (eds) 2000. *Community Supports for Aging Adults with Lifelong Disabilities*. Paul H. Brookes Publishing Co., Maryland, USA.

Very relevant chapters on ways to approach facilitating community for older people with a disability. Provides useful examples, clear directions on what to do, raises and addresses issues.

Kultgen, P, Harlan-Simmons, J.E. and Todd, J., 2000. 'Community Membership' Chapter 10 in Janicki, M.P. and Ansello, E.F., (eds) *Community Supports for Aging Adults with Lifelong Disabilities*. Paul H. Brookes Publishing Co., Maryland, USA, pp.153-165.

Looks at the role of the facilitator of community inclusion – the community builder who seeks natural supports in the environment the person has chosen and uses a person-centred approach, offering a clear vision for the important role this person can play in developing a vision, getting individuals connected and strengthening relationships.

Mahon, M.J. and Mactavish, J.B ‘A Sense of Belonging: Older Adults’ Perspectives on Social Integration’ chapter 3 in *Community Supports for Aging Adults with Lifelong Disabilities*. Paul H. Brookes Publishing Co., Maryland, USA. Pp.41-53

Mansell, J. and Ericsson, K. (eds) 1996, *Deinstitutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA*, Chapman and Hall, London.

Offers broad perspective on issues in deinstitutionalisation including chapters on institutional closure and replacement, models of community service, the impact on service users and the impact on families of service users.

Chapter 4 describes a UK staff housing model whereby particular attention is paid to involving the residents in activities of daily living, breaking down activities into components that can be done, providing assistance to promote independence. In these houses there were markedly higher levels of engagement in meaningful activity, increase in adaptive behaviour and more social integration. Mansell notes that having clear goals is critical and ways of not only creating shared values but clarifying how to operationalise those values to get the best outcomes for individuals.

In some homes the high level of time spent on bureaucracy and minimal time spent interacting with residents was dispiriting and demonstrates a lack of attention to quality of life issues. Interventions to improve quality of life have had limited success, because of the overriding emphasis by management on other issues which take the focus away from achieving positive outcomes for the person with the disability. Factors such as reorganizations, funding cuts, limited rewards, sceptical and defensive staff and an indifference to quality of care by senior managers.

A description of supported living in the USA is offered in Chapter 7 where the role of the support worker is described as working alongside the individual with a primary role of teaching choice or decision-making.

Research conducted by Felce in the UK suggests that what happens at the interface between residents and staff is dependent not only on the structure of the services provided in a home but on its detailed orientation, procedures, staff training and management practices. Where these were well-developed there were better staff: resident interaction and resident engagement, showing that the pursuit of quality in ordinary housing services entail more than just the provision of ordinary environments. This includes:

- Emphasising resident participation rather than traditional care model
- Actively encouraging participation in activities by all
- Motivating residents to achieve a level of functional activity required to live an ordinary life
- Establishing level of commitment, staff competence and managerial monitoring to ensure the above happened.

Chapter 15 ‘From complaining to campaigning’ highlights the way that professionals can work with parents who usually have a long-term commitment to the welfare of their son or daughter but are in a vulnerable position when it comes to challenging the services that are on offer. It suggests ways of creating new alliances with parents, recognizing the important role they play in bringing about positive change.

McLeod, Nelson and Associates Pty Ltd., 2000. ***Community Inclusion - Enhancing Friendship Networks among People with a Cognitive Impairment,*** **Performance, Planning and Research, DisAbility Services, Victorian Government Department of Human Services.**

http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/research#friends

See Chapter three in this report for details – provides definitions of what is friendship, explores barriers to social inclusion and looks at ways of maximizing opportunities

Ozanne, E., Bigby, C., Forbes, S., Glennan, C., Gordon, M. and Fyffe, C., 1999. *Reframing Opportunities for People with an Intellectual Disability*. A report by the Myer Foundation undertaken by School of Social Work, The University of Melbourne.

Schwartz, D.B., 1992. ***Crossing the River: Creating a Conceptual Revolution in Community and Disability*****, Brookline Books, USA.**

Provides several examples of connecting people with a disability to community. Looks at the role of the bridge builder in the community – person who is well respected, has no ties to the human service world, yet has influence and can use their networks to integrate people into community life. Based on understanding a person's interest, abilities and personalities. The concept of clients evolving into citizens through engaging in meaningful activities in the community, whether it be volunteering, joining a church, being involved in support groups for others.

Also discusses citizen advocacy and how ordinary competent citizens can represent and promote the well-being of others who may be vulnerable and at risk.

Community inclusion needs a fertile ground – supportive environment where experimentation is encouraged and the focus is on "talents, hidden gifts and desires', rather than needs and deficits (p.27)

Chapter 8 discusses the importance of ideas such as social inclusion, connectedness and sense of place, Chapter 9 describes practice implications and Chapters 10 and 11 focus on risk management.

Person-centred planning and active support

O'Brien, J. and Lovett, H. 1992. ***Finding A Way Toward Everyday Lives: The Contribution of Person Centered Planning,*** **Pennsylvania Office of Mental Retardation, Pennsylvania, USA.**

Person centred planning:

- challenges the practices that separate people and perpetuate controlling relationships
- operates on the basis of respect for the dignity and completeness of the focus person
- asks the questions "Who is this person? and What community opportunities will enable this person to pursue his or her interests in a positive way?" (p.5)
- is based on creating a compelling image of a desirable future and inviting people to join with the focus person to make it happen, by strengthening personal relationships and helping people to plan, act and learn by reflecting on their successes and failures.
- increases system uncertainty by:
    - Strengthening the person's alliances
    - Clarifying individual interests and needs
    - Energising new demands on system and community
- Offers a problem-solving process to move towards the desired future

Barriers that exist:

- Where interests and gifts are unclear, hard to discern

- Requires hard work to develop relationship if person hard to engage with
- Family who have lost touch
- Defining people in clinical terms ie focus on deficits

Sanderson, H., Jones, E. and Brown, K. ‘Essential Lifestyle Planning and Active Support’.

Tindall, B. ‘An introduction to active support’, http://www.united-response.co.uk/asintro.htm

Quality of Life

Nota, L. and Soresi, S., 2002. ‘Quality of life in adults with mental retardation’, University of Padua.

Schalock, R.L., 2002. ‘The Concept of Quality of Life: What we now and Do Not Know’, IASSID-Europe Conference Plenary Session, Dublin, Ireland, June 12-15, 2002.

CASL Reports

Attendant Care Coalition, 1999. *Living Well: Community Living Solutions for Victorians with a Disability who have Significant Health Needs*, Attendant Care Coalition.

Generations Productions, 2000. *Challenging Institutions: Community Living for People with Ongoing Needs*. *Plain English Version.* AMIDA, Melbourne.

Coalition Against Segregated Living, 1998. *A Coalition Against Segregated Living Information Kit*

Disability Support and Housing Alliance, 1999. *Living Independently: Access to Choice*. Report of the 1st National Forum of the Disability Support and Housing Alliance.

McNamara, C. 2001. *Living not existing: Flexible support and housing for people with a disability*. Disability Support and Housing Alliance.

Housing and Support

A number of the following references come from the Australian Housing Urban Research Institute website, which is http://www.ahuri.edu.au/research. This is a useful site for keeping track of current Australian research in housing issues. Each project consists of a *Summary* of the intention of the project, a *Positioning Paper*, which outlines the literature, methodology and preliminary findings, the *Final Report*, which summarises all the project findings, and *Research and Policy Bulletin*, which is an abbreviated version of the project. At each step of the project these reports are posted on the website.

Bostock, L., Gleeson, B. McPherson, A. and Pang, L., 2001. *Meeting the Housing Needs of People with Intellectual Disabilities: Research Bulletin*, Australian Housing and Urban Research Institute, UNSW – UWS Research Centre. http://www.ahuri.edu.au/pubs/findings/bulletin_deinst.pdf

Bostock, L., Gleeson, B. McPherson, A. and Pang, L., 2001. *Deinstitutionalisation and Housing Futures: Final Report*, Australian Housing and Urban Research Institute, UNSW – UWS Research Centre. http://www.ahuri.edu.au/pubs/finalreports/final_deinst.pdf

Bostock, L., Gleeson, B. McPherson, A. and Pang, L., 2000. *Deinstitutionalisation and Housing Futures: Positioning Paper*, Australian Housing and Urban Research Institute, UNSW – UWS Research Centre. http://www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf

The key points raised in this study were:

- There are approximately 6,000 people with an ID living in institutions in Australia

- Deinstitutionalisation appears to be slowing in most states, except New South Wales and Victoria
- The separate evolution of Commonwealth funding agreements for housing, and for people with disabilities, poses a policy coordination barrier and may work against achieving stable accommodation for people with complex needs.
- A tension exists between the policy aim to be more responsive to diverse client needs, and funding constraints, eg group homes, which provide economies of scale, are often preferred over other more expensive models which cater more explicitly to individual needs.
- There is a need to ensure that housing built for people with an ID today is appropriate for future generations, with younger people preferring individual or share housing, which could lead to an oversupply of group homes in the future.
- New funding frameworks that tie funding to individuals and are portable between service providers could improve individual client control and choice in housing and support.
- Greater use of the private rental market may ease cost pressure on public and community housing agencies in providing suitable accommodation to this group of people.

Bridge, C., Kendig, H., Quine, S. and Parsons, A. 2002. *Improving Housing and Care for Adults with Disabilities: Research Bulletin*, Australian Housing and Urban Research Institute, Sydney Research Centre.

Bridge, C., Kendig, H., Quine, S. and Parsons, A. 2002. *Housing and Care for Young and Older Adults with Disabilities: Final Report*, Australian Housing and Urban Research Institute, Sydney Research Centre. http://www.ahuri.edu.au/pubs/finalreports/final_youngolddisabilities.pdf

Bridge, C., Kendig, H., Quine, S. and Parsons, A. 2002. *Housing and Care for Young and Older Adults with Disabilities: Positioning Paper*, Australian Housing and Urban Research Institute, Sydney Research Centre. http://www.ahuri.edu.au/pubs/positioning/pp_youngerolderdis.pdf

The key points raised in this study were:

- There is no national framework for delivery of housing and support services to adults with disabilities, hindering efficient and fair service provision.
- Linkages between programs are informal and vary in effectiveness.
- A whole-of-sector approach to support is critical.
- Two-thirds of adults with a significant disability live in cared accommodation, mainly nursing homes.
- Younger adults (20-59) with disabilities are more likely to reside in the community.
- Trends toward deinstitutionalisation and ‘ageing in place’ for adults with disabilities have increased the demand for community care, whilst resources to meet that demand are inadequate.

Folkestad, H., 2002. ‘On the interaction between residents and staff’, Paper presented at the *Inaugural Conference of IASSID Europe*, Dublin, 12-15th June 2002.

Mansell, J., Beadle-Brown, J., Macdonald, S. and Ashman, B. ‘Functional grouping in residential homes for people with intellectual disabilities’, Paper presented at the *Inaugural Conference of IASSID Europe*, Dublin, 12-15th June 2002.

Meininger, H.P., 2002. ‘The client-staff dialogue. Exploring a new professional ethics. Paper presented at the *Inaugural Conference of IASSID Europe*, Dublin, 12-15th June 2002.

National Electronic Library for Health: Learning Disabilities. ‘Housing: Residential Care or Housing Support?’ http://www.minervation.com/ld/housing/residential/lessons.html

O'Brien, A., Inglis, S., Herbert, T. and Reynolds, A., 2002.*Linkages Between Housing and Support – What is Important from the Perspective of People Living with a Mental Illness: Final Report* Australian Housing and Urban Research Institute, Swinburne/Monash Research Centre, Ecumenical Housing Inc. http://www.ahuri.edu.au/pubs/finalreports/final_mentalillness.pdf

Reynolds, A., Inglis, S. and O'Brien, A., 2002. *Linkages Between Housing and Support – What is Important from the Perspective of People Living with a Mental Illness: Positioning Paper,* Australian Housing and Urban Research Institute, Swinburne/Monash Research Centre, Ecumenical Housing Inc. http://www.ahuri.edu.au/pubs/positioning/pp_mentalillness.pdf

This study interviewed 50 people with a psychiatric disability successfully living in rental housing. A key point raised in this study was that even people with complex needs can maintain stable housing and live independently with appropriate housing and support. This project has built on and extended the work of an earlier AHURI project (Reynolds, Inglis & O'Brien 2001). The findings from this earlier AHURI project have been assessed against the findings of this review to see how closely the perspectives of service providers, government officers and previous research align with the views of the individuals interviewed. While the earlier project sought the views of those involved with program development and service delivery, this project sought the views and experience of people living with a mental illness.

Reynolds, A., Inglis, S. and O'Brien, A., 2001. *Effective Program Linkages – an examination of current knowledge with a particular emphasis on people with a mental illness: Final Report,* Australian Housing and Urban Research Institute, Swinburne/Monash Research Centre, Ecumenical Housing Inc. http://www.ahuri.edu.au/pubs/finalreports/final_effectiveproglinks.pdf.

This project explored the foundations for developing effective approaches to link housing and support for people with complex needs. One of these findings was that it is important to have a diversity of choices in housing and support to meet individual preferences and needs. Linkages need to be coordinated across government programs, and there is a need to continue to develop more formally integrated and specialist housing and support models for those with complex needs.

Schwartz, C. and Rabinovitz, S., 2001. 'Residential facilities in the community for people with ID: How neighbours' perceptions are affected by the interaction of facility and neighbour variables', *JARID, 14, 2.*

Social Capital

Cox, E. 2002. *The Social Audit Cookbook: Recipes for auditing the way we connect*. Funded by the Lance Reichstein Foundation as a contribution to community groups wanting to use surveys and audits as part of processes of social change, University of Technology, Sydney.

Putnam, Robert D., 1995. 'Bowling Alone: America's Declining Social Capital: An interview with Robert Putnam", *Journal of Democracy 6:1,* pp.65-78.

Information specific to Kew Residential Services

Kew Parents Association website

http://www.kewcottages.alphalink.com.au

DHS Updates on Key Residential Services

http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/org_kew

Office of Public Advocate site re updates on Kew Residential Services

http://www.publicadvocate.vic.gov.au/CA256A76007E8265/All/32EA283ED0F4DB98CA256C1E001D0C81?OpenDocument

Office of the Public Advocate *Accommodation Models Discussion Paper* 4/6/02, prepared by Andrew Burbridge.

Other

***Community Tool Box* http://ctb.lsi.ukans.edu**

This site includes very practical advice and instruction on such aspects as:

- A trouble –shooting guide to community planning and action
- Developing a plan for advocacy
- Problem-solving approaches
- How to develop a strategic and action plan

Standards Australia, 1999. *Risk Management*, AS/NZS 4360: 1999.

Walker, R., 2000. *Collaboration and Alliances: A Review for VicHealth*, Victorian Health Promotion Foundation. http://vhpax.vichealth.vic.gov.au/publicat/canda.htm

Appendix B: List of Key Contacts

Name	**Affiliation**	**Contact details**
KRS representatives		
Alma Adams	KRS - Manager	alma.adams@dhs.vic.gov.au
Anne Leonard	KRS – Assessment Team	anne.leonard@dhs.vic.gov.au
Rod Carracher	KRS – Project Officer	rod.carracher@dhs.vic.gov.au
DHS staff		
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Anna Donne	DHS Disability Training Unit	Anna.donne@dhs.vic.gov.au
Jacky Close	DHS Eastern Region	Jacky.close@dhs.vic.gov.au
Patsie Frawley	Disability Advisory Council Worker	patsie.frawley@dhs.vic.gov.au
Geraldine Long		Geraldine.long@dhs.vic.gov.au
Astrid Reynolds		Astrid.Reynolds@dhs.vic.gov.au
Researchers/consultants		
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Josie Prioletti	DASSI Attendant Care	Ph: 94812355 Josie.prioletti@dassi.com.au
Office of Public Advocate		
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David Sykes	OPA	Ph: 9603 9500 David.sykes@justice.vic.gov.au
Andrew Burbidge	OPA	Ph: 9603 9500

People with a disability		
Peta Ferguson		
Daisy Serong		
Doug Pentland	Consumer – Self advocate, Reinforce	Ph: 9650 7855
Parents		
Ethel Temby	Parent	
Tony Tregale	Parent	
Bill Westgarth	Parent	
Disability Services		
Michael Bink	Scope	Ph: 9536 4237 mbink@scopevic.org.au
Brigitte McDonald	Interact Learning Centre, Fairfield	bmcdonald@interactaust.com.au Ph: 9497 3444
Jill Lane	Interact Learning Centre, Fairfield (since left the organisation)	
Jackie Price	Activate.COM	Ph: 9326 2700 activate@scopevic.org.au
Greg Kent	CEO at Colanda	Ph:52329201 greg.kent@dhs.vic.gov.au
Sue Jackson	Service Provider Churchill fellowship Community Inclusion CIDA	Ph: 84150155 cida@bigpond.com.au
Judy Buckingham	Gawith Villa	Ph: 9244 6632; 0438 052 220 jmb@deakin.edu.au
Rob Nicholls	Uniting Care Community Options	Ph: 9890 6933 robn@ucco.org.au
Advocacy Services		
Cath McNamara	Disability Rights Victoria	c.mcnamara@advocacyhouse.org
Pauline Williams	AMIDA	
David Craig	ACL	d.craig@advocacyhouse.org
RuralAccess		
Bill Lawler	RuralAccess Worker Latrobe City	Ph 5173 1400 or 5133 6932
Paul Dunn	Department Human Services	Paul.dunn@dhs.vic.gov.au Ph: 9616 7714

The following are people recommended to us who we did not have time or were unable to contact, who nevertheless might wish to be informed of future projects.		
Karen Nankervis	RMIT + President CIDA Coordinates training in disability	9925 7363 Karen.nankervis@rmit.edu.au
Elaine Nyberg	OPA individual advocate @ Kew	
Deb Rouget	Person to Person Project	
Dr Kelly Johnson	Deakin University	
Jo Tomlins	HACSU – was invited to Focus Group but was unable to attend	jot@hacsu.asn.au
Mary Nolan	Parent advocate - Son has a profound disability	
John Kenwright	Redlands (ex-CLASS)	
Jacqui Ward	Author of Challenging Institutions Report	
Sue Tate	Chairperson IDRP	
Amanda and Colin Hiscoe	Reinforce	
Kate Kennedy	Ex-community visitor, ex-volunteer Caloola	
Alan Blackwood	MS Society	
Lyn McKenzie	Consultant with VALID	9416 4003 (VALID)
Penny Melba		
	Karingal, Geelong	
Chris Mathieson	DHS re State Disability Plan	
Philip Ripper	Transport Accident Commission	
Sue Jamieson	DHS	
Diana Heggie	Spastic Society	

Appendix C: Other Key Terms

Following is a description of the concepts of advocacy, recreation and natural supports which can play an important role in increasing a person's inclusion in their community.

Advocacy

Victorian advocacy groups have developed a number of principles that guide and define advocacy for people with disabilities. Advocacy is work that is intended to support people in asserting their rights and interests, or asserts their rights and interests with them.

Elements of advocacy:

- Being on the side of the disadvantaged party and representing their interests or wants.
- Advocacy support should be supportive and empowering, a partnership where possible.
- Advocacy effort needs to be directed to major needs and welfare.
- Conflicts of interest for advocates should be minimised.
- Advocacy support should demonstrate fidelity and persistence.
- Advocacy should demonstrate vigour of action
- Advocacy needs to be mindful of other disadvantaged groups and the need to avoid further harm through advocacy efforts.

Types of advocacy support:

- **Self-advocacy** refers to the capacity an individual has to be assertive in pursuing their rights and having their own needs and aspirations met.
- **Individual advocacy** refers to advocacy that is done with an individual or group of individuals.
- **Group advocacy** refers to advocacy that is done within a self-help or collective action approach where a group of people address a common issue or set of issues together.
- **Systemic advocacy** is advocacy effort that is directed to changing systems that affect a much wider group of people and often impact on the whole community.
- **Citizen's advocacy** refers to a volunteer driven advocacy model that recruits citizens to support individuals with a disability to know their rights and address barriers to community living.
- **Specialist Advocacy** refers to advocacy that focuses on issues that affect people with a specific type of disability or are focussed on a single issue such as employment or accommodation.

Approaches used in advocacy include:

- Use of legislation, such as Disability Discrimination Act and Equal Opportunity Act, to address issues of disadvantage or discrimination.
- Use of political influence with government and political parties to shape policy and service development decisions.
- Community awareness and community education campaigns.
- Taking direct action in the form protests, blockades including some activities that may involve civil disobedience or passive resistance.

Recreation

Recreation and leisure are highly valued elements of the lifestyle of Australians. Our national image is heavily identified with sports, outdoor activities and involvement in a wide variety of active and passive pursuits. Consultations for the development of the Victorian State Disability Plan and research undertaken by Disability Services Branch through the “Aspirations” study and the “Enhancing Friendship Networks for People with a Cognitive Impairment” reinforce the view that people with disabilities are equally passionate about recreation and leisure options and the personal outcomes that can be developed within community settings.

The National Recreation Policy developed by NICAN describes recreation as “activity that a person chooses to participate in during their discretionary time which generates an attitude characterised by feelings of enjoyment and satisfaction.” It defines leisure “as a state of being, an attitude of mind, or a quality of experience” that “is distinguished by the individual’s perceived freedom to act”. More importantly, the policy develops an outcome definition of recreation that proposes that recreation is a key vehicle for people with disabilities who are often marginalised from community life to—

Move from …	***Towards experiences that provide…***
Feeling separate from the real world	Belonging to and being a part of community
A life of constant or frequent boredom	Adventure and challenge
Loneliness	Companionship, increased social networks, strong friendships
Dependence on others or isolating levels of independence	Interdependence and mutual relationships
Restricted choice and freedom	Sense of freedom and spontaneity
Feeling controlled by others	Sense of control and power over own lifestyle
Constant sense of failure and inadequacy	Improved self image through achievement of personal goals
No sense of future or anticipation	Hope and enthusiasm for the future
Routine programming & limited scope for growth and challenge	Experimentation with life leading to personal growth and change

The historic and systemic devaluation of recreation within service and policy development for people with disabilities has significantly undermined the potential of people with disabilities with higher support needs to gain access to improved quality of life and increased participation in cultural and social life of our many and diverse communities. The development of good recreation opportunities for people with disabilities is a key platform for successful ventures in community living.

Voluntary Relationships

Community inclusion for people with disabilities with high support needs will almost always depend on some level of voluntary support from other members of the community in which this person lives. The degree and nature of voluntary involvement ranges from structured and tightly managed volunteer programs run by service providing organisations through to informal and “natural” supportive relationships.

Natural Supports

People like John McKnight and O’Brien advocate for forms of voluntary involvement where “community bridging” workers link people with disabilities to neighbours, clubs, church groups, local business people, etc who become a supportive network of people. Setting up these social networks and person-to-person links endeavours to engage citizens in voluntary support relationships that don’t require structured funded programs but rather rely on the natural existing community supports in a given neighbourhood. Some criticisms of this approach include:

a) Reliance on this type of support is unrealistic as it is difficult to find enough people in the community to support all those who might benefit.
b) Cultural and demographic changes in our society have led to longer working hours, reduced interest by younger generation in voluntary associations and community service.

Volunteer Programs

Organisation of volunteers through structured programs for the purpose of addressing particular needs within our communities is a long established practice. Principles set out by peak volunteer bodies define volunteers as people who provide a service:

a) that benefits the community
b) of their own free will (this excludes work for the dole, work experience programs or any other unpaid work that is linked to benefits or obligation)
c) without financial payment (this does not exclude reimbursement of out of pocket expenses).

Volunteers programs usually require formal registration, police record checks, training, commitment to organisation’s policies and specified job descriptions. In return, volunteers can expect to be covered by insurance, receiving training and supervision and have out of pocket expenses reimbursed. Criticism of this more formalised approach to volunteer management include:

a) That it can assume a “charity ethic” or do-gooding culture that is unacceptable to many people with disabilities.
b) That volunteers become agents of the service provider rather than agents of the community. Thus volunteers can be used to sustain the specialist, segregated service delivery rather than acting as an agent for community inclusion.
c) Volunteers become captured by agency policies and procedures that limit the flexibility and naturalness of normal relationships.