

# **MORE THAN COMMUNITY PRESENCE: SOCIAL INCLUSION FOR PEOPLE WITH INTELLECTUAL DISABILITY**

**Proceedings of the  
Fourth Annual Roundtable on Intellectual Disability Policy**

**Held on Friday 23 October, 2009**

Edited by  
Christine Bigby and Chris Fyffe



ISBN 978 192 1377 853

Published by School of Social Work and Social Policy  
La Trobe University  
Bundoora Vic. 3086  
Australia

Created by Allardice Group  
Blackburn Vic. 3130

Bigby, C., & Fyffe, C (2010).  
*More than Community Presence: Social Inclusion for People with Intellectual Disability.*  
*Proceedings of the Fourth Annual Roundtable On Intellectual Disability Policy.*  
Bundoora: La Trobe University.

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# More than Community Presence: Social Inclusion for People with Intellectual Disability.

Christine Bigby & Chris Fyffe

The Roundtable on Intellectual Disability Policy is an annual event convened by the School of Social Work and Social Policy at La Trobe University in collaboration with key stakeholders in disability policy, practice and program delivery. The Roundtable seeks;

*To provide a space for fearless debate, among interested groups, about policy within both the disability and the broader human service sectors for people with intellectual disabilities, with the intention of naming issues, clarifying concepts and ideas, exploring challenges, articulating solutions and informing practice.*

The theme of the 2009 Roundtable was social inclusion of people with intellectual disability. The starting point for discussion was current policies both in Australian and internationally that commit governments to 'take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right [to live in the community] and their full inclusion and participation in the community (United Nations, 2006, p. 13). Specific policies that envision the social inclusion of people with disabilities reflect the broader Australian social policy agenda that is 'about ensuring every Australian, wherever and whoever they are, has a chance to develop themselves and participate fully in community life'(Commonwealth of Australia, 2009).

As in past years commissioned papers, circulated prior to the Roundtable and posters prepared for the day provided the catalyst for discussion. Four overarching questions were posed:

- What does inclusion look like for people with intellectual disability?
- What does it take to achieve inclusion?
- What are the obstacles to making it happen?
- What are the priorities for action?

This collection of papers adds to debates about the meaning of social inclusion for people with intellectual disability and extends understandings about the tensions that arise in translating policy into practice or programs that influence people's everyday experiences. The papers report research and program evaluations that illustrate possibilities of social inclusion for people with intellectual disabilities as well as the challenges. It is hoped they will generate further reflection

about the nature of the task that confronts governments, community service organisations and community members and stimulate new ideas about the strategies necessary to implement social inclusion policies. This introduction synthesises the key issues raised by the papers, and the varied perspectives participants contributed to the small group and plenary discussion. In bringing together these views, the purpose is not to critique existing policies but to add to knowledge that might inform policy.

More so than in previous years, the value of space for discussion and dissent was endorsed. Jennifer Clegg (2010) for example, suggested that despite its multiple dimensions and the complexity of conceptualizing the meaning of inclusion for people with more severe intellectual disability dogmatic adherence to particular interpretations and accompanying moral judgments were prevalent in some arenas. She proposed the need to rethink some of the very foundational ideas, such as normalisation, that have underpinned policy implementation for the past 30 years and that by stepping outside these frameworks different ways of thinking may be found. Her paper sparked debate about the paradoxes inherent in ideas about social inclusion and 'an ordinary life' for people with intellectual disability. Such ideas encapsulate a constant tension between regarding people with intellectual disability as the same as everyone else but at the same time acknowledging that for visions of inclusion to be put into practice their uniqueness and differences must be recognized and adjustments made, but in such a manner that doesn't devalue or draw attention to difference and obstruct inclusion. As Ramcharan (2010) suggested the very nature of intellectual disability poses problems for the more standard remedies proposed for social exclusion that are based on models of equal opportunity 'where merit and achievement remain seen to be the only rightful arbiters of access to position which inevitably relegate many people with intellectual disabilities to the bottom of the 'merit ladder'. This point was reinforced by Clegg's suggestion that even where people with mild intellectual disability do experience success on some indicators of social inclusion such as employment or living independently they continue to experience not rejection but abjection as they are tolerated rather than accepted by those around them. These points all reinforce the proposition that achieving social inclusion entails significant change on the part of 'included' community members, and will not be achieved simply by change on the part of excluded individuals. The question remains how this can be achieved. This paper considers the reasons for the ill defined nature of social inclusion and the consequences of this particularly in respect of

people with more severe intellectual disability. It goes on to explore, the sense from participants that the many guises of social relationships lie at the heart of social inclusion for people with intellectual disability. A brief overview of research that demonstrates the imperatives to address the absence of diverse social relationships in the lives of many people with intellectual disability is followed by a consideration of the multi dimensional strategies to achieve change already being implemented and exemplified in some of the papers. Finally consideration is given to where continued leadership of these and new initiatives should lie.

### **Social Inclusion an Ill Defined Concept**

A central theme was a lack of certainty about the meaning of social inclusion. Also the sense that this term is increasingly being used as a slogan or rhetorical device for policy romanticism that 'glosses over significant disabilities and social disadvantage'. Repeatedly raised was the impact of the ill defined nature of social inclusion for implementation strategies which obstructs the translation of policy into programs and practice, and hampers clear description of what is expected, securing funding or demonstrating outcomes. For example Ramcharan (2010) suggests that calls for community inclusion have 'failed to be accompanied by definitions of how this might be accomplished or guidance or models of community development'. Bigby and Clement (2010) highlighted the consequent variable interpretations of group home staff, which commonly meant they understood their task as seeking community presence rather than fostering social relationships. In situations such as this where visionary policy is not underpinned by sub goals and strategy, it has been suggested that front line staff determine its nature and the aspects that take precedence (Lipsky, 1980) which can result in both inconsistent application of policy intent and unintended consequences.

The ill defined nature of social inclusion is replicated in much research in this field. For example, two recent systematic reviews have drawn attention to the absence of the use of theoretical or conceptual frameworks in empirical studies of social inclusion or social participation of people intellectual disability or those with challenging behavior (Bigby, 2010; Verdonschot et al., 2009). One of the most commonly used approaches in research has been that adopted by Clement and Bigby (2010) which follows O'Brien's distinction between 'social presence' –the use of facilities or services in the community available to everyone, and 'social participation' – being part of a growing network of relationships that includes people with and without intellectual disability.

However it was noteworthy that several papers from service providers had adopted definitions that differed from this (Shanks & Young, 2010), more focused on processes and the role of staff in supporting inclusion.

### *Difficulties interpreting social inclusion for people with intellectual disability*

Social inclusion is a multi dimensional concept, and it is unlikely that all its elements will be relevant to all people all the time. As Clegg suggests, 'it depends on the person and the context'. Many of the indicators emerging from work in mainstream policy to more clearly define social inclusion, such as literacy, educational attainment or employment were perceived as either not relevant or insufficiently nuanced to provide guidance to staff working with people with more severe intellectual disabilities. For example, whilst literacy or voting are potentially meaningful for a person with mild intellectual disability they have no meaning or significance to the quality of life of a person with a profound level of intellectual impairment.

The diversity of people with intellectual disability and the multiple dimensions of social inclusion result in uncertainty and many 'what if' questions' which pose significant obstacles to creating a coherent narrative of social inclusion for people with intellectual disability. 'What if', for example, the person 'chooses' to be lonely and isolated or not to leave their home or 'prefers' the company of other people with intellectual disability, or the prevailing attitudes within their local community threatens their emotional or physical well being? How can decisions made by a person with little experience of potential choices be acknowledged but also challenged to enable further horizons to be explored without exertion of pressure or control? How can staff or family members avoid imposing their own values and preferences? How can a people with more severe intellectual disability who can't dream or make their own choices be engaged in voicing their preferences? Such questions are core issues for the entire service system set up to support people with intellectual disability, and are very different from the issues encountered in thinking about inclusion by the community in general.

Issues such as these lead to a central dilemma of how to conceptualise frameworks for action that are sufficiently prescriptive to guide relatively untrained and unprofessional front line staff, but flexible enough to take account of the 'what ifs', without giving the impression that 'anything goes'. The absence of such conceptual frameworks helps to explain the 'dogma and what are perceived as 'politically correct' interpretations that can

prevail in situations where social inclusion is an imperative of planning or service delivery. Clegg (2010) exemplifies the dangers of doggedly applying normative notions of social inclusion to young adults with intellectual disability. She says for example

*It was evident that the various parties were struggling to identify the 'right thing to do' in a complex and fraught context, often with little sound information on which to base predictions about the likely outcomes and, indeed, with limited confidence that resources would be available to support whatever decision was eventually made. As school leaving dates drew closer, creative discernment was undermined further by the rhetorical use of moral polarities that devalued alternative points of view and pushed some contributions outside the realm of the morally acceptable... We found that the ideas shaping services, such as adulthood, inclusion, and choice, did not map well onto the needs of these young people; they also left parents precariously balanced on a shrinking moral terrain between over- and under-protectiveness.*

Such dogma and accompanying moral judgments about the meaning of inclusion can mean some options are not considered at all and may also impede co-operative planning or collective attempts to generate solutions about potential roles and activities.

Clement suggests that Mead's distinction between 'cult' and 'functional' values is useful in understanding why such difficulties arise in the application of social inclusion to people's lives; "cult values are idealisations in which real life obstacles to what we want to achieve are ignored" whereas "functionalised values are interpretations of cult values in ordinary, real-life situations (Stacey cited in Clement 2010). He suggests that considerable effort over 30 years has been spent transforming normalisation from a cult to a functional value by thinking through its practical application to everyday situations and then disseminating these viewpoints. For example, attendance at intensive Passing workshops and other normalisation training left a lasting legacy which is still evident in many group homes that equipped workers with the capacity to apply the principles of normalisation to every situation they are likely to encounter (Clement & Bigby, 2010) . Such processes have not yet occurred for social inclusion which remains an idealisation or cult value.

A key process to functionalising is the generation of conflict and debate through which the paradoxes and dilemmas that arise in applying values to the enormously diverse 'what if' situations likely to be encountered are exposed. Accepting the necessity

for uncertainty and possibly foreclosing debate about dilemmas too quickly could lead to the current situation where either anything goes or rigid dogmatic stances are adopted. These ideas resonated with Clegg's proposals about the need to generate new ways of thinking which include permission to doubt and pose questions about current practices. The proposition here is that normalisation and associated values have not enabled thinking to be extended beyond the way it has been already been functionalised which means that more complex dilemmas associated with social inclusion have not been sufficiently considered. For example Ramcharan (2010) exposed the different concepts used to think about social inclusion in the past and suggested that the capability approach which is founded on the humanness of each individual and their unique capabilities of each person rather than some normative benchmark may provide different ways thinking about social inclusion Through the processes of functionalising (ie making practical) social inclusion, not only will new ideas such as this be explored but the shift can occur from dealing with diversity by an 'anything goes approach' to more shared interpretations about the application of first principles in diverse situations.

A contrary theme was that many of the so called new examples of good inclusion practices are not new at all but reflect developments that have stemmed from normalisation over the past 30 years. Some participants pointed to the potential dangers that may therefore arise if new ways of thinking discard learnings from the past. Perhaps it is important to acknowledge that normalisation was an important starting point, and its approaches to social inclusion should not be regarded as static but developed further rather than simply discarded.

### **Social Relationships as a Core Component of Social Inclusion**

Social inclusion was perceived as a multi-layered concept that required action at all levels of society: the individual (micro), organizational and community (meso) and structures and government (macro) (see figure 1 in Wilson & Jenkin, 2010). Its relational nature (the antithesis of social exclusion) which was central to the early conceptualisation of inclusion as a phenomena differentiated from poverty (Bradshaw et al., 2004) occurred again and again in the papers and discussions. Clegg (2010) suggested that 'relationships should become the building-block of a new approach' and Rouget that inclusion is 'what the human race wakes up to everyday. It's our neighbours, families, schools, associations, friends, businesses and governments'. However, accepting the centrality of relationships evoked a focus on the diversity of relationships.

The importance of avoiding a prescriptive checklist approach to social inclusion, provoked questions for each individual with intellectual disability about which type of relationships, with whom, for what purpose and how to determine whether some were more important than others.

The tendencies for researchers or advocates to focus on certain types of relationships for people with intellectual disability such as with people without intellectual disability, rather than others types, such as with family, staff, or peers with intellectual disability were challenged. Rather it was suggested that relationships with different people offer very different things and it is the mix and diversity of a person's relationships that are most important. Perhaps however, the absence of relationships with people without intellectual disability from social networks is the reason they are accorded more attention. In the process however, they may seem to be accorded more value. Care must be taken to avoid devaluing or diverting attention from other types of relationships. Ideally each relationship offers a different value that adds rather than detracts from the benefits gained from a person's entire social network.

The nexus between 'community' relationships and social inclusion was challenged, on the basis that the 1960s notion of community, as a place where people lived, worked, played and had strong social connections, no longer existed. Instead it was suggested that although many people may be alien to their neighbourhood, they could still be connected to a community characterised by ties to a common interest or group of people rather than place. Johnson et al., (2010) also questioned whether relationships necessarily had to occur in public places or be external to the private world of the individual, for those who found such places difficult to tolerate. Leighton and Hampson (2010) highlighted however, the continuing importance of place to some communities such, such as the Jewish community in Caulfield, Melbourne.

By describing the valued but more momentary interactions between a young woman with severe intellectual disability and communication difficulties and members of her network, Johnson et al., (2010) drew attention to the less typical forms of relationships and social interactions, which do not rely on conversation or shared activities but are nevertheless both meaningful and reciprocal. In a similar vein on the importance of departing from the typical expectations of social interaction Clegg alluded to the importance of moments of meeting, between people with and without intellectual disability. In the field of urban planning Fincher and Iveson (2008) use a similar idea when they talk about 'encounter's which can be both convivial

and fleeting or more sustained when people share a common purpose'. However, Clegg (2010, 2007) has suggested the unease that ordinary members of the community can experience when meeting a person with more severe intellectual disability for the first time are potentially a significant obstacle to such encounters or their conviviality.

### *Belonging*

A sense of 'belonging', being part of a network of others emerged as central to relationships, but mixed views were expressed about the proposition that the type of group from which one gained a sense of belonging was unimportant (i.e. 'mainstream' – including people without intellectual disability or 'segregated' – comprising only people with intellectual disability). Leighton and Hampson (2010) used as a negative example, segregated recreational groups created for the purposes of respite and driven by funding imperatives, which emerged too often without full consideration of whether individualized inclusion in existing community groups were possible or desirable. Whilst drawing attention to this they did not negate the value of such segregated groups but suggested potentially greater value could be gained from belonging to a mainstream group of children. Similarly Rouget too suggested that her organization avoided defending segregation and congregation, which was also the position of Cocks and Craig (2009). Such views are based on the idea that such groups are chosen due to insufficient experience of other more mainstream possibilities. In contrast, Shanks and Young (2010) and Wilson and Campain, (2009) suggest some of the time people with intellectual disabilities will make informed choices to spend time in segregated groups where they enjoy spending time with peers. The key question here is whether people are segregated on the basis of their informed choice and affiliation with other group members and not simply because others decide for them that they have in common the characteristic of intellectual disability. These papers all suggest the need to interrogate more deeply how and why segregated groups are developed.

Hall (2010) demonstrates clearly that two types of belonging may coexist, and thus the importance of both mainstream and segregated group membership. He suggests for example that members of an arts group for people with intellectual disability gain a significant sense of self identify from the group but also belonged through their interactions with other groups to the wider arts community. Similar examples are found in self advocacy groups or in sport where 'special' teams play a competition alongside the mainstream teams in the same tournaments. Stumbo et al., (2010) paper illustrated the emphasis

on self help or mutual support groups in services for people with brain injury which does not seem to be valued in a similar manner by services for people with intellectual disability, perhaps due to the long history of segregation for other less benign purposes.

Ideas about belonging led to suggestions about the evolving processes involved in developing relationships and their changing nature over time. This was raised particularly in respect of relationships with staff that are often expected to be transitory but may also last in a different guise when staff move positions. Dutch researchers such as Reinders (2010) and Schuengel et al. (2010) have given considerable attention to the importance of care relationships and staff presence in interactions. They have resisted the notion that paid relationships are unimportant and simply a commodity to be directed by the consumer, recognizing the incongruence of this notion when staff are working with people with severe and profound intellectual disability. Reinders (2010) suggests that staff need to draw on both their tacit knowledge [derived from a deep sense of knowing the person] and good judgment to develop relationships. He points to the need to acknowledge that each staff member will have a different relationship with the people with whom they work, thus for example the experience of an activity will differ when a person is supported by different staff. Their work proposes that core component of delivering care or support must be development of relationships, watching and coaching this on the part of supervisors.

Focusing on the centrality of relationships introduces the emotional and subjective dimension more clearly to ideas about social inclusion that are not found in some of the mainstream literature on social inclusion. It also highlights the importance of broadening ideas about the forms of reciprocity, though it may be important to distinguish between this and benefits derived from altruism. For example, is the acceptance of help and the existence of a person with intellectual disability in another person's life that leads to a sense of enrichment derived from reciprocity or altruism (see for example Grant et al., 1998).

### **Strategies to Build Social Inclusion**

Even if relationships are central to social inclusion, multi-faceted strategies are required that draw on an ecological perspective, recognising that barriers exist both within the person and externally in their immediate context and/or the broader social environment. Several papers presented schemas for the different strategies used to build social inclusion that range from one to one work, providing a bridge or link between the individual and the

community to more broadly based community development approaches (Ramcharan 2010; Bigby & Clement, 2010; Wilson & Jenkin, 2010). However the papers by Rouget (2010) and Shanks and Young (2010) demonstrated that work at the micro level can result in change to organizations that impacts well beyond the particular individuals concerned and leads to broader social change, which challenges the suggestion that work with individuals leaves the 'community' unchanged. A poignant example was given by Shanks and Young (2010) who described funding a school caretaker to work extra hours to support the employment of a young man with intellectual disability which not only changed his immediate social relationships but those of many members of the school community. Conversely Wilson and Jenkins demonstrated the interdependent nature of 'inclusion work' at different societal levels, whereby the success of individual opportunities is likely to be dependent on the social milieu within which they occur. Using the UK experience Ramcharan (2010) illustrated this issue in respect of hate crime and the use of anti social behaviour disorders against people with intellectual disability to illustrate the lack of tolerance of difference that exists in that community. Whilst Clegg (2010) referred to the experience of people with mild intellectual disability who are in open employment or mainstream education where they are tolerated rather than accepted and may chose to return to segregated spaces 'find company in a few refuges oriented towards acceptance and tolerance: their families, clubs for PWID, churches, community centres'.

The endorsement that social policies such as inclusion are a form of social engineering came to the fore in these discussions with the suggestion that building relationships between people with and without intellectual disabilities may be attempting to impose something that is outside the norm as people should be free to choose relationships and tend to associate with others who are like themselves. This however raised the importance of others knowing the person well enough to step beyond their identity as person with intellectual disability and find other identities that they would be more likely to have in common with community members. Thus attention to the processes of individual relationship building requires a depth of knowledge about the person and the social context. Both Rouget (2010) and Johnson et al., (2010) gave provided examples of the time and skills necessary to do this effectively.

### *Community development strategies to effect organisational and system level change*

Attention to the 'community' and actions to strengthen its capacity, such as community

education generated considerable discussion. The poster from annecto, and several papers (Leighton & Hampson, 2010; Wilson & Jenkin, 2010) gave detailed case studies of community development strategies at the meso and macro levels. Much of the discussion focussed on the potential to manipulate existing 'disability' spaces so they are opened to the general community and avoid the creation of new disability spaces. Suggested too was the importance of disability organisations reaching out to mainstream community organizations and government and highlighting what either they or particular individuals with intellectual disability had to exchange and could bring to relationships and collaborations. Potentially too, the 'post code' initiative by annecto is demonstrating how disability organisations can foster a greater sense of connection among all people who live or regularly use a particular locality.

It was suggested that social inclusion policies have big expectations of the people and organisations in the community but takes little account of the composition and perspectives of these. The discussions suggested that some communities/localities were more welcoming and supportive of inclusion than others, dependant on the nature of that community and the way people with intellectual disability were situated within it. Variables proposed were housing design, type of neighborhood/locality in terms of its religiosity, density, culture, socio-economic status, ethnicity composition, diversity or geographic location. For example a common assumption is that rural communities are more inclusive than inner city neighborhoods. This raises some key questions for research, such as 'what are the barriers and opportunities to social inclusions in particular communities' or 'what is it about some communities that generate inclusion'. Propositions that some communities are more welcoming have not been investigated and little evidence exists about these. Leighton and Hampson (2010) suggested that State governments had focused community capacity building efforts on economically and socially disadvantaged neighborhoods which could be interpreted as an implicit assumption that wealthier localities do not require effort to build their capacity to be inclusive. Pertinent too is the impact on local communities and opportunities for inclusion of the recent newer style 'cluster' accommodation developments, such as Glen Eira Road built by Jewish care, which was raised by Vizel at the 2008 roundtable, and whether such designs impact differently in local communities from more traditional group homes or individualized housing options.

### **Who Leads Inclusion Work**

The centrality of families to building and sustaining social relationships both for people

who live at home and those who live in group homes was given particular prominence by Rouget (2010). Whilst inclusion work was considered to be central to most organizations, few are specifically funded to initiate and sustain broader community development initiatives. Rather Leighton and Hampson (2010) demonstrate the pit falls, such as whose client is the person who has been enabled to attend a mainstream group, when a different approach to achieving outcomes couched in service delivery terms is attempted. Whilst the importance of champions to lead community development or beacons to illuminate pathways to inclusion was noted, funding for such roles is not part to the current service system. Similar issues arise with unit cost funding were organisations go beyond the particular activity for which they are paid in order to achieve the best possible outcomes for their clients and were noted in respect of individualised funding models (Bigby & Fyffe, 2009) which fail to take into account developmental costs of supporting options that involve more than an individual.

Community development often occurs serendipitously as part of initiatives by day programs such as Shepparton access (Shanks & Young, 2010), small non government organisations such as like PLA described by Rouget (2010) and large multi program disability organisations such as Jewish Care and Scope (Leighton & Hampson, 2010; Wilson & Jenkin, 2010). This posed the question of how the prominence of inclusion work can be raised across the whole disability system rather than operating at the level of smaller boutique programs. However, there was also a strong sense that the in-depth work undertaken by small organisations with each individual which varies in intensity over time cannot be replicated across whole systems and there may indeed need to be a boutique program in every suburb. A recurring theme however, was that greater likelihood that people with more severe intellectual disabilities would be left out of individualised inclusion work or fail to benefit from broader community development work, as they are more likely to be without individualised funding packages, to live in block funded group homes, to have no family or history of informal relationships and pose complex and time intensive challenges for staff to come to know their preferences. The contradictory position that some people still occupy by continued residence in large institutions demonstrates the capacity of a forward looking system to leave some people a long way behind the leading edge. The question was posed whether the disability system has the capacity to build circles of support for everyone or even to ensure that everyone with an intellectual disability has one person who knows them well

and is committed to achieving for them an optimal quality of life, in the absence of underpinning rights or entitlements.

A greater focus on supporting the building of relationships and other types of inclusion work will require organisational reform, a reformulation of job descriptions, staff training, and supervision to ensure it becomes core to the mission and day to day delivery of support by organizations. Clegg suggested the role of staff would be central and the use of their experiential knowledge of individuals to forge relationships, interpret and better represent better people with intellectual disability to the community. Johnson et al (2010) for example demonstrated the value of research in understanding and then sharing the how and why of communication and interaction used by a young women. Suggestions were made that existing competence based training is not relevant to relational work, and it is difficult for staff to do inclusion work if they don't know the local area of the people they are supporting. More attention may also need to be paid to differentiating what staff bring to their role, working out for instance which staff are best suited to work with particular people and communities.

### **Imperative for Action on Social Inclusion**

Disability policies over the past 30 years have succeeded in significantly improving and changing some aspects of people's lives. But even the more recent focus on broader social change in conjunction with the provision of individual specialist services has made few inroads into aspects of social inclusion such as relationships between people with and without intellectual disability. As Clegg (2010) suggested 'while normalisation has improved the living conditions and situation of people with intellectual disability significantly, it has had no impact on other desired outcomes such as social relationships'. Several papers highlighted this lack of progress using the findings from the recent *Making Life Good in the Community* study, which drew attention to the *distinct social space* that people with intellectual disabilities continue to occupy following a move from institutions; despite increased participation in activities situated in local communities, residents in new group homes remain socially disconnected from other community members with social networks that comprised family members, paid staff and others with a disability (Clement & Bigby, 2009). Attention was also drawn to the similar limited success of person centred planning processes, implemented in the UK as part of the Valuing People strategies, to effect any significant change on the strong markers of social inclusion such as more inclusive social networks or increased employment (Robertson & Emerson,

2007). Using another marker of social inclusion Frawley and Bigby (2010) drew attention to the significant under-representation of people with intellectual disability in participatory bodies such as Disability Advisory Councils and difficulties such bodies have in adjusting their modes of operation to support participation. Summing up the scope and challenge of implementing current policies of social inclusion Ramcharan (2010) suggested that before now policies have not sought to achieve 'community living, social justice, community acceptance and well-being *together as a matter of course for people with intellectual disabilities*'.

### **Conclusions**

The discussions did not canvas priorities for action although the importance of building relationships did occupy a central place. A little time was spent pondering employment as another dimension of social inclusion and why the proportion of people with intellectual disability in the workforce had declined. Suggested was the importance of not just disability advocates taking a lead in expanding employment of people with disabilities in large organizations, such as government departments and universities. Perhaps most telling was an endorsement of Reinders (2002) view that while a rights agenda can open doors into communities or institutional roles, achieving social inclusion and a sense of belonging for people with intellectual disability in the form of individual social connections or civic friendship requires change on the part of community members, which cannot be mandated. The challenge remains to turn social inclusion from a cult or idealized value to functional value, so that understandings of how it can be done are embedded in the service system. By doing this the goals of social inclusion for the lives of people with intellectual disability will be more clearly understood and embraced by the entirety of the disability system who are tasked with a significant part of the responsibility to bring about the social change required to make it a reality. Importantly however, social inclusion is only one of the determinants of a good quality of life, and it must be set within a context of thinking about maximising a person's capabilities and the good life for people with intellectual disability. These Roundtable discussions have helped to explain the nature of the task, why it is so difficult and provided some useful frameworks and case studies for tackling it.

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# A Moment of Change

Jennifer Clegg

## Preamble

Over the last few years I have been involved in two projects that inform this paper. The first is a longitudinal research study with a cohort of school-leavers carried out with Elizabeth Murphy, Kathryn Almack, and more recently Alison Pilnick. Our analysis explores ways that the duress of transition reveals conceptual tensions embedded within policies shaped by normalisation, and how these affect different parties. The other is an evolving reconsideration of the way specialist services should be designed for people with ID mental health problems, carried out with Richard Lansdall-Welfare and more recently John Ballatt. I am indebted to each of these individuals for some exhilarating conversations, and to members of clinical-academic networks in Nottingham and Glasgow who have provided such responsive sounding-boards. I can no longer be sure who first crystallised what idea, so draw on ideas and publications from both projects. Responsibility for the way these are deployed to address the roundtable's interest in participation, and for the concluding implications, lies with me.

## Introduction

Despite the centrality of 'autonomy' to neoliberal cultures, people with ID – like everyone else – need to live in relationships. They require help to manage their daily lives and to express themselves through various roles and activities, but they also want and need acceptance, concern, warmth, understanding and companionship. With such relationships in place, daily life becomes more possible for all of us. Without them life can become seriously impoverished: health and well-being may deteriorate, the practicalities of living may become problematic and life may get increasingly lonely, frightening and without point.

For many people with ID, their disability itself is a minor barrier to forming such relationships. Stigma and poverty of opportunity threaten their well-being, along with vulnerability to abuse or exploitation. What matters primarily is whether those around them offer welcome and respect, and have the sensitivity, thoughtfulness, skills and generosity to form supportive relationships. A mixture of difficulties can stretch the capacity of people with ID and those around them to build and sustain enduring, productive relationships. Physical and cognitive disabilities may interact with health problems and restricted communication; the implications of neuro-developmental disorders such as autism or ADHD may be

imperfectly understood. Challenging behaviours resulting from combinations of disabilities and environmental stressors can make it difficult to build, or threaten the continuation of, vital relationships.

In this paper I argue that we are at a moment of change, then make and justify the proposal that relationships should become the building-block of a new approach which could emerge from this moment of change. I do so by drawing on the following evidence, argument and examples.

1. Recent research questioning the status quo in ID contributes to the growing view that we, and possibly society, are at a moment of change. In this section I focus primarily on UK research since it may be somewhat less well known in Australia, but this view is not restricted to the UK.
2. New international perspectives on ID that could reinvigorate inquiry were explored at a multi-disciplinary seminar 'Counterpoint' held in Nottingham earlier this year: they are summarised.
3. Addressing two particular issues which I draw from this research:
  - a. The social isolation experienced by significant numbers of people with ID;
  - b. The judgemental 'moral order' which inhibits the decisions and actions of staff and parents/carers.
4. Continuing to occupy the conceptual landscape that ID as a discipline has inhabited for the last 35 years will prevent us from addressing either of these issues, because they are fundamental components of that landscape. There are good reasons why ID tends to be an isolationist discipline, but this is the moment to look beyond our protecting veil and find out how new assumptive worlds are created, established and sustained.
5. The concluding implications identify some possible directions for acting into this moment of change: they act as an invitation for others to step onto this plane of development too.

## Questioning the Status Quo

As the introductory notes to this roundtable stated, there is growing research evidence to show that while normalisation has improved the living conditions and situation of people with ID significantly, it has had no impact on other desired outcomes such as social relationships. This is an example of recent and in my view significant research in the UK which questions the status quo.

## UK research

- Burton, M. & Kagan, C. (2006) Decoding Valuing People. *Disability & Society*, 21, 299-313
- Emerson, E. (2005). Adults with learning difficulties in England 2003/4. Survey report downloaded from [www.dh.gov.uk/en/Publicationsandstatistics/DH\\_4120033](http://www.dh.gov.uk/en/Publicationsandstatistics/DH_4120033)
- Forrester-Jones, R. Carpenter, J. Coolen-Schrijner, P. Cambridge, P. Tate, A. Beecham, J. Hallam, A. Knapp, & M. Wooff, D. (2006). The social networks of people with ID living in the community 12 years after resettlement from long-stay hospitals. *Journal Applied Research in Intellectual Disabilities*, 19, 285-295.
- Hallam, A. Beecham, J. Knapp, M. Carpenter, J. Cambridge, P. Forrester-Jones, R. Tate, A. Coolen-Schrijner, P. & Wooff, D. (2006) Service use and costs of support 12 years after leaving hospital. *Journal Applied Research in Intellectual Disabilities*, 19, 296-308.
- Hall, E. (2005) The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & Place*, 11, 107-115.
- Redley, M. & Weinberg, D. (2007) Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment. *Sociology of Health & Illness*, 29, 767-786.

These studies span a variety of methods: discourse analysis, a national survey, large-scale health economic analyses of the effects of deinstitutionalisation, and qualitative research into current experiences. They identify policy romanticism which glosses over significant disabilities and social disadvantage. They document social isolation that is not relieved by community placement; and increasing levels of social disengagement 12 years after deinstitutionalisation, associated with a steady reduction in funding. It seems it was not so much living in an institution or the community that made the difference, as levels of funding. They show that those people who have mild disabilities and who succeed on 'inclusion' criteria (mainstreaming, independent living and open employment) nevertheless experience not quite rejection, but abjection. They find company in a few refuges oriented towards acceptance and tolerance: their families, clubs for PWID, churches, community centres. Finally, there is a detailed analysis of a 'parliament' for PWID. This intended to bring together public sector decision-makers and PWID (at vast but uncalculated expense if the time of senior staff were to be costed). The parliament was structured according to involvement research that generally enables people without public

speaking skills to be included (small discussion groups, preparation, buddies): yet the research showed that PWID were still unable to speak truth to power. Either they did not speak at all, or they spoke incoherently, or their buddies created a semblance of discussion by coaching them about what would be a relevant thing to say.

Of course there is also plenty of positive research in ID which attests to increased quality of life in much better physical environments, and much more choice within the domestic setting. The current policy agenda has improved things for people with ID and their families. These studies highlight what is not working, not least in initiatives that simply squander limited resource. None of this will change if policy goals remain the same.

## Transition research

- Clegg, J.A. Murphy, E. Almack, K. (in press) Transition: A moment of Change. In *Learning Disability across the life-cycle*, 2<sup>nd</sup> edition, G. Grant, P. Goward, M. Richardson, P. Ramcharan (eds) Open University Press/McGraw-Hill.
- Pilnick, A. Murphy, E. Clegg, J. & Almack, K. (in press but available online). Questioning the answer: Questioning style, choice and self-determination in interactions with young people with Intellectual Disabilities. *Sociology of Health & Illness*
- Murphy, E. Clegg, J. & Almack, K. (in press). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Jnl Applied Research in Intellectual Disability*,
- Almack, K. Clegg, J. & Murphy, E. (2009) Parental negotiations of the moral terrain of risk in relation to young people with learning disabilities. *Journal of Community and Applied Social Psychology*, 19 (4), 286-299.
- Clegg, J. Murphy, E. Almack, & K. Harvey, A. (2008) Tensions around inclusion: reframing the moral horizon. *Jnl Applied Research in Intellectual Disability*, 21, 81-94.

In this longitudinal cohort study most (21/28) of the young people achieved acceptable placements but distress was very high for parents. It was also high for transition staff, half of whom left their jobs during the 18 months of data collection, while the remainder took significant periods of sick leave or reported significant stress. The chronic and international nature of transition difficulties suggests that the problem originates in what people are attempting to do. We found that the ideas shaping services, such as adulthood, inclusion, and choice, did not map well onto the needs of these young people; they also left parents

precariously balanced on a shrinking moral terrain between over- and under-protectiveness.

As well as problems arising from the conceptualisation of service goals, we observed how an environment of moral judgement impeded co-operation or collective attempts to generate solutions. It was evident that the various parties were struggling to identify the 'right thing to do' in a complex and fraught context, often with little sound information on which to base predictions about the likely outcomes and, indeed, with limited confidence that resources would be available to support whatever decision was eventually made. As school leaving dates drew closer, creative discernment was undermined further by the rhetorical use of moral polarities that devalued alternative points of view and pushed some contributions outside the realm of the morally acceptable.

### Counterpoint

This seminar questioned the common belief that service shortcomings stem from mere failure to implement normalisation properly. Thirty people talked together for 3 days.

<b>Hosts</b>	Nottinghamshire Healthcare NHS Trust & University of Nottingham
<b>International</b>	Australia, Germany, Holland, USA
<b>National</b>	Birmingham, Cambridge, Cardiff, Dundee, Leicester, Oxford, Northumbria, Nottingham, Warwick
<b>Disciplines</b>	Education, ethics, geography, history, management, nursing, philosophy, politics, psychiatry, psychology, social work

Papers are currently being revised for publication in a special supplement to the Journal of Intellectual Research next year. This is a summary of the key topics or themes:

#### *New ideas need new language*

This session was run by Nick Everett, an academic specialising in creative writing, who encouraged participants to describe their experiences as vividly as possible, in order to generate new understandings and terms that might prove useful. Participants who were less involved in services were struck by the vagueness of the resulting explanations, posing these questions:

- What is the topic of this work? It was described as very busy, as very hard, as very eager, but nobody could describe what happened: what is the topic, what is the deeper sense of this work?

- How strange it is that these accounts of the setting don't seem to give any indication of what really is being engaged in.

This unexpected observation resonates with the puzzlement often expressed by members of society who struggle to understand people with ID and therefore how clinicians or social care staff work with them. It is a reminder that the heterogeneity of ID, and its socially constructed and consequently shifting boundaries, make it a very slippery concept. Those inside the ID world generally feel they know what is done and how to talk about it to one another, but the 'it all depends' nature of the explanations (whether or not the person can talk, walk, has challenging behaviour, autism, or any of a number of other possible health or social difficulties or circumstances) frustrates outsiders and probably impedes access to research grants and support for service developments. It was a reminder that the way ID is represented is vital, since limited funding inevitably follows from politicians receiving vague messages that they cannot communicate to the electorate. Deinstitutionalisation was made possible by public outrage at the demeaning practices revealed by enquiries into underfunded hospitals. Without a similarly coherent narrative of the present, there is a risk that support for people with ID will be cut without limit until appalling conditions initiate another round of inquiries.

A point that emerged more clearly from this exercise was confidence in relating to these unique persons.

- On the frontline we're all doing it, we're all investing ourselves in that person we're working with.
- There is one experience where the whole problem of meaning evaporates and it is the experience of joy, the experience of being around someone and having this sense of connectedness.

Narrative research involving one of the participants (Wilson, Meininger & Charnock 2009) gives a more detailed examination of staff accounts about their relationships with people who have ID. Counterpoint started a process of thinking about how to communicate the pleasure of finding a moment of meeting with the uniqueness of people with ID: it only touched on the possibilities that flow from this. For example, what effect might this understanding have if it was experienced by people who make policy decisions about policy and funding? Moreover, since the failure of the general public to become involved with ID has been lamented by users (Stewart 2009) and carers (Smellie 2009), could professionals use their experiential knowledge to forge better connection between the public and people with ID?

### *Who's the expert?*

How can we move beyond a cacophony of voices to streamline slow and meeting-heavy decision-making? Perhaps this squandering of human resource could be the focus of change, the point at which money and time are retrieved and used to better effect. Yet ID is a heterogeneous condition where nobody can ever have all the answers, and so some collective or co-operative support will always be necessary. A paper from Carlson (philosophy) distinguished two kinds of authority: moral and epistemic.

- Moral authority: how to define the good life, justice, what kinds of claims we make.
- Epistemic authority: who makes knowledge claims, produces bodies of knowledge

Carlson's analysis provides the basis for much more consideration of this issue, both from a conceptual/ethical perspective and from a management perspective where recession demands that wasted time be reduced. Many services carry out meetings with scant regard for effective process, formulation or outcome. They are required to hold them and quality assessed if they do so, irrespective of their utility: much of the record is provided by reports written in advance of the meeting. Requiring services to follow ideal processes, such as person-centred planning, fails to recognise that the knowledge, discernment and authority of those present, and their relationships, are likely to be much more crucial to a satisfactory outcome than a naïve facilitator following a particular set of procedural stages.

### *Building relationships*

A number of papers looked at this complex matter from different perspectives, and it was a matter of celebration that they did not all agree.

- Reinders (philosophy): questioned the effects of quality assessment on professional practice. He argued that it implies that a particular, personal relationship between staff and person with ID is inefficient because it is idiosyncratic: quality assurance seeks to ensure that the person has the same experience (going swimming) whoever takes them. Reinders argued that particular relationships are most important, not general and quality-assured ones. Such intense relationships draw on tacit knowledge and good judgement by staff.
- Schuengel (psychology): Yet sometimes the quality of interaction between caregivers and clients is poor: these are not relationships to be celebrated. Staff benefit from coaching.
- Hall (geography): To be socially included requires you to be active, participating, useful,

self-reliant. Not only can few people with ID achieve this ideal, many of the most able have decided they do not wish to do so.

- Gleeson (geography): Periods of intense transition in ID ideology always reflect social transformations. Examination of the two key moments of change in ID, shaped by industrialisation & then post-industrial deinstitutionalisation, reflect wider points of social transformation. If we are now in a third moment, it may concern a focus on the collective, inter-dependency, & reflection on what 'community' means.

### *What if we vary the time-scale? What lessons does history teach us?*

- Toms (History) reviewed Tizard's Brooklands experiments 1958: why then? Why Fountain Hospital? In the '60's and '70's it was important to emphasise the mutability and humanity of PWID. 1958 Brooklands approach saw human beings as emotional beings. Fountain Hospital been making a name since the Second World War as a research centre. Med Dir of Fountains close to communist party, deputy was a communist involved in civil liberties; Tizard was a member of the communist party in his youth and of a forerunner of the Campaign for Nuclear Disarmament. Strongly probable they had a different theory of society as well as a new theory of childhood and therapy.

### *Concluding plenary session themes:*

- Deep disenchantment with status quo.
- Names of policy documents show we constructed people as normal: The Same As You, Ordinary Life etc. We've failed miserably to achieve it: Why? The way we've constructed what we're trying to do. We need to construct people as human beings, not as citizens and not as consumers.
- Reached the end of the social model. Wouldn't matter if we had more money and more time and more resources: we may not be able to do better. There's going to be a time of necessity. We have to start thinking beyond resourcing, about the very foundations of what we're doing. Overnight people with ID were changed from prisoners of institutions to consumers: we need to imagine other possible roles.
- We need to have a different way of respecting the inherent humanity of people with ID: not just different versions of ourselves because they are themselves.
- If things have gone wrong then somebody has to be to blame and so we all try to make sure

we don't end up getting blamed. Yet we need to take a risk: saying we shouldn't simply be treating people with ID as a version of normality. There are things that are distinctive about these people that we need to attune to.

- Yes we can give people with ID a voice, but be clear about who has the right to give that voice and who has the expertise to understand.
- There's a need for people to write new ideas, new ways of thinking.
- We have to remind ourselves to be courageous, and to create spaces where we can think and act more radically.
- We should be seeking to build relationships between people with ID and other people.
- Change requires a new building block. Putting emotional worlds and relationships at the core of the new direction, and putting research and spaces for developing staff into place, would start a different story.

## Two Significant Issues

### *The social isolation experienced by significant numbers of people with ID*

There are probably many issues that could be covered under this heading but I wish to focus on two. Firstly, the social environments that result in people being killed by 'friends' who torment them, or single mothers committing suicide with their children who have ID because they have been unable to obtain protection from long-term abuse by community members. This is a problem of class and poverty, and requires more community action.

Second, the individuation of service structures that turned group homes into supported living tenancies framed by person-centred plans. These leave the least qualified and experienced staff to work out alone if and how to facilitate relationships between residents, and between residents and members of the community, a task at which, not surprisingly, most fail. Social relationships need to be considered a priority, not assumed to be a by-product that will flow from other service goals being achieved.

### **The Judgemental 'Moral Order' which Inhibits the Decisions and Actions of Staff and Parents/Carers**

People in our transition study devoted far too much energy creating a semblance of inclusion, or justifying why they chose to use specialist services or avoided going into community settings. Some staff expressed surprising degrees of certainty about how people ought to live. In 2001 Gleeson & Kearns argued for 'doubt as a moral virtue',

and we hope that it will prove possible to move into the next moment of change without the condemnation which has characterised many of the interactions between staff and staff, and staff and families of people with ID. Rather than continue to undermine key members of the affective community around people with ID, developing ways to talk to each other that maintain rather than destroy relationships would be a very good place to start.

### *Beyond the protecting veil*

Continuing to occupy the conceptual landscape that ID as a discipline has inhabited for the last 35 years will prevent us from addressing either of these issues, because they are fundamental components of that landscape. In 2003 we (Clegg & Lansdall-Welfare) elaborated an observation previously made by Reinders, that the development of meaning and defence against its dissolution is a central problem for parents and staff involved in ID. It tends to be an isolationist discipline because isolation protects ideas that allow people in difficult circumstances to go on. Nevertheless, this is the moment to look beyond our protecting veil and find out how new assumptive worlds are created, established and sustained.

The constructionist philosophers Deleuze & Guattari (1994) argue that the creative act involves clearing a plane where new concepts can flourish: "Nothing positive is done, nothing at all, in the domains of either criticism or history, when we are content to brandish ready-made old concepts like skeletons intended to intimidate any creation" (p83). The dominance of normalisation ideas over the past 35 years, combined with support from an individualist culture which readily embraces related concepts such as person-centred planning, makes originality and creativity even more difficult. We will need to be vigilant if 'rubber-band thinking' is not to pull us back into familiar dimensions and ideas.

Our concepts should conjure or invite actions and events that help people with ID and those associated with them to flourish. Deleuze & Guattari (1994) argue that new ideas develop in philosophy from paradox. Thus the dilemmas we saw many parents and some transition workers struggling with in our research may be the seeds of change.

The radical architect Zaha Hadid (Schumacher 2004) has drawn on Deleuze & Guattari's (1994) ideas. Hadid's buildings aim to exhilarate users, in order to encourage them towards renewal and creativity. Being in her buildings is experienced as dynamic: at best akin to flying. For her good design originates in identifying and then addressing the central problem that the structure must solve, while

constantly struggling against clutter. Merging this starting-point with Deleuze & Guattari's (1994) use of paradox to initiate creativity identifies the following issues for reflection.

1. Exactly what do services for PWID aim to do? They address intellectual disability but rarely increase levels of intellect; perhaps this central conundrum was what made it so difficult for people involved in ID to describe their work in our creative writing exercise.
2. People with ID (especially those with mental health needs) want and need supportive relationships, but their behaviour elicits from other people the opposite of what they need.
3. In all residential services and many community services, direct care staff and parents/ carers are potentially significant change agents: but the more professionals treat care staff and parents like pawns or tools of the trade, the more dehumanised the whole service becomes.
4. Parents want to share the burden of care but many do not trust public services.

### Conclusions: Implications for Practice

These concluding implications are some ideas of directions that could flow from acting into this moment of change, and an invitation for others to step onto this plane of development too. They are informed mostly by the transition research: elaborating the implications of the above (and other relevant) paradoxes will take longer to reach practical implications.

1. Increasing social participation requires that we get relationships right for more people with ID as a foundation for them experiencing a sense of belonging to whatever communities make sense to them and those to whom they are connected. Insights from community psychology [www.compsy.org.uk](http://www.compsy.org.uk) such as how to work with the grain of local groups, rather than setting up new ones that collapse when funding is withdrawn, may inform this work.
2. Achieving this requires the development of a more textured understanding of need by juxtaposing awareness of the obdurate reality that ID is a group characterised by significant heterogeneity, alongside continuing resistance to the objectification and infantilisation of any individual.
3. Specialist mental health services will provide the help that carers and health and social care professionals need to build and sustain their own relationships with people who have ID, and to facilitate the development of relationships between each person and particular communities of interests where they may experience a sense of belonging.

Such a service should be ideologically neutral about whether those communities of interest do or do not include other people with ID.

4. Professionals will emerge from a rule based approach to practice and the moral clarity associated with asserting client empowerment as a service goal, because this results in an underplaying of the constraints that people with ID experience, and because it excludes key members of their affective community from the picture.
5. Services will no longer focus exclusively on outcomes but rather describe the whole system: what is done, how it is offered and how it should be experienced not just by users but also by carers and staff. This is one possible example, for a specialist mental health service:
6. "To provide a calm, purposeful, effective Assessment & Treatment service that aims to minimise distress and/or disruption resulting from mental ill-health or poorly managed neuro-developmental conditions. Conceptual coherence and purposiveness is established not at the assessment but at the formulation stage. Formulations specify what the service believes to be at issue for each person, and the care they need in order to thrive; and the service follows up where necessary in order to keep therapeutic interventions alive and so prevent relapse. The service does this in ways that reduce rather than increase the social isolation that amplifies many of the difficulties encountered by people with ID."
7. The trend towards single-person placements for people with the most challenging behaviours should be reversed whenever possible. Both their isolation and their cost make them problematic. The challenge for research and practice is to develop new ways to enable those who tend to be managed in isolation to tolerate and occasionally enjoy the company of others.
8. Professionals and policy staff and people with ID should be encouraged and supported to act into the change: to develop, explore and examine new ideas and approaches. Doing so will require reflection about possible risks for clients or carers, and everybody learning how to tolerate and find their way through moral uncertainty.

Deleuze & Guattari (1994) evaluate new concepts not against truth criteria, but by assessing the importance of the events to which its concepts summon us. Perhaps an important event might emerge from something that has been explored here.

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# Capability and Inclusion

Paul Ramcharan

A significantly long history has seen people with intellectual disabilities living or existing on the margins of society, their lives self-fulfilling prophecies of others' definitions of them. They have been possessed, changelings, vagrants, village idiots and inmates. Although agrarian economies might support some people with intellectual disabilities to be economically productive, any absence of such paid work or family will have produced harsh and difficult lives. Increasingly unable to meet the demands of heavy labour as industrialization unfolded their lives in the poor houses and then the purpose-built institutions were no less inhumane. And whilst deinstitutionalization, inclusion and community living have been the approach of contemporary policy in Australia and much of the developed world, these too have brought new problems.

Never before, then, have community living, social justice, community acceptance and well-being been achieved *together as a matter of course* for people with intellectual disabilities.

In this paper the preoccupation with 'community inclusion' as an end in itself in policy rhetoric is examined and the policy, service-related and academic strands contributing assumptions about community and inclusion examined. By examining the deinstitutionalization movement from the 1960s in the UK as an example it will be shown how attempts at social engineering have consecutively sought to reproduce:

- The characteristics of communities
- The characteristics of everyday community living and normal lives
- A level of personal choice and autonomy akin to members in the wider community
- And, more recently and, in prospect, the application of a common framework of human rights for citizens

It will be argued that the approaches adopted to date have produced 'lifestyle' changes but are yet to accomplish community living, social justice, community acceptance and well-being together. This is true, *ipso facto*, since we also know that compared to the general population people with disabilities remain disproportionately excluded. They are excluded from the everyday housing market, largely from employment, continue to have significantly worse health outcomes, are a focus of threats and exclusion within their communities and have lower scores on nearly all indicators of life quality when compared to the population at large.

## Reproducing the Characteristics of Communities

The plan for a move to community care in the UK was first set out in the Hospital Plan 1961 which detailed the figures for deinstitutionalization of people with mental illness. Research publications around that time pointed to the problems of 'inmates' in such asylums and their unacceptable living conditions (Goffman, 1959; Barton, 1959). However, alongside these negative factors postwar optimism and economic vibrancy was supplemented by social research pointing to the nature of communities as being far warmer, nurturing and caring environments than institutions.

Willmott and Young (1960) seminal study in the East End of London showed how strong reciprocal bonds tied people together and sustained people by providing mutual aid. People were found to share child care, to help out regularly with household tasks, to look out for each other particularly for those who were more vulnerable and dependent upon the support of others. Geographically isolated, such community localities encompassed employment, leisure, spiritual and other collectives leading to a significant fabric of social and supportive ties demonstrating warmth, a sense of belonging and a system of mutual care and support. In such communities the currency of exchange was the recognition that if I rely on you today then, at some point, you can rely on me in the future, i.e. you scratch my back and I'll scratch yours.

Policy in the years preceding the Hospital Plan emphasized a community development approach to social work and the provision of care in the community. Reflecting the social research of the time however, The Seebohm Report recognized that communities within localities were breaking down as people became more mobile both in terms of transport and in terms of higher paid employment. This meant all the services within bounded community settings were beginning to span different localities. As Seebohm said:

*"Although community has traditionally rested upon geographical locality, and this remains an aspect of many communities, today different members of a family may belong to different communities of interest as well as the same local neighbourhood. The notion of a community implies the existence of a network of reciprocal social relationships, which among other things ensure mutual aid and give those who experience it a sense of well-being." (Seebohm Report 1968: 147)*

This position assumed that despite the breakdown of locality as community that 'communities of interest' would emerge across localities and,

further, the features of mutual aid, trust and support would be *taken to be present* within such dispersed communities of interest. Like many pieces of academic work it was easy to find in other research a formula to link these policy pronouncements with models of support. In his influential work on 'neighbourhoodism' for example Philip Abrams (see Bulmer 1986) hypothesized that forms of care would differ dependent upon the *personnel* involved and on what *setting* the care is provided (Diagram 1). As such professional care in institutions leads to an 'institutional treatment' model, but where that care is provided by non-specialists it becomes an 'institutional care' model. In contrast, in the community, professional care will yield a 'community treatment' model and lay or non-specialist inputs will produce a 'community care' model – i.e. care *by* the community. It was easy to link the ideal of community care with a community care model and to convince government Ministers that the little that was left to do would be covered using a community treatment model and a social work approach as suggested by both Seebohm and later in the Barclay Report 1982.

**Diagram 1 – Representation of Abrams Framework for Forms of Care**

		Personnel	
		Professional's	Non-specialist's
Setting	Institution	Institutional treatment	Institutional care
	Community	Community treatment	Community care

Both Abrams and Seebohm saw the means through which such community care could be developed as being through building neighbourhood groups, good neighbour schemes, participation in local voluntary organizations and in developing 'communities of interest'. But the model had simply failed to take account of a number of factors which made the vision almost impossible to accomplish:

1. A significant debate in policy ensued around whether community teams should be treating people with recognized mental illness or preventing mental health problems in the general population (on the assumption that prevention would lower incidence of diagnosed mental illness). However it was shown that up to a quarter of the population at any one time had a mental health problem (Goldberg and Huxley, 1980) and treating the 'worried well' rather than the 'unworried unwell' was rather akin to 'drinking the sea'.

2. Communities were not found to be warm and supportive and, indeed, the Not-in-my-back-yard (NIMBY) lobby was large and significant of voice. Indeed Willmott and Young's work had also shown that many, particularly those in the younger adult age-bracket, were leaving tight-knit communities for looser-knit suburban life leading to the argument that, 'Community turned out to be a function of shared adversity, something that those who were benefiting from the prosperity of the 1960s chose to escape', (Chapman, 1999: 40). Indeed those with mental illness and later intellectual disability were perceived by much of the community to be a source of *adversity* themselves. And where families had disposable income sufficient to survive independently, mutuality was seen as '*surplus to requirements*'.
3. Moreover, with the emergence of consumer society and the assumptions of a materialist philosophy within community life mutual care becomes a 'good' over which to barter. In this model a person provides care (for example after school care or looking after children) to a similar level to the person with whom they are sharing tasks (Ramcharan, Whittell and Grant, 1994). As many families in this study pointed out, the cost to neighbours and others in the community was too high where additional support was required from them to look after their relative with a disability and the most they could rely upon was 'help in an emergency'. Furthermore there were parallel but not interconnected communities where people with disabilities did not share the same transport, daily routine, activities and places of work, training and leisure. Their paths seldom crossed and no opportunity structure for mutuality existed.
4. The nature of what people wanted from their communities also began to change at this time. A secondary analysis of socializing patterns in the U.S. General Household Survey between 1974 and 1996 (Guest and Wierzbicki, 1999) show a slow but continual decline in social ties, a small growth in non-neighbourhood socializing and highest levels of socializing amongst older people, those with children and the most disadvantaged. Moreover Bridge et al., (2004) in their review of neighbouring suggest, 'Neighbourliness involves distance and privacy as well as closeness and conviviality'

Society had itself therefore begun to change significantly and the warmth of the community upon which the (at least the ideals) of policy were built gave way to the post modern community,

consumerism and to the ideals of individualism and choice as opposed to collectivist and reciprocal. In the new communities contracts were short term as exchange of good at a point in time requires immediate contracting rather than a contracting over the life course. Some of these differences are set out in Table 1 below.

**Table 1 – A comparison of elements of the ‘warm’ and the ‘(post)-modern’ community**

The ‘warm’ community	The (post)modern community?
Reciprocity on the grounds of neighbourliness	Reciprocity on the grounds of equal exchange of service or good
A sense of identity out of belonging to a mutually supportive community	A sense of identity and belonging only with those who share interests
Stronger together supporting all members	Stronger together with those with whom one shares an identity based upon personal interest
Commitment is voluntary and there is a volunteering commitment	Commitment based upon personal choice and personal gain
A sacrifice of some privacy – spontaneity to meeting up	A maintenance of privacy – meetings are planned

Many of the problems of community care for people with intellectual disabilities were therefore less to do with such people and more to do with societal change, with evidence that was out-of-date at the point of publication and with the experience of people with mental illness who were being discharged for nearly twenty years before the resettlement period began for people with intellectual disabilities.

### **Reproducing Characteristics of Community Living and Normal Community Lives**

For people with intellectual disabilities in the UK deinstitutionalization was very slow with early efforts at resettlement managed by health and social services moving people to a varied assortment of independent living, hostels, some smaller group homes and to adult placement or fostering services (Emerson and Ramcharan, in press). Many of those resettled early were people with ‘mild’ disabilities who continued to use services provided by the very hospitals from which they had come.

With the emergence of normalization in the 1980s its emphasis on ordinary lives (King’s Fund, 1980) and socially valued roles a number of pilot schemes involving smaller group living arrangements (Lowe and de Paiva, 1991) were developed and evaluated setting the scene for

the development of ‘ordinary’ housing for people with intellectual disabilities over the next forty years. However, by the 1980s social policy was itself undergoing huge transformation with the rise of consumerism (Burton and Kagan, 2005). In this model those in receipt of welfare were being recategorised as individuals in receipt of services with rights as consumers. It was always likely given these developments that in Abrams’ terms a ‘community treatment’ rather than a ‘community care’ model would flourish. Furthermore the government had to manage not simply the transfer of people with intellectual disabilities from the institutions but the transfer of service workers and professionals to new community teams too.

Individual planning introduced in the 1983 All Wales Strategy was accompanied with the exhortation to *involve* people with intellectual disabilities in all aspects of planning, managing and implementing services (Felce et al., 1995). and ‘An Ordinary Life’ (King’s Fund, 1980) advocated a focus on smaller non-institutionalised residential settings, increased employment opportunities and a focus on developing friendships and networks in community settings. In other words there was a move to introduce the characteristics of community life to people with intellectual disabilities, i.e. to reproduce the community that others in the population took for granted.

But the services in the community in Wales were found to be ‘unplanned, fragmented, poorly co-ordinated and without adequate mechanisms to involve individuals and their families in decision-making’, (Felce et al., 1998: 49).

Indeed,

*‘the function of services in relation to the community was not spelt out clearly enough. Hence the operationalisation of something as vague as ‘mobilising community resources’...had no ready template...The new tangible services developed were the clearest manifestation of this activity, though they were often the result of ‘top-down’ planning processes’, (Felce, 1995: 67).*

As with a plethora of subsequent policy since the AWS the call for community inclusion has signally failed to be accompanied by definitions of how this might be accomplished nor by guidance documents or models for community development. In the absence of these the vacuum has been filled with a number of common-sense ideas and understandable claims by professionals that they are doing all that they can do.

The evidence from Wales was clear and unequivocal yet never addressed in subsequent policy. For example segregated Adult Training Centre (the ATSS in Australia) provision saw only a gradual move to satellite systems and in a

survey eleven years after implementation (Beyer, Kilsby and Lowe, 1994) over two-thirds of person-hours were still spent at the ATCs and of these over half the activities were arts and crafts or contract work. The contract work itself involved menial work such as packing bags (for example with screw and dowels for DIY furniture) for which a measly pocket-money rate was paid so as “not to affect welfare benefit payments” and only 5% per annum of people attending ATCs went on to any form of open employment. Pockets of opportunity in alternative day opportunities and open employment were also achieved and for the latter employers estimated integration into the general workforce for over half of these workers was ‘excellent’ (Beyer, Kilsby and Willson 1995).

Even thirty years later Valuing Employment Now (Department of Health, 2009), present policy on employment for people with intellectual disabilities estimates that only 10% of people with intellectual disabilities are in paid work. Setting a goal of 45% employment (the same as ‘other’ disabled people) by 2025 the document says the present employment rate, ‘...represents a waste of talent and opportunity for people with intellectual disabilities, employers and our wider economy and society’, (Department of Health, 2009:11). But there is no additional funding but a proposed organisational solution instead. Even were the policy to succeed there is likely to be a significant wait in prospect for people with intellectual disabilities wishing to enter the employment market. Moreover, top-down community treatment models of service provision, even if seemingly co-ordinated do not necessarily lead to significant change and there are a number of reasons for this as we will discuss shortly.

The experience of residential options also proves instructive. Like employment housing represents an *opportunity structure* through which the wider benefits of community living were supposed to have been accessed and experienced. Small scale group homes dispersed in the community are more likely to provide best outcomes for residents (Emerson et al., 2000), for example: leisure activities have been found to be greater and more varied in smaller community settings (Mansell, 1994; Golding et al., 2005); larger social networks have been found in smaller settings as compared to the large institutions (Golding et al., 2005; Stancliffe and Keane, 2000); leisure, social network and community activities were found to be greater in group homes than in cluster housing (Emerson et al., 2000; Emerson, 2004). Yet when set against the expectation of community inclusion such changes have been modest of not very small Robertson et al (2001a, b).

So why has community inclusion under the

post war UK policy failed to meet the ideals or expectations of the early days? Firstly there has been a continued focus on changing the individual rather than the community and, associated with this, a ‘graduation model’ (Taylor, 2001). In the ‘graduation model’ the preoccupation is with ensuring the person has the skills to ‘graduate’ to have the right to a new life. This may explain why more people with ‘mild’ intellectual disabilities were the first to leave the institutions and why people with challenging behaviours or complex needs have been the last. One can ask in relation to the ‘graduation model’ why it is that virtually without complaint from government, academics or others that people with intellectual disabilities are in a completely different queue for housing than the rest of society. Why are group homes acceptable for people with intellectual disabilities but not for others? And why don’t we see a queue of people from the wider community hoping to access community residential units (CRUs)?

Once again there is an implicit and yet unspoken assumption that at some point distant people with intellectual disabilities will graduate to ‘real’ housing and ‘real lives’. In this respect Reinders (2008) asks, ‘why maintain a hierarchy of (human) being that is premised by the faculties of intellect and will? Why not ask how to conceive of our own common humanity regardless of any state or condition...’ (p.53).

It is in making this leap that the issue of ‘capabilities’ (which will be discussed later) enters the debate. Inclusion is STILL a debate about difference and not a debate about our common humanity. In a society based on such hierarchy, many people with intellectual disabilities never graduate. Instead they are caught in a lifetime of segregated services with the ‘promised land’ always that vital step away.

The person with an intellectual disability must be taught and must comply with training on the right behaviour and right skills before they can move on to real work, ordinary homes, or community leisure. And this explains why there has been so much emphasis on behaviour management and social skills training within services and as a research outcome measure.

The second assumption explaining the difficulties of accomplishing inclusion is associated with the first. Implicit in the graduation model is an ‘equality of opportunity’ model where merit and achievement are seen to be the only rightful arbiters of access to position and, consequently, economic resources. Such equality of opportunity gives differential access to resources, and since people with intellectual disabilities are nearer to the bottom of the ‘merit ladder’ their quality of life is lower. Equality of opportunity therefore

*produces inequality.* That inequality is also carried through generations.

The early efforts to create lives displaying similar characteristics to the spread in the wider population have found people with intellectual disabilities at the 'tail of the bell curve', with a collection of life circumstances and outcomes in amongst the lowest for any group of citizens. Despite best efforts the assumptions of economy and policy have made a spread of life chances similar to others virtually impossible to accomplish.

That being said, two further conditions need to be satisfied to accomplish equality of opportunity. Firstly people should be provided equal access to education and to employment, and society should take away the obstacles that disable people through inaccessibility. This is the position of the social model of disability. The second is the need for support to make these accomplishments a reality. Innovative strategies for change in these regards are considered below.

### *Innovation and professional support*

At the edges of most policy there tend to lie a smaller number of and more innovative approaches to developing inclusion and a number of these in the early days of deinstitutionalization came from North America. Four of these strategies with particular relevance today were outlined in the seminal publication *Making friends: Developing relationships between people with a disability and other members of the community* (Roehrer Institute, 1990) and these are summarised and discussed further below.

1. *One-to-one or matching* – If getting people included starts with a friend in the wider community then why not start find people willing to volunteer as such friends? The ideas around citizen advocacy, the best known one-to-one matching strategy were based on the manufacture of such exclusive long-term friendship which over time led to a network of friendship and support which started with but was not exclusive to the citizen advocate. Additionally the citizen advocate would support instrumental change for the person in their life circumstances where they were unable to speak for themselves. In most countries with citizen advocacy schemes it has been found that there are a limited number of people in the community willing to commit to such partnerships making recruitment time-consuming and in some cases very costly and inefficient. Despite this *Valuing People* (2001) the first national English strategy for people with intellectual disabilities in a generation specifically funded such advocacy.

2. *Bridging to the community* – That the citizen advocate remains in the person's life may lead to some criticisms that the relationship remain paternalistic and, indeed at worst, potentially exploitative. An additional strategy makes the assumption that once a person becomes connected to the community that they can more autonomously make their choices around maintaining and developing the social and supportive network. In this 'bridging model' someone employed through an NGO acts as a 'connector' or 'guide', Having built 'associational maps' of the community they introduce the person to new places and opportunities, guide the person to new relationships and establish links with valued members of the community before fading out (in contrast to citizen advocacy). In fading out the person can bridge several people at once and move on over time, a more efficient approach than in the citizen advocacy model. Both the bridging and citizen advocacy models share a focus on building trust and in recognizing the gifts people bring to their communities. The bridging model in particular believes that people with intellectual disabilities have not been included because no-one has asked the community in the right way. In this model we can see the ideals of *diversity* and *positive regard, non-discrimination and support* sufficient for, but not so cloistering as to prevent, self determination and choice, (Amado, 1993).

The models of simply 'being there' are important. As Reinders (2008) says,

*Not many people in our society believe that spending time with an intellectually disabled person will contribute to the "quality" of their lives; therefore it is also true that not many people would know what it is to be a friend of such a person. This is not necessarily their fault. Even though disability is claimed to be "out of the closet" it is still true that many people with intellectual disabilities live in protected environments. It takes an effort to reach out and meet them' (p.7).*

The being there models have been exemplified by ethnographic accounts such as those in the volume by Taylor and colleagues (e.g. Taylor and Bogdan, 1989; Taylor et al., 1987; Taylor, Bogdan and Lutfiyya, 1995). These accounts show how the features of everyday human life, the struggles with work, identity, sexuality, membership can play out for people with disabilities in ways little different to others and that 'being there' is an essential prerequisite upon which any form of inclusion is based.

3. *Community development* (with self advocates)  
 – The first two approaches share the idea that linking people with other community members is sufficient and does not require any change in the community other than that produced by the presence of people with intellectual disabilities. The Roeher Institute (1990) saw self advocates as playing a central role in supporting the development of links with the community though the self advocacy movement itself does not seem to have pursued this as a major strand of their work. Indeed, some authors suggest that it is limiting to see self advocacy as taking place only in groups with that name and that, indeed, we should look at the everyday active involvement of people with intellectual disabilities in the community and their resilience in producing identities and roles chosen by and constantly reworked by themselves (Goodley, 2005:342). In other words this is about choosing how they want to construct their own identity, ‘border-crossing’ (Peters, 1996) from the disability identity to an ‘included’ identity, rather than one predicated on professionals’ views of people, their behaviour and their skills.

The right to accessible environments championed by the disability lobby and social model theorists has empowered community initiatives to make use of a raft of legislation since the 1980s designed to improve accessibility (e.g. Disability Discrimination Acts 1995 and 2005). This recognition of the responsibility of the State to adapt environments has been supplemented by more technical community development models such as the Kansas based community toolbox (<http://ctb.ku.edu>) which has significant resources around:

1. Understanding Community Context (e.g., assessing community assets and needs)
2. Collaborative Planning (e.g., developing a vision, mission, objectives, strategies, and action plans)
3. Developing Leadership and Enhancing Participation (e.g., building relationships, recruiting participants)
4. Community Action and Intervention (e.g., designing interventions, advocacy)
5. Evaluating Community Initiatives (e.g., program evaluation, documentation of community and systems change)
6. Promoting and Sustaining the Initiative (e.g., social marketing, obtaining grants).

The approach has similarities to the emergent literature on social capital which (e.g. Putnam, 1998) which sees inclusion as being formed through: formal and informal engagement, links

with institutions which are public regarding and private-regarding; the building of bonds of trust to repair cleavages, immediacy in response to new connections; durable, intense and multi-stranded networks and social ties through neighbourhoods or new media. The social capital approach is yet to feature substantively in disability policy but nevertheless offer the prospect of now well-rehearsed models and procedures.

These models have begun to reflect new values that challenge the ‘policies for the average person’ approach seen to date. Kenny (2006) suggests these values as a set of common commitments to: powerless people and social justice; citizenship and human rights; collective action; diversity; change and involvement in conflict; liberation, open societies and participatory democracy; accessibility of human services programs; and, empowerment and self-determination. And, indeed, the fourth area identified by the Roeher Institute lies in the area around reproducing change through extending personal choice and autonomy and, as such, falls into the next section of this paper.

However, the approaches outlined in this section are worth considering in terms of filling the gaps in policy around the nature of community inclusion and about how it might best be accomplished.

### **Reproducing Personal Choice and Autonomy of the Wider Community**

#### *Using social networks and circles to build friends*

For many the gap between a person’s choice and a life that is self-determined relies on additional support (O’Brien and Lyle, 1987; Boyle, 2008). At an interpersonal rather than a community level such friendships are usually between people who see themselves as equals and they provide several from amongst a group of human needs such as intimacy, nurturance, reassurance of worth, guidance as well as reliable assistance leading to social inclusion (See Bayley, 1997 who draws the categories from Weiss, 1975).

There are now also a significant number of studies which demonstrate that where competence is distributed amongst a group that the life quality is better (Lunsky and Benson; Odom et al., 2004) and similar studies are emerging in relation to people with intellectual disabilities. In other words, seeing the individual as the focus of the interest in building friendships misses the point that the competences of friendship are located within larger groups and not the person only. For example, Nuttall (1998) has shown how by taking the name of a ‘spirit child’ (a deceased and distant relative) newborns (including those

with intellectual disabilities) amongst Greenland Eskimos create a system of distributed competence for the child's welfare which draws distant family into the child's life. Booth and Booth (1998) have similarly shown in their study of children with at least one parent with a intellectual disability that better outcomes are produced where competencies are widely distributed. And if such networks do not exist naturally it is possible to develop 'purposive networks' (Wenger, 1992) to fill the gap until they do (without losing sight of the need to ensure that purposive professional networks are not an end point but a staging post).

In its original conception for example in the U.S. largely around people with acquired brain injury 'circles of support' (Willer et al., 1993) were established with a purposive nature,

*"The overriding purpose of these circles is to build inclusive communities, to enable people with disabilities to participate fully in their community, to contribute their talents, to receive support and to be accepted as valued community members by building onto, or replicating natural networks in the community". (Rowlands, 2002:56).*

The early work on circles (which are now at the centre of modern person centered planning) saw them as community based. Professionals were not seen as the rightful owners nor facilitators and, indeed, daily active involvement in their everyday lives was seen as an important defining feature leading to claims that professionals have colonized person centered planning and undermined its community roots. But have the circles of support within person centered planning achieved community inclusion where other strategies have failed?

Latest evidence is equivocal suggesting that although PCP can lead to benefits in community involvement, contact with family and friends and choice, it had little impact on social networks and that its benefits varied across different groups and contexts (Robertson et al., 2007). It might be argued that for those who do benefit from PCP in terms of community inclusion that the benefits are about 'lifestyle' changes not to the hard structures of daily life such as housing or employment status for example.

The movement towards choice and self-determination manufacture a glue between the individualization with diversity and consumerism with community engagements. But the foundational relationships that need to withstand the tests of time remain elusive leaving people excluded. Are there then, any further prospects to which inclusive policies and practice might look for the future. This is the focus of the following section.

## The Community in Prospect

The review so far has provided an account in which change has occurred around inclusive education, around day services and supported employment and more fundamentally around housing but that these have not challenged the architecture of exclusion nor its felt experience by people with intellectual disabilities. The majority are still in segregated schools, most, albeit in smaller settings, still live with people they do not choose to live with and a huge majority are not employed and show few signs of becoming so. The modest successes recounted amount largely to 'lifestyle' changes in leisure and friendship patterns.

But even today the community is still as unaccepting of people with intellectual disabilities as it has always been. For example, anti-social behavior orders (ASBOs) empower the community to seek such orders for behaviours people in the community seen to be of threat. And it appears that people with intellectual disabilities are much more likely to have an ASBO applied than others in society (Ramcharan, McClimens and Roberts, 2006) and that acceptance of difference is still unlikely especially where the community is empowered to police itself. And this still leaves open questions of social justice and well-being which are further considered below.

As already argued, equal opportunity cannot be achieved where environments, community and infrastructure are inaccessible or where the level of support is insufficient to allow competition on an equal basis. Talking of those with the most profound disabilities Reinders argues that,

*"Our humanity is an endowment, not an achievement. Therefore the fact that profoundly disabled humans cannot claim achievement because of their absence of purposive agency does not affect their humanity in any way" (Reinders, 2008: p.50).*

In this view there is a necessity for social justice and distributive justice as *outcomes* which recognize society's commitment to producing the good life for all citizens independent of equality of opportunity. The UK has its own Human Rights Act (see Finnegan and Clarke, 2005) and is, together with Australia, signatory to the UN Convention on the Rights of People with Disabilities (CRPD). Under various Articles the CRPD offers significant mechanisms to protect rights as humans, to produce equality under the law, to support participation in the political process and other areas that affect their lives. Rights to freedom of association and movement alongside the right to free speech, freedom of religion and thought are supplemented by a number of economic, social and cultural rights. Some of these

rights that have a relation to community inclusion are outlined in Box 1 below:

*Box 1: Some articles from the UN convention on the rights of people with disabilities*

*Article 19*

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

*Article 27*

States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work

*Article 28*

States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

However, there are detractors some arguing that 'the impact of the Convention on countries that already have disability legislation in place...seems to be minimal' (Lecomte & Mercier, 2009, p.66). The potential of human rights frameworks and the application of a human rights-based approach to the fulfillment of rights in everyday life is yet

to be fully-tested but other arguing from a more fundamental position suggest:

*"By raising issues of equal rights and social justice advocacy movements have successfully altered the course of public policy...But it is important to realise that these have been in the domain of citizenship and have left unaffected the domain of personal intimacy'...Apart from the institutional barriers that can be removed by public policy, there are cultural barriers that are entrenched in people's hearts and minds. This is the reason why we need to think beyond rights and justice" (Reinders, 2008: p. 6).*

So if human rights are insufficient what other possibilities are in prospect? One approach relates to 'capabilities' (Nussbaum, 2000; 2006) based upon the observation that unequal political and social circumstances create inequality for the poor, for women and for people with disabilities. This leads not to proposals for the need for equality of outcome, goods and services but instead to i) a metric for distributive justice and ii) a framework for measuring well-being. In the metric for distributive places a responsibility on the state to ensure that material and institutional resources are provided to support well-being as defined by the *capability* of life, health, bodily integrity, imagination and thought, emotions, practical reason, affiliation, regard for other species, play and control over one's own environment (Nussbaum, 2007). It is in fulfilling such life needs to the maximum possible that, for Nussbaum, the good life is experienced. So the capability approach does not anchor outcomes against externally set objectives of state or state policy but against personal capabilities themselves. This approach would solve, for example, some of the issues around whether employment should be a stated policy and outcome for *all* people with disabilities. The approach means it is possible to commit resources independent of any personal *achievement*. The problem, however, is whether it will ever be politically expedient to commit resources in this way and whether communities can accept and live with such diversity. Table 2 outlines some of the key values that have supported inclusion and the relevant support structures and outcomes.

The capabilities approach takes us away from the implicit reliance on equality of opportunity which produces inequality, whilst at the same time distancing itself from the communist and socialist policies of equality which have proved so unpalatable for liberal government in the developed world. In providing an alternative philosophy and a mechanism for how to calculate how the good life can best be accomplished along with a level of support required to achieve self

determination it provides a way of calculating what exactly the State owes its citizens, all of them, in supporting them to have *better lives*. And maybe it is better lives rather than inclusion that we should indeed be pursuing. Capability, then, may have the potential to replace a fifty

year history in which the promise of graduation to an included life has been dashed on the rocks of service dominated models and of a graduation model, which mimics life but which is not really for real.

**Table 2 – Values that support community inclusion, their focus, support structure and outcomes.**

Value supporting community inclusion	Focus	Support structure	Nature of outcome	Problems and Issues
Normalization/ SRV	Change person – replicate what is valued by society	Institutional closure culturally valued analogue services	Valued means to valued ends leads to valued people; supported deinstitutionalisation	Change the person not community; what is valued?; Community treatment not care
Ordinary lives	Housing, education, work, leisure	Facilitating access and providing support for lives in mainstream	An ‘opportunity structure’ supporting everyday relationships, social networks common to the community	Outcomes limited when set against the ideal of inclusion; many options remained segregated and not community-based; assumption of graduation; inequality of equality of opportunity
Autonomy and choice	Individual’s hopes, dreams, aspirations	Person centred planning, family circles of support, social networks and professionals	Trust, love, reciprocity, a life defined by non-negotiables	Evidence from PCP equivocal; lifestyle’ change not inclusion; suits those with ‘lower support needs disabilities’
Diversity	Recognising worth, acceptance of difference, positive regard	Simply ‘being there’ and supporting the community to change its attitudes by confronting it with presence and participation	Heterogeneity; border-crossing to included identity,	Community attitudes are often negative and recalcitrant to change; rights and inclusion not assured nor protected
Community development and social capital	Bridging, bonding, accessing, funding initiatives for inclusion	Community initiatives tie people into communities in sustainable way: Fading out	Community ‘care’, ‘support’ and ‘belonging’; communities of interest;	Costly; Yet to be fully tested; finding a system of exchange that does not disadvantage
Human rights	Protecting and fulfilling rights	Human rights-based approach	Equality with citizens around civil, political, economic, social and cultural rights	Limited evidence for human rights based approach to changing everyday lives and culture; Rights cannot legislate relationships but can build a supportive structure and address infringements
Human capabilities	Supporting the acquisition of resources to maximise capabilities and potential	Focus on self actualisation and fulfillment of well-being	Distributive justice and well-being as a human	Yet to be tested; political will given unknown funding implications; a charter for those who see disability as limitation

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## **Social Inclusion of People with More Severe Intellectual Disability Relocated to the Community between 1999-2009: Problems of Dedifferentiated Policy?**

*Christine Bigby & Tim Clement*

Changing interpretations of intellectual disability and resultant social policies were evident during the twentieth century. Bradley (1994), for example suggested a three stage paradigm shift occurred between the late 1960s and 1990s, which reconceptualised the rationale for policy and practice in this field. She suggested the medical model of understanding intellectual disability characterised by institutionalisation, dependence and segregation was replaced in the mid 1970s with the developmental model and an era of deinstitutionalisation. This period until the mid 1990s, which saw the creation of group homes and other specialised services, furthered the physical integration into the community of people with intellectual disabilities. In Victoria for instance, the development of large institutions was halted (Victorian Committee on Mental Retardation) and St Nicholas Hospital and other institutions were closed. Between 1976 to 2000 the institutional population of people with intellectual disability fell from 4,439 to 873 whilst the group home program expanded from zero in 1976 to 1050 in 1996 (Forbes, 1999). Research on the outcomes of institutional closure and relocation of people with intellectual disabilities to the community during this period, both in Australia and overseas, demonstrated the advantages of small group living in terms of increased quality of life and improvement across a range of lifestyle and adaptive behavioural domains (Kim, Larson & Lakin, 2001; Emerson & Hatton, 1996; Young, Sigafos, Suttie & Ashman, 1998). Positive outcomes were demonstrated for people with severe and complex intellectual disabilities as well as those with a mild intellectual disability. The trends are well summarised by Emerson and Hatton who state;

*“the move from more to less institutional environments is associated with improvements in material standards of living, increased user satisfaction, increases in adaptive behaviours, increased participation in community based activities and increased contact with family and friends... However, the literature also indicates that such gains are far from inevitable consequences of the move to the community. On all measures of outcome the variation within community*

*based services was substantial. This suggests that for a significant minority of people, life in “the community” would appear to be relatively indistinguishable, on these measures of outcome at least, from life in hospital” (1996, p.30)*

Consistently research also found that although people with intellectual disabilities participated in more activities in local communities they remained socially disconnected from other community members and continued to experience social networks that often did not include friends or acquaintances without intellectual disability (Barber, 1994; Cambridge et al., 2002; Cummins & Dunt, 1990; Cummins, Polzin, & Theobald, 1990; Lord & Pedlar, 1991; Robertson et al., 2001). The suggestion by Todd et al., (1990) that people with intellectual disabilities lived in ‘a distinct social space’ captured their small and highly restricted social networks that generally comprised other people with intellectual disability, close family members and paid staff. Such findings supported the view that if deinstitutionalisation was to be successful it required more than institutional closure and specialist services such as group homes and sheltered workshops. Gallant for example suggested, “the success or failure of deinstitutionalisation will rest with our ability, collectively to prepare our communities to accept persons with intellectual disabilities as valued and contributing members of society” (Gallant, 1994, p. 33).

Bradley saw the third stage of the paradigm shift as one of ‘community membership,’ and suggested it was still emerging when she wrote in 1994. It was marked by “an emphasis on functional supports to enhance inclusion and quality of life as defined by physical as well as social integration” (p.13). As the shift to a dominant paradigm of community membership for people with intellectual disabilities continued to evolve, the emphasis on both social inclusion and human rights strengthened (see for example, United Nations Convention on the Rights of Persons with Disabilities, 2008, <http://www.un.org/disabilities/>; Department of Health, 2001; 2009, Department of Human Services, 2002). Significantly, this trend has paralleled broad social policy directions. For example, Gleeson (2004) suggested Australian social and urban policies in the 1990s were characterised by ‘the new social yearning; the desire for a secure place in social networks based on reciprocity, trust and mutual respect’. The Bracks government that came to power in 2000 in Victoria emphasised community development designed to combat social exclusion and create greater community cohesion (Victorian Government, 2001; 2005).

Social models of disability were influential in shaping the changes to disability policy and

new strategies to achieve social inclusion, by reconceptualising the nature of disability from a focus on individual impairment to the interaction between impairment and social processes; "It is not physical, cognitive or sensory impairments that cause disability, but rather the way in which societies fail to accommodate natural aspects of difference between people" (Priestley, 2003, p. 13). Disability was conceptualized as the collective experience of people with impairments, created by society, and as a form of oppression, similar to racism and sexism. This theoretical base has underpinned policy developments during the 1990s and 2000's. Arguing that actions to achieve change should be directed at social arrangements rather than the individual, social models of disability successfully expanded the foci of policy beyond specialist to mainstream services, and to the political economy, built environment, institutional practices, and culture of society. Nevertheless, as well as the removal of disabling barriers, both the social model of disability and new policy directions acknowledged the need for individual support, but adopted a human rights perspective to inform its provision. Barnes suggested for example, it is "a way of demonstrating that everyone, even someone who has no movement or sensory function... has the right to a certain standard of living and to be treated with respect" (Barnes, Mercer, & Shakespeare, 1999, p. 31).

During the period of Bradley's paradigm shift, neo-liberal ideology and public choice theory gained dominance, driving significant reform in welfare systems and the adoption of market models as service delivery mechanisms (Baldock & Evers, 1991). Such reforms though originating from a different value position align closely with the shifting paradigm of disability. As a result in disability and other sectors, human services have become more focussed on the individualised delivery of support that fosters independence and the explicit utilisation of informal relationships with family, friends, and community members as sources of support, through, for example, person-centred planning and circles of support (Bigby & Ozanne, 2001).

By the beginning of the twenty-first century, the a key aspect of the 'problem' of intellectual disability was that of social exclusion, the failure to be included as active participants in the social and economic life of the community. Policy proclaimed that as citizens, irrespective of their degree of impairment or appearance, people with intellectual disabilities along with those with other types of impairment had a right to be part of the community and the support necessary for participation. For example, the vision of the Victorian State Disability was. "If you have a disability in 2012 you will be as much a part

of things as anyone else. As a citizen, you will choose the role you play in society alongside other citizens. Your rights and dignity will be respected and upheld by people around you" (Department of Human Services, 2002, p. 7).

There are potential tensions however between the community membership paradigm and the social model of disability which both suggest a collective approach to dismantling social barriers and the strong thrusts towards individualised support that emanated from neo liberal individualism, welfare reform and a rights perspective. Increasingly, the allocation and provision of support is based on determination of individual need rather than membership of a particular category of impairment. An outcome of the tension between collective approaches and individualism has been what the Scandinavians termed the 'dedifferentiation' of policy: the dismantling of arrangements for specific groups of vulnerable people and formulation of policies and programs that focus on the community in general or all people with disabilities rather than just specific groups (Sandvin & Soder, 1996). This has meant in policy and program terms that people with intellectual disability as a group have become less visible, and are regarded instead as 'individuals', 'citizens' or 'people with disabilities'. Such a shift was evident in Victorian disability policy during the 1990s, as the Commonwealth State and Territory Agreements dating from 1992 took a dedifferentiated approach, the major planning exercises, such as State Plans shifted focus from people with intellectual disability to all people with a disability, government administration reorganised to have an all of disability focus, and specific legislation for people with intellectual disability was replaced by a more generic disability legislation.

Since the early 1990's disability policy in Victoria has been dedifferentiated; applicable to all people with disabilities which necessitates its pitch at a high level of generality. Increasingly too funded programs and other implementation strategies are also dedifferentiated with few targeted at particular groups (though the exceptions are beginning to emerge, such as development of specific plans for people with brain injury and autism). Two key policy goals are pursuit of individual lifestyles and building inclusive communities (DHS, 2002). Although notions of social inclusion and participation lie at the heart of policy, neither their meaning nor specific indicators are explicit in policy documents. Expected outcomes are vague and unspecific, such as 'to strengthen the Victorian community so that it is more welcoming and accessible, so that people with a disability can fully and equally participate in the life of the Victorian community (DHS, 2002) or advance the inclusion and participation in the

community of persons with a disability (Disability Act, 2006). Sub-goals for specific groups have not been developed and it is hard to glean from policy or program documents a sense of what being included in the community means for someone with a more severe intellectual disability. This reflects a similar lack of clarity about the meaning of social inclusion evident in the broader social policy arena. For example, in his introduction to the Social Inclusion Board Report on Indicators of Inclusion (2009, p vii) Vinson suggests the power of terms such as inclusion and exclusion come not from 'analytical clarity, which is conspicuously lacking, but from their flexibility'. The proper question he suggests should be 'what we mean by it'. Seldom however is this question posed or answered in disability policy documents.

A 'whole of government' approach also characterises dedifferentiated disability policy in the new paradigm, stemming from the need for collective responses to dismantle barriers and adopt strategies in addition to the provision of disability services. This approach relies on all government departments, associated quasi government and non government organisations playing a role in effecting change to social structures and processes (Commonwealth of Australia, 2009).

### **Institutional Closure in a New Paradigm**

This brief review of the nature of disability policy provides the context in which Kew Residential Services (KRS) was downsized in 1999 and finally closed in 2008. It was a very different context from the earlier downsizing and institutional closures that had occurred in Victoria during the 1980s. These had been part of less ambitious and less multi-faceted intellectual disability policy, which had not been embedded in broader social policies with similar goals of social inclusion. This paper discusses the findings from two separate studies conducted since 1999 that have explored the social inclusion of residents with more severe intellectual disability who have moved out of KRS. The studies were both mixed methods and had very similar findings with significant triangulation between the qualitative and quantitative data. Although some of the data from both studies is published in separate papers and reports (Bigby, 2008; Bigby et al., 2009; Clement & Bigby, 2008a, 2009) the aim of this paper is to bring together succinctly in one place the data relating to social inclusion, to consider tentative explanations for the low levels of resident social inclusion found and the implications for future policy formulation and implementation.

### *Elements of Social Inclusion*

Following O'Brien (1987), but also reflecting more recent conceptualisations which list the

nature of an individual's social relationships as an indicator of social inclusion, two distinct elements of social inclusion were defined (Australian Social Inclusion Board, 2009). The first was 'community presence', the sharing of ordinary places that define community life. The frequency that people left their home and the nature and type of activities undertaken outside the home were used as the indicators of community presence. The second dimension is 'community participation', which O'Brien (1987) defines as the experience of being part of a growing network of personal relationships that includes people other than other clients, paid staff and immediate family. The nature of personal social networks such as size, relationships, and frequency of contact were used as indicators of community participation.

## **Methods**

### **Study 1.**

The first study was conducted between 1999- 2004, and had as its focus the group of 55 residents of KRS who moved to small group homes managed by non government organisations during 1999/2000. Twenty seven randomly selected residents who were relocated to 9 separate group homes participated in the study. Three residents died during the course of the study, which means the complete data set is reported for 24 residents. All residents had been labelled as having an intellectual disability, and had been assessed before they left the institution as having moderate or severe intellectual disability. Their ages ranged from 39-68 years.

### *Data collection*

Four waves of data were collected, the first while residents were still living at KRS, and then 1, 3 and 5 years after they moved. At each wave, a structured interview lasting approximately 2 hours was conducted with the unit or house supervisor. The interview schedule consisted of a range of open-ended questions, standardised outcome measures, and global rating scales on the following domains: living situation, general health and well-being, personal development, community integration, and interpersonal relationships. Questions were asked about the resident's formal and informal social networks, including the relationship of each identified person to the resident, as well as frequency, location, and nature of the contact. These questions allowed a social network analysis to be conducted for each resident, based on the technique suggested by Tracey and Whittaker (1990). Anyone who was perceived to be a friend by either the person or the key informant, who lived outside the person's household, and was not paid to have contact with them and was in contact at least once a year was included in a person's

informal social network. Both phone and face-to-face interactions were categorised as contact. Family members of 20 residents participated in a telephone survey conducted 1, 3 and 5 years after the residents were relocated to the community. This survey sought information including family satisfaction with the move to the community, as well as patterns of family contact and interaction with the resident before and after the move.

A series of in-depth qualitative case studies was undertaken with a purposive sub-sample of 11 residents from four houses. Each resident was visited at least twice while still living in the institution, and then at 4-monthly intervals for the first 12 months after the move, and then after 3 years in the community, at similar intervals for the following 2 years. During these visits, the researchers were participant observers and used a checklist of elements to be observed as a guide both to conducting the visits and to writing field notes. This checklist included items such as: personal appearance, resident's use of space, social interactions with staff and other residents, community participation/integration, personal autonomy/decision-making, and social networks.

### *Analysis*

The quantitative data were analysed using descriptive and non-parametric statistics with SPSS (SPSS Inc., 2005). The qualitative data were analysed thematically, with the assistance of the "code", "search", and "retrieve" functions of NVivo software (Qualitative Solutions and Research, 2007). Data about each resident's network were categorised on the basis of composition, frequency of contact, and function.

### *Study 2.*

Residents relocated to group homes as part of the closure of KRS between 2004-2008 were the focus of the second study. The study had two main components. The first was an in-depth ethnographic and action research component conducted with the 26 residents and the staff groups of 5 newly opened group homes. Houses were purposively selected in an attempt to gain a cross section of relocated residents. The second component of this study was a large survey to gauge the outcomes for 100 residents and views of their house supervisors about inclusion one year after they moved from the institution. A stratified random sample of KRS residents was selected on the basis of those who would move to dispersed group homes in the community (offsite) and those who would move to group homes on the redeveloped KRS site (on site). As 4 residents died within a year of leaving KRS the complete data set is only available for 96 residents.

No formal testing of residents was conducted but updated assessments undertaken before they left the institution indicated that 20 of the 26 residents in the ethnographic study and 60% of the residents in the quantitative study had severe or profound intellectual. The age range of residents in the ethnographic study was from 34 – 64 years and in the quantitative study residents ages ranged from 34 – 71 years.

### *Data collection*

The overarching focus of the ethnographic study was resident participation and inclusion in the community and in their daily lives. Data were collected primarily through participant observation by working shifts alongside staff. In addition the researchers attended some staff training sessions before the houses were opened and house staff meetings. In three of the five houses staff also participated in a half-day sessions, where simple ethnographic descriptions of day-to-day life in the houses were discussed. These contained little of the researchers' interpretations as the aim was to facilitate discussion with the respective staff teams as a way into cycles of action research. Two hundred and sixteen hours of participant observation were undertaken by three researchers, ranging across the five houses from 36 to 59 hours. In addition eight interviews were conducted with staff and four with family members. A total of 159,196 words of field notes were written. Following the period of participant observation action research projects were conducted in three of the five houses and field notes compiled of these projects.

Two waves of data were collected for the quantitative study, the first prior to the residents leaving KRS and the second a year after they moved. A structured interview with the unit manager or house supervisor for each resident was used to complete a survey that consisted of a range of open-ended questions, standardised outcome measures, and global rating scales. Similar instruments and domains were used to those that had been employed in study 1. In addition, at the second wave of data collection an open-ended survey with 13 questions sought the views of house supervisors about the nature of social inclusion and participation for each resident in the study and the particular obstacles encountered in achieving these outcomes.

### *Analysis*

All field notes were shared and the research team met regularly to reflect on the data and discuss emerging propositions and interpretations. During this early analysis discussion focussed on questions such as, how was it that the opportunities

that existed for residents to enjoy a good lifestyle in small housing were not being fully exploited? How were the low levels of participation and choice to be accounted for? How could the negative attitudes towards the goal of building inclusive communities be explained? This led to further discussion about the attitudes held by staff that appeared to inform their practice and eventually to the proposition that some staff did not appear to believe it was feasible to implement the policy visions of choice, inclusion and participation for the people with whom they worked,

The data was further analysed with the above proposition in mind. A 'start-list' of codes was developed prior to systematically analysing the data (Miles & Huberman, 1994). McGuires' (1985) conceptualisation that attitudes comprise affective, behavioural and cognitive components was used to guide the code development and analysis. The language used by staff about residents and policy goals, their comments about residents and their work, and their behaviour towards residents were considered. The data was reread looking for all examples that illustrated both positive and negative staff attitudes towards goals of choice, inclusion, and participation, which were then grouped into sub-themes (Denzin & Lincoln, 2000). The coding, search and retrieval functions of NVivo (Qualitative Solutions and Research, 2007) were used to assist the analysis and manage the large volume of data.

The quantitative data were analysed using descriptive and non-parametric statistics with SPSS (SPSS Inc., 2005). Content analysis was used to categorise and then code the open-ended data from the survey of house supervisors.

In both studies consent was given on behalf of all the residents with intellectual disability, either by their formally appointed guardian (if one existed) or otherwise by their next of kin. Both projects received ethical approval from the DHS and La Trobe University's Ethics Committees.

## Findings and Discussion

### *Community Presence*

Survey data from both studies showed an increase in resident activity in the community. In study one the mean number of times residents went out into the community almost doubled from 4.74 to 8.37 times a week and in study two, the mean number of times increased from 7.3 to 9.70 which was a statistically significant increase. The qualitative data in study one showed that in 5 of the 11 case study houses notably those with residents with more severe intellectual disability outings were predominantly group-based. Similarly, the qualitative data from study two showed a pattern of group outings for residents. For example, over

a period of a month one resident, Brian went out 3 times alone with a staff member, twice with another resident, and the other 4 times with 2 or more other residents in addition to staff members. The qualitative data from both studies suggests that most outings take the form of activities to relatively anonymous public places, such as shopping centres, parks or other bus trip destinations. For example, in a month Brian went once to the hairdresser, bowling, swimming, the museum and on a train ride, and shopping 4 times. The nature of these community-based activities were generally unlikely to lead to the formation of new friendships or even acquaintances with other community members. Nevertheless it was clear that people went out more often, in smaller groups, to a greater variety of places than they had done when they lived in the institution.

### *Community Participation*

Minimal changes occurred to residents' social networks during the 5 years for study one and one year for study two since they had left the institution. In both studies there was a slight reduction in informal social network size, from means of 1.92 and 1.75 people to 1.83 and 1.15 respectively. In study one there was a drop in the number of residents in contact with family members whilst in both studies the average number of family in touch with each resident declined. In study one 50% of residents had no one regarded as a friend other than staff, 25% had a friend outside the house, and 13% (3) had a friend without intellectual disability. Such detailed data is not yet available for study two but the initial analysis shows that no new friends or acquaintances were reported for residents after the first twelve months in the community.

### *Understanding Outcomes*

#### *Unclear and doubtful staff expectations*

As already discussed the key policy documents that guided practice in group homes were fairly vague and unspecific about the expected nature of social inclusion for people with intellectual disability. This was not clarified at the several sessions of staff training observed as part of study 2 or in any more detailed documents available to staff such as the practice manual (DHS, 2007). As a result staff did not receive strong clear messages about the meaning of social inclusion for the residents they worked with nor were they given indicators with which to measure success. Not surprisingly there was little consistency in the way staff and house supervisors in the five houses involved in the qualitative component of study two understood social inclusion. They found it hard to differentiate between community

presence and participation, and used these terms interchangeably. Most commonly, their interpretation of inclusion referred to residents' capacity to conform to social norms, visit public facilities, use commercial outlets such as shops and restaurants, or participate in social groups established for people with disabilities that operated from a base in local communities.

The indication from this qualitative data that some staff conceptualised social inclusion as social activity and presence in the community was mirrored in the majority of responses by the house supervisors of the 96 residents who participated in the open ended survey in study two. Overwhelmingly, this survey showed supervisors did not perceive community inclusion to be about new relationships, maintaining or developing residents' social networks to include non disabled community members. Staff understanding of social inclusion aligned with the type of activities they supported residents to undertake, such as shopping and other trips into the community, and goes some way towards explaining the low proportion of activities (less than 20%), such as regular attendance at a community group or activity associated with a person's interest which might have led to new acquaintances or friendships.

When staff were confronted with more explicit definitions of community participation in the action research projects in study two, it was apparent that some were sceptical about its feasibility for the residents with whom they worked. Some staff saw their residents with severe and profound intellectual disability as 'too different' from the rest of the community to either form relationships with other community members or for these to be meaningful. Though some staff thought a policy objective such as community participation might be a good idea in general, their view was it would not work for the men they worked with. This perception was not confined to direct care staff but sometimes also shared by supervisors and the few family members involved in the study. A separate survey of 144 staff confirmed the hypothesis that emerged from the qualitative data, that whilst staff accepted community participation in principle, they did not see it as feasible for people with more severe intellectual disability (Bigby, et al., 2009).

The lack of clarity about the nature of inclusion and outcomes sought for residents and the scepticism of some staff about possibilities for community participation helps to explain too why some house supervisors and staff did not regard it as a priority and why personal care and household tasks were often given precedence over other types of activities.

### *Organisational issues and public attitudes*

A cultural analysis of elements of the organisation that managed the houses in study two suggested that not only was there no consensus among staff about the mission of community inclusion but some elements obstructed rather than supported staff practices that would support community participation (Clement & Bigby, 2008a, 2008b). An obvious example was the provision to all houses of large multi-seater buses, that some staff found difficult to park, and implicitly endorsed group-outings and sometimes led to ease of parking rather than more resident-related issues dominating choices about activities. It was evident too, that the organisation did not have a strong culture of supervising or monitoring staff day-to-day practices, and had few mechanisms in place to enforce its policies about supervision of front line staff. This was compounded by rostering practices that meant house supervisors did not regularly work alongside all staff, which led to an absence of opportunities for house supervisors to exercise the various guises of practice leadership (Clement & Bigby, 2007). For much of the time front-line staff were left to implement their own understanding of inclusion in their day-to-day practice, without, coaching, role modelling, monitoring or active supervision.

Staff in the 5 houses in the qualitative part of study two identified significant obstacles to social participation in the external environment, most notably negative public attitudes towards people with intellectual disability. They talked about people staring or moving away from residents in public places, and the need to educate the general public about people with intellectual disability. These views were not reflected by the respondents in the open-ended survey, although this may have been due to the absence of an explicit definition of community participation for staff to comment on. Respondents to questions in the open-ended survey about difficulties of supporting inclusion or participation referred most commonly to the characteristics of residents and insufficiently of staff resources to provide one-to-one support.

### *Possible Problems Stemming from Dedifferentiated Policy*

Despite relocation to the community occurring within a policy context with a much stronger emphasis on social inclusion, the outcomes for people with more severe intellectual disability in these studies are very similar to those found in previous decades when relocation occurred within a much narrower policy paradigm of 'deinstitutionalisation' – people with intellectual disability continue to be present in local communities but not participating members.

These findings raise questions about the nature and effectiveness of the current policy. The dedifferentiated disability policy found in Victoria lacks clearly specified indicators of outcomes for broad aims such as inclusion. It relies on dispersed staff to deliver individualised support, in for example in group home programs, and multiple communities or organisations to become more inclusive. This type of policy does not measure well against the conditions that policy implementation theories suggest are necessary for effective implementation, which include clarity, minimal ambiguity, jurisdiction to achieve goals, simple workable models, involvement of limited 'players' and a clear chain of accountability (Bridgeman & Davis, 2001; Sabatier & Mazmanian 1979).

For example Lipsky's (1980) work on policy implementation illustrated the potential for ambiguous policies to be diverted from original intentions through reinterpretation by street level bureaucrats; "the routines they [street level bureaucrats] establish and the devices they invent to cope with uncertainties and work pressures, effectively become the public policies they carry out". This resonates with the findings of our studies, where in the absence of clear guidance from policy or supervisors many staff construct their own interpretation of social inclusion or decide its feasibility selectively, which clearly influences outcomes both sought and achieved for residents. Front-line staff working in organisations without effective supervisory structure left free to impose their own (mis) interpretations and priorities are shaping the policy aim of inclusion for residents to be one of community presence rather than both presence and participation. Whilst our findings provide evidence of this occurring in group homes, the absence of policy guidance about inclusion for specific groups indicates the potential for policy intention to be undermined in other program areas such as day support.

The nature of social participation, the support required to foster it, and the obstacles likely to be encountered differ not only with an individual's social circumstances and characteristics but more generally by severity and type of impairment. For some people with a disability, community presence, achieved through provision of equipment, accessible transport or buildings may be sufficient to create self-directed opportunities to pursue interests and interactions that lead to community participation. For others, particularly those with more severe intellectual disability who will always require paid or informal support to take advantage of opportunities for social interaction, more intensive strategies that stretch far beyond access or presence may be needed if they are to achieve community participation. This

suggests a need for dedifferentiated disability policy to be supported by strong mid-level policies or guidance about the nature of social inclusion and its applicability to each of the diverse sub-groups who now fall under the umbrella people with disabilities. Differentiated implementation strategies are more able to take account of the differing pathways and support that may be required to achieve community participation, and reinforce participation as an aim that is equally applicable to all people with disabilities, not just those who are more able.

At the more micro-level of policy implementation through group home programs, our findings highlight the need for significant work to achieve greater organisational coherence, translation of broad policy aims into much clearer guidance for staff backed up by much stronger front-line management. How this might occur is discussed in detail elsewhere (Clement & Bigby, 2008a, 2009). These findings also raise questions about the breadth of expectations placed on group home programs, the consequent multiple roles to be played by staff and diverse skill sets thus required. Almost sole responsibility lies with house staff to: provide day-to-day personal care, monitor health, administer finances, manage the household, assess, formulate and implement short and long-term plans around issues such as skill development, pursuit of interests, community presence and participation, domestic participation, and longer term issues such as retirement, provide support and nurture relationships between residents and families, support residents to exercise choice and protect their human rights. House staff are expected to be housekeepers, attendant carers, case managers, social workers, advocates and community developers. All these are complex roles and at times contradictory. Yet most staff have no tertiary qualifications. Where demands on staff time exceed resources and tensions exist between different roles, staff attention is most likely to be held by those tasks they feel most comfortable with or that are most immediately obvious if left undone and will pose most risk in the short term – attendant care, household management and supporting community presence.

The question is then how can importance and time be accorded to community participation for residents of group homes, who are increasingly likely to be those with more severe intellectual disability, even if a greater consensus is reached about its meaning and applicability. It seems that the group home program is regarded as the sole strategy to implement community participation for residents rather than being one of multiple strategies as envisaged by the new policy paradigm. Perhaps, in line with the multifaceted community membership paradigm additional

strategies to compliment group home programs should be devised to develop participation for residents. These may be the type of small scale local programs or voluntary parent run initiatives discussed below that are found both in Australia and overseas that have as their sole mandate the creation of social relationships for people with intellectual disabilities who require significant support. Currently however, such programs seldom include residents in group homes or those without strong family advocacy support.

Our findings provide some indication of the likelihood that like staff, some community members are sceptical about possibilities of social participation for people with more severe intellectual disabilities. Strategies such as community development or education are not individualised, and primarily work at the meso level, with organisations, communities and local institutions. There was no evidence in our studies of the impact of these broader policy implementation strategies, such as the metro access program or the work of the Office of Disability, that seek to change social structures or processes and make local communities more inclusive for people with disabilities among whom are the residents of group homes. It may be that the dedifferentiated nature of policy and the absence of clarity about specific outcomes is hampering the effective implementation of this type of social change strategy at the local level. For example, Ryan (1999) suggests that where, as is the case in Victoria, reliance is placed on partnerships with other organisations such as local government or clubs and sporting associations to implement policy, the focus should be on ways to measure and monitor outcomes, i.e. what actually happens for people, rather than specifying inputs or processes by which these will be achieved. Similarly, Roger's (1995) diffusion of innovation theory suggests the importance of policy having 'observability' – a clearly expected or measureable outcomes to be achieved. As already discussed this is not the case for disability policy in Victoria.

The as yet unpublished doctoral work of Fiona Reidy (2009) suggests that local governments, one of the key partners in broader community development strategies have struggled with the generic nature of disability policy aims, finding these difficult to operationalise and thus to implement strategies at the local level. There are other indications that broader dedifferentiated strategies about social inclusion have had little impact on people with intellectual disability. For example, Disability Action Plans now required under both State and Federal legislation have been criticised as being vague and generic based on stereotypical views of people with disabilities using wheel-chairs (Goggin & Newell, 2005),

people with intellectual disability were not found to have the same clear benefits from disability discrimination legislation as people with physical and sensory disability (Productivity Commission 2004) and very few people with intellectual disability are included on national, state or local advisory committees and when they are, are poorly supported (Frawley, 2008).

There is no reason why more finely grained differentiated approaches, directed at specific groups should not be used to effect broader social change under the umbrella of dedifferentiated policy. More targeted strategies, such as community education with the aim of equipping community members with ideas about interacting with people with intellectual disability, or the establishment of community development targets, such as each local community organisation having at least one member with an intellectual disability may be both easier to implement and more successful than broad dedifferentiated strategies that target all people with disabilities. It is remarkable however, that the Victorian Office of Disability, which is responsible for implementing broader community development and whole of government initiatives does not see a place for more targeted or differentiated strategies for different groups of people with disabilities (personal communication). Tensions about differentiation of strategies and clearer specification of goal or sub- goal need to be identified and debated if policy is to have an impact on people with more severe intellectual disabilities. Questions need to be asked about all proposed implementation strategies, such as, how will it improve participation for people with intellectual disability? Does it take account of the obstacles they may encounter? and if not how can it be made to do so?

Finally these findings about the apparent continuing failure to achieve community participation for people with more severe intellectual disability raises the question, posed by one of the senior DHS staff during the course of study two. 'Is it feasible for inclusion to be more than community presence for people with more severe intellectual disability?' We would argue it is. Support for this position is demonstrated by the case studies found in the academic and grey literature which recount successful examples of relationships being developed between ordinary community members and people with severe intellectual disabilities (Taylor & Bodgan, 1989; Taylor, Bogdan & Lutfuyya, 1995; O'Brien, & O'Brien, 2002; Planned Individual Networks; Wightman, 2009).

Such case studies illustrate the work of programs which whilst centred on an individual also involve community organisations and other community members. One approach is deliberate network

building, illustrated by the work of Planned Lifetime Advocacy Network [PLAN] ([www.plan.ca](http://www.plan.ca)) in Canada, whose work has informed Planned Individual Networks [PIN] ([www.pin.org.au](http://www.pin.org.au)) in Australia. These are parent run organizations that support the development of a 'personal network' around an individual with a disability. They aim to build a web of relationships, not only between each member and the focus adult but also between members, thus developing the network's collective identity and strength. Individuals are deliberately and carefully recruited and cultivated to form a relationship with the adult. A paid facilitator oversees a three stage establishment process – exploration, development and maintenance. The facilitator is a person who has knowledge and connections with the local community and compatibility with the person with a disability and their family rather than a human service professional. The first phase involves an exploration of the person, their interests, aspirations, capacities, and seeks out possible connections and contacts in the local community. A plan is made for network development which is implemented in the next phase. Members are recruited by the facilitator, goals, strategies and commitment are made and the network fashioned in the development phase. The final phase is networks maintenance, where the facilitator supports regular meetings; ensuring follow through on commitments and adaptations to change are made. It is estimated that initial network formation takes up to 40 hours of facilitator time over an 8 month period with ongoing support taking about 3 to 4 hours a month. Keys to this type of network development are a vision of what is possible, the willingness to look beyond traditional social service systems and the ability to ask for support and involvement of others.

Other examples of formal programs that support the formation of relationships take as their starting point regular community presence, and are based on the premise that participation in community based activities or acquisition of valued social roles are the means to individual relationships. An example, of this type of approach is the Community Membership Project in Indiana (Harlan-Simmons, Holtz, Todd & Mooney, 2001; Kultgen, Harlan-Simmons, & Todd, 2000). This program uses person-centred planning techniques to build up a picture of the person with a disability, their capacities, interests, aspirations strengths and preferences. A paid 'community builder' gets to know the person in a range of different social contexts at the same time exploring the local community for sites and activities where the person with intellectual disability may play a valued role or contribute to community life. The community builder facilitates the introduction

of the person to activities, and seeks out and support natural supports within them. The degree to which friendships develop depends on attentive listening, strategy, persistent support and sometimes luck. Community builders are risk takers, creative, and flexible with an ability to take an unbounded approach.

Approaches such as this require significant investment of time, intensive in the exploratory stage and less so but often continuing in the long-term. The nature of such programs are very different from employing a one-to-one support worker whose role is often simply to support a person to participate in community activities or accompany them to community facilities such as coffee shops. Descriptions of programs that seek to build and support informal relationships demonstrate the intensive and lengthy processes involved that requires planning, commitment, resources and a positive outlook. Although many such examples are drawn from small scale initiatives often driven by resourceful and committed family members, there are also instances where human service programs, such as the recent Connecting People project conducted by the Foundation for People with Learning Disabilities have successfully built new social relationships and fostered social participation for people with more severe intellectual disabilities (Wightman, 2009). However, building social networks is likely to be a low intensity task that stretches over a considerable period and programs do not easily fit into formal service system requirements like episodes of care. It is notable however, that common features of programs such as these are often a small size and focus on clearly articulated aims.

If the aspirations of current disability policy are going to be realised and more than presence for people with more severe intellectual disability to be achieved, it may be necessary for disability policy to be more differentiated and as Vinson suggests spell out much more clearly what is meant by social inclusion, which will support the implementation of more differentiated and targeted strategies for the very different groups that comprise people with disability.

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# Inclusion in Political and Public Life: The Experiences of People with Intellectual Disability on Government Disability Advisory Bodies in Australia

Patsie Frawley & Christine Bigby

Marshall (1965) conceptualised citizenship in terms of the relationship between community members and the state. Both he and others since have suggested that a key responsibility of citizens is engagement in civic and political life of the state (Wilenski, 1986; Wolfe, 2002). As policy change over the past two decades has recast people with intellectual disability from dependants to citizens, their right to participate in the political life of the community alongside other citizens have been asserted and was identified as one of the components of full and effective participation and inclusion in the community set out by the United Nations Declaration of the Rights of People with Disabilities (2006). More recently the capacity to influence decision makers on issues of community importance has been flagged by the Australian Social Inclusion Board (2009) as an indicator of social inclusion.

In Australia the landmark 1976 report of the Royal Commission into Government Administration was instrumental in forging a greater emphasis on citizen participation in policymaking processes through various consultative mechanisms (Yeatman, 1990). Since then diverse approaches have developed to enable participation which have not always framed participants as citizens. Dalton, Draper, Weeks & Wiseman (1996) for example, suggest individuals have also been cast as stakeholders, consumers, service users or individuals whose mandate to participate in policy making stems from individual, political or community power. Formal 'participation forums' include variously constituted advisory bodies and reference groups established by different levels of government, time limited reference groups or consultation processes constituted around specific issues, regular access to senior policy makers and submission to Senate or other enquiries.

Since Arnstein's 1969 commentary, mechanisms for citizen participation have been extensively critiqued and often regarded as a means to legitimise rather than formulate policy (Arnstein, 1969; Patemen, 1970; Van Til, 1984; Wilenski, 1986). A significant body of literature, which cannot be reviewed here, has consistently raised four themes; issues of tokenism, power within

forums, representativeness of membership and the voices heard, and provision of support for participation. Similar issues have been identified in respect of participation in these forums by people with disabilities (Barnes, Newman & Sullivan, 2007; Richardson, 1983; Wolfe, 2002). However, the inclusion of people with intellectual disability in participation forums is a relatively new phenomenon, as until recently they were exempted from the concepts of citizenship and its associated civic and political participation (Carey, 2003). Rather the view was often held that 'others' including parents, carers, advocates or service providers were better placed to represent them. Concern was expressed not only about their ability to participate, but the credentials as people with an intellectual disability and representativeness of those who did (Beresford & Croft, 1993). This comment from a self advocate sums up the concerns well:

*The initial objection to us taking part was that we hadn't got the skills. Then we got involved and spoke up and they said we were unrepresentative. We hadn't really got learning difficulties. We weren't typical of disabled people. Or they'd say someone put us up to it! They just couldn't believe we can speak for ourselves. (Beresford & Croft, 1993, p. 18)*

In the last decade disability advisory bodies have been a key plank used by Australian governments to canvas the views of people with disabilities and involve them in the processes of policy making. For example, the Commonwealth Disability Strategy (2000) suggested that:

*By involving people with disabilities in consideration of issues which affect them through inclusion on boards, advisory committees and reference groups. This is an efficient and effective way of ensuring that their needs are met at the time that policy is being developed and programs are being planned'.*

In a similar vein, the Disability Act (2006) established the Victorian Disability Advisory Council, as a 'way for people with a disability to have a say in decision making on whole-of-government policy issues' (DHS, 2007). Though now more formally recognized as citizens and the highest users of government funded disability services in Australia, people with intellectual disability are under-represented on disability advisory bodies at all levels of government (Frawley, 2006).

Australian disability advisory bodies are mandated to include all the diverse sub-groups that fall under the rubric of 'people with disabilities', which is very different from the more differentiated approach taken in the UK where bodies are established to seek solely the views of people with intellectual disabilities. This difference heightens

the concerns raised by research that people with intellectual disability in such forums lack of adequate support, have difficulty understanding information and that despite efforts to address tangible barriers, they can still feel disempowered and incompetent to have a say (Grant, 1997; Whittell & Ramcharan, 1998; Simons, 2000; Redley & Weinberg, 2006). For example a study of the Parliament for People with Learning Disabilities in Cambridge, found that, 'though explicitly designed to honor the liberal democratic principles of political voice and participation, it seriously faltered in its efforts to realise the principles in practice (Redley & Weinberg, 2007, p.29). While accessible practices like easy English documents and processes that enabled interjection when they did not understand were useful these were not sufficient to influence the way participants felt about participating. The failure Redley and Weinberg concluded was due mainly to the difficulties people with an intellectual disability faced "in situ" dealing with the interactions of the parliament and their feelings of vulnerability in these environments. Similarly, Colcannon (2005) in a study of participation in service planning forums found neither the structures nor the way they operated gave people with intellectual disabilities any power. He echoed the commonly used phrase in relation to inclusion that people with intellectual disability were present but not participating.

These UK studies specifically about the inclusion of people with intellectual disability in participatory forums suggest a need to address both practical means of supporting participation and the more intangible social and interactional nature of the environment and the dynamic operating therein, so that participants feel confident to participate. No Australia research has either considered the perceptions of people with intellectual disabilities have about their political influence or their experiences in participatory forums alongside others with different types of disability as well as those who are non disabled. This study explored the political orientations that the small number of members with an intellectual disability bring to disability advisory bodies and their experience of participating in order to consider the types of support necessary to support their participation. This paper draws on a much larger unpublished doctoral study completed by the first author (Frawely, 2008

## Method

The study used a qualitative methodology, which takes an interpretive, naturalistic approach to its subject matter. The qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in

terms of the meanings people bring to them. (Denzin & Lincoln, 2000 p.3) This suited the research aim, which was interested in people's experiences of participation and recognised the importance of understanding these from people's own perspectives. It drew on both a case method and ethnographic traditions (Creswell, 1998) The ethnographic tradition which uses in-depth interviews, observation and document analysis, was chosen as it enabled the researcher to be immersed in the micro environment where the experiences were occurring for this group, and to understand the shared meanings of these experiences through prolonged engagement with the research participants (Hammersley & Atkinson, 1995). This particular approach to ethnography is described by Morse and Richards (2002) as a focused ethnographic study. Studies of this nature aim to, "elicit information on a special topic or shared experience...the topic is specific and may be identified before the researcher commences the study" (p. 53). Stake notes, "case study is not a methodological choice, but a choice of what is to be studied" (cited in Denzin & Lincoln, 2000, p. 435). Here, the people with an intellectual disability and the advisory bodies themselves were studied. Creswell (1989) calls this a 'bounded system', a case or cases that are bounded by time and place and can be a program, an event, an activity, or individuals (p.61). The study was conducted between 2005-2008. All the fieldwork was undertaken by the first author, whilst the second author acted as supervisor and peer debriefer.

## Participants

The central participants were the nine people, who in 2005 were the only people with an intellectual disability who were members of disability advisory bodies in Australia at a national state or Victorian local government level. They were members of 6 disability advisory bodies, one national, two state and 3 local government (some bodies had more than one member with intellectual disability). Membership of these bodies is in the public domain and participants were directly invited to participate and gave their own informed consent after being sent information about the study in plain English and meeting with the first author to go through this material in detail. Four were female and the other 5 male and most lived independently. Though they had all used some form of disability support service in the past, only three used services at the time of the study. One person worked full time in disability supported employment and the others worked in a range of jobs including in self advocacy and self employment. In addition, 12 secondary participants were involved in the study. These were people associated with the central

participants' membership of the advisory body, and included support workers, other members or chairpersons and government employees who managed the advisory body secretariats. Table 1 sets out the participant's basic demographic data and the advisory body of which they were a member. All names of participants and advisory bodies have been changed.

**Table 1: Participants**

Central Participants N. 9		Secondary Participants N.12	
Age		Advisory Body (Site)	Position
Hannah	43	Southern – State	Support Worker Advisory body Chair Manager Advisory Body Administration support
Andy	50	Southern – State	As for Hannah
Jana	50	Central – National	Support worker
Karla	40s	Northern – State	Support Worker Chair person Advisory body member
Kieran	40s	Seascape – Local	Social Planner Advisory body member
Martin	21	Hilltown – Local	Disability access worker Chairperson Advisory body member
Phillip	50s	Greentown – Local	Disability access worker
Tyler	20s	Greentown – Local	As for Phillip
Christine	21	Greentown – Local	As for Phillip

### Data Collection

Data collection methods included review of key documents relating to each council such as terms of reference, recent minutes and annual reports where available. Two and in several instances three in depth interviews were conducted with each central participant. Though largely unstructured an 'aide memoire' as suggested by Booth and Booth (1998) was used to provide a framework for

the interviews. Shorter more structured interviews were conducted with secondary participants which sought information about the support they provided to central participants. All interviews were recorded and transcribed. In addition, at three sites non participant observations of between two or three hours were conducted of the proceedings of the council meeting or an associated forum or working group. Detailed field notes were written shortly after these observations. The details are summarised in Table 2.

**Table 2: Summary of Data Collection**

Participants	Method	Number/ duration
Central participants.	In-depth face to face interviews	2 to 3 x 2 hours
Secretariat staff, chairs and other council members	Face to face interviews (individual or shared)	18 x 1 hour at 6 sites
*Support workers	Face to face interviews	3 x 2 hours at 2 sites
Participants at council meetings or other council activities (forums, working groups)	Observation	2 x up to 2 hours at 3 sites

**\*Only three sites employed individual support workers. In one site this support worker supported two people. This same support worker also supported a person in a third site**

### Analysis

The data about each central participant was collated into a chronological narrative about their own previous experience of self advocacy or other forms of participation, their rationale for involvement and experiences of being a member of the advisory body. Included in this narrative too were any comments made by secondary participants about their relationship with the central participants and their view on the nature of their participation. Drawing on the available documents and interview data from central and secondary participants and observations a case study was compiled of each site. This enabled each narrative to be compared to the relevant case study site and a comparison of structures and participation experiences to be undertaken. Finally the case studies and the central participant's narratives were analysed thematically and conceptual categories developed. After several levels of refinement this led to a series of propositions about factors that mediated and supported the participation of participants in the councils.

## Findings and Discussion

### Political Orientation

As table 3 shows the central participants were experienced activists who prior to their appointment to the advisory body had participated in consultations with governments or service providers as self advocates or service users. Although most had previously strong links to the self advocacy movement, they had been appointed to the advisory bodies as individuals on the basis they an intellectual disability with no mandate to report back or consult with any constituency. Their appointments had been by invitation though most thought this was because they were well known as self advocates. Each person brought with them their own distinct political orientation which was reflected in their views about what participation meant for both themselves and other people with an intellectual disability. For all participants, participation in the advisory body was not an end in itself but a means to achieving personal or political ends.

Across the group three distinct orientations were identified, democratic, professional and communitarian. These are summarized in table 4.

**Table 3: Participants Prior Experience of Political and Civic Engagement**

Experience	
Hannah	Self advocacy, reference groups, consultations
Andy	Self advocacy, service boards, consultations
Jana	Self advocacy, reference groups, consultations, self advocacy boards/ committees
Karla	Self advocacy, intellectual disability advisory committee, justice advisory committee, self advocacy board
Kieran	Self advocacy board, disability service client board
Martin	No previous experience
Phillip	Self advocacy board, disability service committee, Government department advisory committee
Tyler	Self advocacy board, disability service committee
Christine	Self advocacy committee

**Table 4: Typology of Orientation to Participation**

Orientation and notion of participation	Goals and Expectations	Reference point for participation	Identity
Democratic Participation as a right	Increased involvement of people with an intellectual disability in participatory opportunities. A role model to other people with an intellectual disability. Educate 'others' that people with an intellectual disability can participate.	Self advocacy Life experience of a range of people with an intellectual disability gained through self advocacy.	Self advocate  Person with an intellectual disability
Professional Participation as a status symbol	Be recognised as a leader with an intellectual disability. Have contact with people in power. Be a spokesperson and to be paid to do this.	Own life experience as a person with an intellectual disability and ability to succeed as an individual.	Questioned application of label of intellectual disability to themselves.
Communitarian Participation as a role for community members	Raise community awareness, change community attitudes, address social and structural barriers to community inclusion	Own life experience and shared experience of disability.	Person with a disability – associated with difficulties with learning

Jana, Karla and Kieran had a similar democratic and rights based orientation which was characterized by a belief that participation was a right and more people with an intellectual disability should be involved in participatory forums. They saw their role as representing and furthering the interests of all people with intellectual disability.

*Give [us] a chance to prove that they are wrong. [We] have got the power. If I can do it then somebody else can do it. Don't shove [us] under the mat [we] are not roots under the tree. People with all disabilities can do it. I've lifted the umbrella open so they can see what people with an intellectual disability can do. Lift the umbrella*

*up so they can see what is there ... Oh this person with a disability has got good thoughts and ideas and brains and opinions ... (Kieran 10/5)*

*I now want to get involved with people with high support needs... you have got to understand people with communication needs. It's about getting the message out. It's very hard when the professionals think they know. I am teaching people about people with an intellectual disability (Karla 02/06)*

*I am heavily involved in advocacy... if they see we can do it then they can just do it too.... (Jana 04/06)*

All three had been young adults when the reform to disability legislation occurred in Australia in the mid 1980's and had witnessed considerable change in the lives of people with intellectual disability as institutions closed. They all continued to have strong connections to the self advocacy group where they had developed their skills and been involved in campaigns around the closure of institutions.

Hanna and Andy, though from a similar generation to Karla, Jana and Kieran, had a very different orientation. They were more focused on being a 'professional' and modeled themselves on the non disabled professionals they worked alongside. They saw their membership as a job and important part of their own self development. Andy for example, equated his appointment on the advisory body with being employed by the State Government. They saw themselves as leaders in the disability policy networks, who as they were now close to power could influence policy as paid spokesman for other people with a disability. They were proud of their success and of being well known, but had severed connections with the self advocacy groups where they had gained their skills, and had began to question the application of the label intellectual disability to themselves. Their orientation could be considered to reflect the principles of normalization and the importance of socially valued roles to self esteem and social acceptance.

*Before I was known nobody wanted Hanna, now that everyone knows that I can do the job everyone wants a piece of me.... It was good just representing myself on the disability advisory body, not an organisation because I didn't have to report back (Hanna 09/05&12/06)*

*Well I guess its not my voice, the people who I am speaking up for.. I am speaking up for the whole lot and I am taking those issues to the Minister, that's right, I am just wanting to sit around the table over coffee or over lunch and have an informal chat.. What can I do for you, what is the problem (Andy 02/06)*

Phillip, Martin, Tyler and Christine, who were all members of local government advisory bodies and with the exception of Phillip much younger than the other participants. They had a communitarian orientation and were interested in bringing about change at the local level, to increase the communities capacity for inclusion of people with disabilities. They saw this could be done by changing attitudes, increasing awareness of disability issues and removing barriers to access. They identified as people with a disability rather than more explicitly as having intellectual disability, though recognized they had some learning difficulties. They drew primarily on their own life experiences of being included in local communities but with the exception of Martin had all been previously involved in self advocacy groups.

*Oh it's going to improve our community..because there is so much stuff around here that needs doing, so we have got to try to improve it, .. In my opinion it is about time we got the community up to line .....That's why I'm involved because I don't want to see the [other people with disabilities] left out if we are not around they are going to be stuffed. Yep trying to get them out in the community (Christine 08/05)*

*Easier access into buildings as well for people in wheel chairs. ..(Martin 09/5)*

These findings suggest that people with intellectual disability like other community members hold different political views which influence what they seek to achieve from participation in civic and political life and the views they will put forward. This demonstrates that it cannot be assumed that there is 'an' intellectual disability perspective that members appointed to this category will bring to advisory bodies. It also suggests perhaps that their selection and appointment should not be solely based on their status as a person with intellectual disability but also as with other members on their political orientation.

## **Experiences of Participation**

### *Rewarding but Hard Work*

Despite their previous experience as activists, who had contributed to consultations and sat on reference groups, participants found their involvement in disability advisory bodies challenging and at times personally confronting. Although for most the work was hard, they found it rewarding both in terms of what they were able to achieve but also from a personal perspective in terms of a chance to travel, meet a range of people and supplement their income.

*I find that what I get out of council is I am teaching people about people with an intellectual*

disability. And I find that people with other disabilities will listen to me. ...I think for the disability council, I think that as a person with an intellectual disability being on this council every person has taken an interest in the issue of people with an intellectual disability, or people with a disability being in institutions or things like that...It's tiring emotionally and physically. (Karla 02/06)

...it is hands on, I don't have to go to [the city], I can come here when I want...And I think if one person sees me on this reference group and thinks, hey, what is he doing there I could do that. That's my niche yes and I am not saying to them deliberately, I want them to see my involvement, I want them to see my reaction and when they have seen how much and why, "Come here you", they will come on board. (Phillip, 09/06)

Over two days, it's full on they are very long days, um the first day, Thursday is from nine to five and the second day if it is in [another city] it is nine to three because people have to catch their flights to get home, but if it is in [another city] it is nine to four... On Thursday night after the meeting we always have a conference dinner... and we always relax but on the Friday I am glad, people are glad to get home, they are very tired [laughs]..It is good, I am learning new things, I am understanding... Would it be bad to say [I like] the money? (Jana 02/06)

Talking about his involvement Andy said,

"Of course ...it's not the money it's the, it's [the] occupation I suppose you would call it". However, he went on to explain that when he was first approached to apply for the position on the advisory body he was not interested because he did not want to go to more "boring" meetings, but when he was approached a second time and advised that he would be paid he accepted.

### Tangible Obstacles

Several people felt ill prepared for their role in terms of their own education or the expectations others held about their membership. Most participants talked about the practical difficulties they encountered that stemmed from the way the advisory bodies conducted business. Issues raised were long meeting, the failure to translate agenda's minutes and other documents into plain English, being adequately briefed on the issues to be discussed at meetings. Andy for example, felt that he was not as well prepared for meetings as the other members noting that he had "no training, no nothing" when he was appointed. Other members talked about their difficulties.

*I am learning and sometimes I do understand what is going on...yeah because I suppose, because the*

*[advisory body] is good because they like to inform people with disabilities what is going on... Some information I do [understand] and some I don't. That is why I take [my support worker] with me and she explains... It is very difficult to get your head around and I feel bored and half the stuff that they talk about goes over the top of my head and even when [Sandy] has a go with me I still have trouble understanding.... Well it would be better [if they were in Plain English] then I could understand what I am reading. ....(Jana 02/06)*

*[Sandra's job was] taking notes for me and putting my notes in Plain English, and that was fine, [she] was good but I never ever got to [have time to] meet with Sandra. It was always like an hour before the meetings so I was rushed, so if I was having a meeting at 10 I would have to meet Sandra at 9 so I never really had that time. Because a lot of people thought that because I have an intellectual disability that [I] couldn't keep everything inside my head for a month ...so [we had to] do it on the day. (Hannah 02/05).*

*In the early stage it wasn't easy because I didn't understand everything on the council and I didn't understand what their goals were and what their philosophy was and what they meant to do and things like that so I found it really hard in the beginning. And then I got to understand it a bit and then it got easier and easier. When I very first started on there and things like that it was very hard for me because I, the things were going too fast and too quick and I didn't understand the big picture very well even though I did have someone to explain it to me....My eyes go like this [crosses eyes] I get so frustrated in the meetings, I have to leave, it's pushing my buttons, the system doesn't know what it's like. This is not about me, it's about people in institutions. (Karla 02/06)*

### Intangible Obstacles and Support

Hannah and Andy talked about more intangible difficulties they encountered in participating in the business of the advisory bodies and felt were dissatisfied with their performance or influence as members. Their feelings were often associated with the way they felt they were perceived by others members or secretariat staff. Hannah for example felt other members did not actively engage her in conversations at meetings, that people spoke over her at meetings and recalled an incident where the Chairperson overlooked her for an invitation to an event. She was serving a second term and contrasted the way she felt regarded within the newly constituted advisory body with its predecessor.

*The new [advisory body] is different because there are parents and people who I thought didn't want me to be there. I just don't get on with the*

Chair and it's like I just feel there are some people [there] now that don't like me and because I am outspoken they don't like that, they want someone who is going to sit there and not be outspoken and I am not one of those people. I am feeling frustrated because I feel I am not being appreciated and they are not using me for the abilities I have got. (Hannah 04/06)

I had trouble from the start. ...She [the secretariat staff] didn't know how to treat a person with a disability so she got me in a little room and she said could you read this bit of paper and I said what's this bit of paper about and she said I just want to check that your reading ability is all right ...I thought it was going to be easy, no sorry, interesting and I thought I might be able to change attitudes of government people and make them look at people with a disability in a different way and it has taken me four years to get people with a disability heard [to] listen to people with a disability. But it hasn't always been smooth sailing because I have had to fight to get heard. Even now I don't get heard. (Hannah 11/05)

Andy, a member of the same body talked about how hard it had been for him to talk at meetings and felt inadequate compared to the others members. One of the reasons for this he said was that the chairperson spoke most of the time but he also blamed himself for not participating well enough:

Oh I think sometimes, oh well, sometimes I don't listen very well ...I am not taking enough interest in what they are talking about. What else?, I am not taking enough time.....Yeah I think they have [more experience] they go to a lot more meetings than I do. ...My knowledge is not as good as other people's; oh I think a lot of people with disabilities haven't got the education, or haven't got the knowledge. Because I haven't been to school... I haven't been to TAFE, I haven't been to uni [sic] to study. (Andy, 09/05)

Both Hannah and Andy were also disillusioned at the degree of power accorded to the advisory body and themselves as members.

Some Ministers are full of promises and some Ministers are there and say we will do this, we will do that, [the Minister] has only been once to a meeting...We don't know what the Minister is going to do. (Andy 02/06)

The problem is you can't always get to the Minister's advisor even on the [advisory body] but it is easier than when you are an outsider. The ...chairperson can meet with the Minister and put up our ideas but people with a disability still get walked over. (Hannah 12/05).

Although all four members of the more formal State and National advisory bodies had problems

understanding information, it was Andy and Hannah as the quotes above illustrate that were most dissatisfied with their participation experience. They did not feel respected by other members and expressed feelings of being less capable and competent than other members. In contrast Jana and Karla felt more able to participate and reflected much more positively about their experiences, as did the members of the more informal local government bodies who talked positively and enthusiastically about their experiences.

I am rapt with what the [advisory body] is doing...Yes, to me I'm going up and down like a kangaroo because I can see something at the end of that little hole. (Phillip 12/05)

Kieran referred to the informal conversations he had with colleagues which made him feel welcomed and included. He felt they listened to him when he was chairing meetings and they supported him when he needed help in the meetings. Jana spoke enthusiastically about her colleagues, recollecting their personal details, and Karla felt well supported by her colleagues, particularly at times when she became emotional in meetings, and she felt that people did respect her.

I just sat and watched then one time they asked who would like to be voted to be chairperson and I put up my hand and said I would like to give it a go. It's a good role; it gives you self-confidence that you can do it... If I can do it then somebody else can do it. Down syndrome people can do it, if someone can't speak they should be on the committee. They might [have to] print a little bit of paper out or have their signs but they can do it. (Kieran, 10/05).

Karla reflected on the way they felt respected, accepted and listened to by other members of the advisory body.

I think every person on council respects me.. every person on that council has treated me as a human being no one has said 'oh we are not working with [Karla] because she is a person with an intellectual disability', or they have never said that people with an intellectual disability should not be on council, never said that and so forth, not since I have been on there. (Karla 02/06)

Kieran and Jana echoed this feeling of respect and the existence of supportive relationships with other members of the advisory body but also alluded to the procedures and ways of operating that encouraged their participation.

Yes, I let them know I have got something to share, and I listen to them yes. There's good communication, there is no one left out sort of. For someone with a disability it works. Someone

is always there for you to help you if you got stuck or something, someone will always be too happy to help you, yeah that is why I am on it for a long time. We talk, if its one thing that might take a bit longer we will plan a meeting for that and we might talk about that one thing on a different night. Then we stick to that and we talk about it. .. I might get a little bit stuck so I get some help from Harry, Oh he's on the [advisory body] Yeah he'll help me if I don't understand something, he'll help me read it out, because he used to be the Chairperson. He sort of knows how it should go. Meetings are pretty all right but sometimes if I get stuck he helps me. (Kieran 10/05).

We go around the table and everyone can have input, what do you think of this? Someone presents then after people present, then we go around and say what do you think of this? and people have their say. He [the Chairperson] gave people a fair go, people put up their hands and that, and people would say "hang on wait your turn", this person is there, first it's [Jana] or this person and that... [my friends]. There is [names member], she's from, I think she is from Adelaide with her gorgeous blind dog, what's his name? oh I have forgotten her dog's name again. And there was another lady, [names her], she is from Western Australia I think, no umm somewhere and she was telling me about her pet snake [laughs]... Jana 11/05.

Mary and Stella who supported the Hilltown advisory group spoke warmly about the role that Martin played in their group.

*Martin is an extremely valued member of the group. He is not lacking in confidence and he is an incredible participant at meetings. He doesn't get any help at the meetings and he rarely misses a meeting. He has something to say about most things on the agenda... I think Martin reminds us that he is the type of person we are working for. Without us working [with Martin] we might not have informed input. Martin gives the group feedback, it is not always on the topic but sometimes it is. At the meetings he comes in with his bag with all the books/minutes in it. He is very organised and connects with this information. He is very helpful.*

Participants who had a sense of confidence and meaningfulness about their participation were also those who felt other members had had a positive regard for their capacity and potential to contribution to the business of the advisory body. The types of relationships they had with other members is similar to Reinders' ideas about civic friendships, which he sees as occurring at the intersect between the peoples' personal and the civic lives, "...people with an intellectual disability need allies and buddies, not only in their

private lives, but also in the formal world of their institutional roles" (2002 p. 4 ). Notably Hannah's comments seem to suggest she previously had this type of relationship which was ignored rather than nurtured.

*Because I am supposed to have an intellectual disability and other people didn't...because I said at that time Mary and Brenda are on the council with me and I know these two ladies well I said 'I won't need someone outside because I know [them]'she [the secretariat worker] said 'oh no you can't have them' ...I was told I couldn't have [them] because [they] were there with their own hats on. So in that time, I did get a support worker but [the two other members] were always helping me. (Hannah 02/05).*

### Types of Support

As already discussed the procedures adopted and social milieu of some advisory bodies were an important source of support in creating opportunities to contribute and the confidence to do so. The nature of the more formal support available to participants took various forms depending on resources available and internal decisions made by each advisory body and is summarised in Table 5. As this table shows, the focus varied from access to information, knowledge development, engaging in processes, forming relationships with stakeholders and skill development. These are the elements identified in a Joseph Rowntree Foundation (2003) report as important in supporting service users to participate in disability organisations. Although at some sites had multiple types of support no one site provided all the elements suggested by the Rowntree report. The most common type of support was individualised provided by a support worker to help with access to information, however help of this nature was also provided through more collective group processes in the smaller less formal local government advisory bodies. However, despite the emphasis as suggested earlier most participants struggled to understand the information or have a good knowledge about both the issues dealt with by the advisory body and its processes.

There was only one site where participants had received training on participation, meeting skills and how to communicate effectively in these forums. The other major gap was in regard to support for building relationships or networks with people outside the advisory bodies to inform or strength their participation.

A recent study of participation by people with intellectual disability and families on the advisory boards of University Centers of Excellence (Caldwell, Hauss & Stark (2009) found five

**Table 5: Approaches to participation support**

Type of Support	Advisory Body	Goal	How it is provided	Focus of support
<b>Individual</b>	Central Northern Southern	Support the individual with an intellectual disability to participate in the meetings	1:1 support provided by a support worker employed on an 'hourly' basis.	Access to information Knowledge development Personal/emotional/moral support
<b>Shared</b>	Seascope Hilltown Greentown [Through the secretariat in Southern, Central and Northern]	Support all members to participate and to support the functioning of the advisory body.	One worker or a number of staff are assigned to the advisory body from the relevant government department.	Access to information Forming/building relationships with stakeholders Engagement with the participation process
<b>Collegiate</b>	Seascope Hilltown Greentown	People supporting each other	People working together as colleagues within the advisory bodies. Evident in groups where shared support was the key approach to support.	Building supportive relationships within the group Engagement with the participation process
<b>Procedural</b>	Northern Central Hilltown	To have meeting procedures that are accessible and inclusive.	Normally facilitated by the Chair and/or secretariat to eliminate procedural barriers to participation	Access to information Engagement with the participation process
<b>Specialist</b>	Greentown	Provide short term, additional support or training.	Bringing in external trainers or advisers on specific topics or skills.	Access to information Skill development Knowledge development

major themes emerged in relation to support for participation; individualised supports, financial support, coordination and communication, leadership development and value and outcomes. Similar to the findings in the present study this study found that there needed to be equal commitment to the tangible and more intangible aspects of support, in particular it highlighted the importance of the attitudes of those 'in power' to ensure these boards are well supported and the input they have is heard and valued. The study also found that where there leadership development was provided for people with an intellectual disability it made a difference to their participation, however only a handful of skilled self advocates seemed to access this training and they were over-utilised on boards and committees. This aligns with the findings in the present study and suggests the need for a better commitment to building the knowledge and skills of people so they can participate meaningfully in a broad range of forums.

### Conclusions

This study demonstrates that some people with intellectual disability can participate in disability

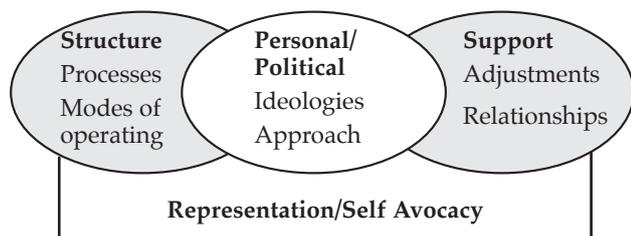
advisory bodies in a way that is meaningful to them, given the right participatory environment that is able to engender collegiate and civic friendships and provide tailored training and support. A significant obstacle for several was a milieu in which they felt they were not respected and which undermined their confidence. All participants struggled to understand the information provided and engage with the issues dealt with in meetings with the type of support provided. These findings suggest that support for participation must be multi dimensional, comprising much more skilled forms of practical support and adjustment to operating procedures which are underpinned by advisory body milieus that respect the capacity and right of people with intellectual disability to participate and foster supportive relationships with other members and secretariat members.

There is no suggestion that this small group of people are in any way representative of people with intellectual disability, rather all except one were experienced activists with many years of political apprenticeship served as members of self advocacy groups. This suggests that a flourishing self advocacy movement with the capacity to

provide such training and experience might be an important foundation for citizen participation by people with intellectual disabilities. In Australia, unlike the UK, the role of self advocacy as a training ground or a source of peer support and legitimacy for people with intellectual disability appointed as members of advisory bodies has not been seriously considered. Though it is seldom mentioned in recruitment processes, and too often people are simply seen as embodying the intellectual disability perspective, it is clear from this study that people with intellectual disabilities bring quite different political orientations to their membership of advisory councils. It may be worth considering therefore the issue of 'representativeness' and the appointment of at least some members with intellectual disability on the basis of their affiliation to the principles of the self advocacy movement. If this were to occur it would provide both a constituency from which to garner views and an important source of peer support for advisory body members.

Figure 1 illustrates a tentative model of the elements that must be taken into account in supporting meaningful participation in advisory bodies by people with intellectual disability.

**Figure 1 Components of meaningful participation**



Central to this model is an understanding of the personal and political reasons that each person with an intellectual disability has for participating. Inclusion of people with intellectual disability in civic and political life will only be achieved if those who are willing to participate are accepted into the policy making arena as members of the disability policy networks with something to say and the milieu, structures and processes of participatory forums are sufficiently well designed to ensure their voices are heard and can be acted on. However, the recent findings that despite a long history and the growth of participatory forums, in 2006 only 29% of all Australian citizens felt they had a say on communal issues of importance is perhaps an indicator that we are only just embarking on this particular journey of inclusion (Social Inclusion Board, 2009).

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# Organising Inclusion Work: Key Factors for Success

Erin Wilson & Elena Jenkin

Note: This paper is a short summary of the report published by Scope: Jenkin, E. & Wilson, E. (2009) *Inclusion: making it happen. Key elements for disability organisations to facilitate inclusion*. Box Hill: Scope. The paper reproduces this material with permission of Scope. The full report can be obtained from Scope.

## Introduction

Despite nearing a decade of formal inclusion policy in Victoria for people with disabilities, research continues to evidence that achieving inclusion is hampered by a number of key factors. Recent research by Tim Clement, Chris Bigby and colleagues finds both a confusion about what the term 'inclusion' means as well as an over focus on inclusion as 'presence' in community rather than active participation within social relationships and communal life (Clement, Bigby, Johnson 2007; Clement & Bigby, 2008). Using O'Brien's (1987) earlier concepts of 'community presence' and 'community participation', Clement and Bigby (2008) present compelling evidence to suggest that for the group of people with an intellectual disability they studied (a sub set of those moved out of Kew Residential Services into community residential units), the focus of inclusion work by disability workers has been overwhelmingly on increasing community presence. It should be noted here that, while not de-valuing relationships among peers with a disability, Clement and Bigby suggest the need for a stronger focus on building 'participation', particularly relationships with non-disabled community members, given the disability sector's success in fostering relationships between peers with a disability. They argue that people with an intellectual disability are limited by the distinct social spaces they inhabit that largely consist of other people with intellectual disabilities, staff and relatives. This is a useful nuancing of the notion of community participation for people with intellectual disability, as it brings into sharper focus the activity of inclusion work in dismantling these social spaces by facilitating new relationships with others particularly those not of these groups.

The focus on O'Brien's concepts of 'presence' and 'participation' appears to have proven useful in changing the focus of disability support workers (Clement & Bigby, 2008). Of course, notions of inclusion also encompass the experiences and structures of exclusion that operate at multiple levels throughout society. Within the disability

literature, inclusion work has been related to the work of creating 'enabling environments' (Swain et al, 2004) and the dismantling of exclusionary practices, attitudes, infrastructure and policies. This is an important aspect of the definition of inclusion to emphasise. Recent research conducted by Scope suggests that this broader analysis might get lost in the focus on person centred planning and the implementation of plans in the micro environments of individuals. This research also identifies that implementation of plans is likely to be stymied by a lack of attention to inclusion work at the meso and macro levels of society. The focus on the broader work of attitudinal, behavioural, and structural change has been described as a 'social engineering' project by Clement and Bigby (2008: 161). Given the difficulties documented by Clement and Bigby (2008) in achieving new understandings about inclusion among support workers even when focusing on the relatively straightforward delineation between O'Brien's presence and participation, it is not surprising that work in relation to this larger social engineering project is not well understood or resourced.

This paper presents the findings of research conducted by Scope in 2007-2009. It proposes a way of categorising the dominant modes or orientations to inclusion work in the disability sector in Australia and identifies the barriers and enablers to it. The research engaged with seventeen 'inclusion workers' or managers in Victoria and Perth, Western Australia and sought examples of successful practice along with the ingredients of success, and outcomes of the work. Coincidentally, the majority of examples provided related to inclusion work with people with intellectual disability, and a minority of these relating to people with severe intellectual disability. This data was analysed to identify key organisational factors required for successful inclusion work. Most importantly, respondents were also asked to identify the outcomes of inclusion work for individuals with a disability and their families, as well as for services, and for the communities with whom they engaged. The paper offers a way of conceptualising the breadth of inclusion work, including work focused on presence and participation, as well as the larger scale activities of social engineering or social change. The paper presents key ingredients for successful organisational approaches to such work.

For the purposes of the Scope research, inclusion work was defined as *supporting people to achieve, do and be in life in the ways they choose and identifying and removing barriers to this in society, services and individuals*. In this way, inclusion work selected for the research encompassed a range of individuals, practitioners or organisations that used a range of strategies to enable:

- people with a disability and their family to achieve their life priorities and /or
- community / communities to include and welcome people with a disability.
- The definition adopted here suggests that inclusion work involves a broad set of change actions that may focus on individuals, families, services, groups, communities and systems.

## **Orientations to Inclusion Work**

Early in the life of the research, Scope researchers identified that disability organisations and practitioners have employed various modalities and approaches towards inclusion work. Some focus on individuals, some on opportunities in community, some on larger systemic changes, and others on combinations of these. These different ways to focus the work were named 'Orientations' to inclusion work, and provide a helpful way to understand the 'what' of inclusion practice.

### **Orientation 1: Individual Person-centred Work Leads to Inclusion.**

*Inclusion and community building happen in direct response to the expressed interests, needs, and aspirations of specific people with a disability.*

Inclusion occurs after and as a direct result of person centred approaches and/or planning where practitioners have listened to people with a disability and consequently identified their aspirations and interests. Inclusion workers then work alongside the individual to build capacity in communities so there is a direct and meaningful link to people's specific aspirations, interests and needs. Clement and Bigby (2008) identify the more pragmatic reality of this for people with severe intellectual disability, where frequently their preferences are not well known and it is staff who typically interpret or name their interests and needs.

#### *Case Study: Orientation 1*

Joe, a 32 year old male, spent the second half of his life in an institution. There came a point, according to the interviewee, that the institution decided Joe could live on his own. The institution set Joe up with limited support in a flat and never saw him again. Joe went from having 24 hour support, to a 1 hour visit every fortnight by a support person to assist him with budgeting. Joe felt frightened and became sad. He stopped going out. The only friends he knew were in the institution and he had lost them. Joe couldn't communicate easily, he didn't know what he wanted and within a year and a half a mental illness developed and he was accessing the mental

health system. Joe met the local inclusion worker who is based in Joe's suburb. They met weekly to talk, and develop a relationship. Gradually, the inclusion worker drew in people to support Joe to achieve his goals to own his own home, gain employment, become a DJ and be involved in the football club. The inclusion worker linked Joe to different people that supported him with various interests. One included a mentor from the local church. Joe met a few men his age and identified the person he felt most comfortable with. The mentor was a similar age and they started going out together. As Joe came to trust the mentor, they went to the pub regularly, had a meal and played pool. Joe attended a modified DJ course through a University and he completed the course and was presented with a certificate. He was then linked with a DJ mentor for a few hours every week to build up his DJ skills. He is now a DJ once a week for a local community radio station and has become well known in his area. Joe's story covers a five year period.

### **Orientation 2: Opportunities are Created in Community.**

*Inclusion and community building require workers to be proactive in identifying, creating and offering opportunities to people with a disability.*

Due to a combination of institutionalisation, a lack of empowerment, as well as limited life experiences and opportunities, many people with a disability have reduced ability to articulate their aspirations and goals. Workers seek out opportunities and develop these based on their own assessment of what is relevant. They may or may not have developed this opportunity with particular individuals' interests in mind. Individuals with a disability are later linked to these opportunities. This is often an ongoing process of experience, trial, expansion and change for people with a disability. In some cases, these opportunities are created around people with a disability as a group, ie a 'block' response (Clement & Bigby, 2008). In others, work is done to prepare generic community activities and groups to include individual people with a disability.

#### *Case Study: Orientation 2*

An inclusion worker surveyed a large number of people with a disability and found that a substantial number of people were interested to try fishing.

The worker then mapped the local fishing clubs and located one that was holding a 'come and try' day for children. 'Come and try' was described by the inclusion worker as an open day where people

were welcomed to the club to try fishing with the support of club members. The aim of 'come and try' days in this context was to promote fishing as a leisure activity. The worker contacted the club and suggested they run a similar day for people with severe and multiple disabilities. The worker explained that a large number of people with a disability are keen to experience fishing and a 'come and try' day would be a good starting point. Over the course of several meetings, and in depth dialogue between the inclusion worker and the club members, a relationship was developed and the request was agreed to. A partnership was then developed whereby:

- Club members would teach fishing skills to interested people with a disability and,
- The disability organisation would organise the registration.

Funding was sought for barbeque and adaptive equipment and the club successfully ran two 'come and try' days in the year with 120 people with a disability participating each time. The events were so successful that the club agreed to continue running the two events per year.

The club strongly supported the two days a year but could not see it expanding or that people with a disability could be members of the club. The worker helped the club to consider fishing as an ongoing opportunity. A disability awareness session was held with local club members and the Department of Fisheries. The session was run by people with a disability and it made a significant difference to the way club members saw and valued people with a disability.

The inclusion worker enabled and supported people with a disability to have a greater involvement in the club. The club has been challenged by notions that people with a disability can be club members, and can fly fish rather than just bait fish. Support staff were also surprised by the fact that people with multiple disabilities can fish. People with a disability learnt how to fish and had a lot of fun.

The inclusion worker is now working with the Department of Fisheries to transfer this model across fishing clubs and also to ensure people with a disability are included in their promotional strategies.

### **Orientation 3: Broad Level Community Change.**

*Inclusion and community building focus on broader structural and attitudinal work.*

Inclusion workers foster opportunities for inclusion by focusing on overarching structures, allocation of resources, skill sets and knowledge of various groups. While this work is most

powerful when it includes or is led by people with a disability it does not always, or even frequently, include people with a disability as actors. This work is general ground-breaking and foundation-laying work with organisations and communities. It may involve work to change policies and procedures that have extended effect (eg the funding allocations for staffing of classes at neighbourhood houses, or public transport facilities), or change practices and attitudes (for example, work to skill psychologists to provide appropriate services to people with intellectual disability and complex communication needs). In most cases it involves re-visioning notions of 'disability' and 'community' services in a range of ways.

#### *Case study: Orientation 3*

A disability agency has redefined and reconstructed their organisation to ensure their relevance to people with a disability, community and government. They have now positioned themselves as a community organisation rather than a disability organisation. For example, the organisation won a tender to operate a community centre (that has 2000 people accessing the centre each week) where they run all activities that are inclusive of people with a disability. The intent is that the centre will benefit people with and without disabilities and will provide opportunities to bring people together. This model is being replicated by a move to operate a second community centre. Other community services delivered by the organisation include: the development of a domestic violence package that includes the issue of violence for people with disabilities and a curriculum that involves disability awareness; and a road safety program (incorporating the link to disability awareness).

### **Breadth of the Work**

The three Orientations offer different starting places for inclusion work. It is clear from the examples above that inclusion work sometimes spans several Orientations. Whilst there are strengths found in each, a combined and deliberate placement of workers across the three Orientations can be seen to strategically support inclusive practice as a whole.

We have already discussed above that inclusion requires addressing barriers that create exclusion. These barriers occur at all levels of society and across multiple environments in which people engage. Barriers can be found within attitudes, knowledge, skill sets, relations between people and groups or between individuals and organisations, behaviours and practices (such as professional or organisational practices), policies and other

structures. Within each Orientation, the inclusion worker focuses on whatever set of these barriers she/he finds.

Each Orientation has a somewhat different focus. This necessarily means that the work will primarily focus on different environments or levels of society. These loosely correspond to a focus at the micro (or personal) level, the meso and macro levels of society.

Orientation 1 work focuses primarily on:

- personal and home barriers;
- barriers in disability services (e.g. residential or day services);
- barriers in non disability organisations (e.g. shops, neighbourhood house etc).

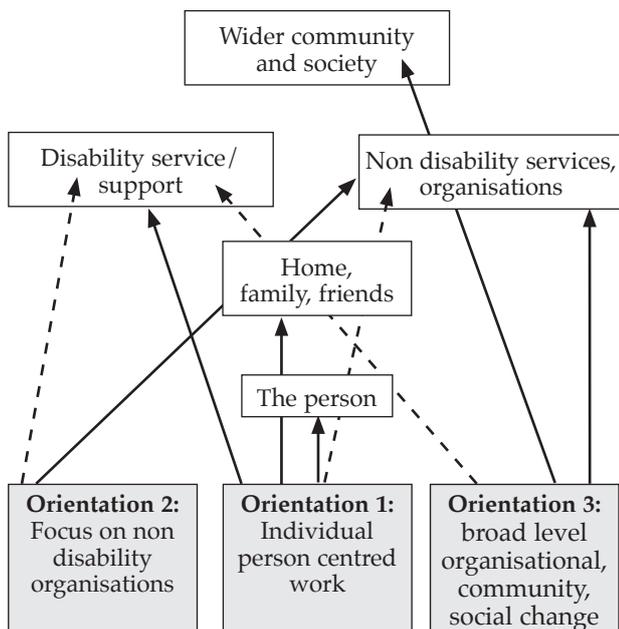
Orientation 2 work focuses primarily on:

- barriers and opportunities in non disability organisations / community.

Orientation 3 work focuses primarily on:

- barriers of policy, program delivery, facilities and infrastructure across non disability organisations and community.

**Diagram 1: The focus of the three Orientations of inclusion work**



**NOTE:** ---- dotted line denotes a lesser focus or decreased frequency to the work.

What this analysis suggests is that inclusion work requires activity (and staff resources) to be focused across all dimensions of a person's life, and to address the barriers to inclusion at a range of levels. Inclusion is a broad-scale activity that requires the combined focus of Orientations 1, 2 and 3 in order to ensure that barriers to inclusion are removed at all levels. However, data from the seventeen case studies in this research identified

that by far the greatest majority of the work was operating within Orientation 1 (94%). Around one quarter of examples were situated in each of orientations of 2 and 3, with forty percent (40%) working across more than one orientation. Organisations took different approaches to structuring their work within each of these orientations. Within orientation 1, organisations largely took a 'case management' style approach, focusing their inclusion work around identified individuals and building responses to their needs and interests. Work within Orientation 2 tended to be structured around interest areas or service types (for example, leisure interests or respite services). In this Orientation, organisations became specialists in particular interest areas or fields and worked to build inclusion opportunities across the field as a whole (eg the field of arts participation, or the field of football). There was only one example of an organisational approach to Orientation 3. This involved total service re-design and re-conceptualisation.

Given that inclusion work is occurring at a range of levels and via the three Orientations, this suggests that the effectiveness of the work rests, to some degree, on the extent to which workers are aware of and collaborate with the inclusion work of others across the spectrum. Rather than treat each set of barriers and issues as unique, the work requires a high level of communication, collaboration and awareness of the breadth of inclusion work in action. This will enable the ability to link up change actions and build upon the successes already established in some areas for more sustainable outcomes.

This analysis suggests a strong kinship with community development work. Drawing on this literature, it is evident that the tasks and activities of inclusion workers are likely to be broad and diverse. Jim Ife (2002) confirms that there are a large range of work roles in community work. He divides these roles into four clusters:

1. Facilitative: techniques to stimulate, facilitate and support the process;
2. Educational: to do with agenda or direction setting, learning/teaching new ways and skills;
3. Representational: interacting with external bodies on behalf of others;
4. Technical: applying technical skills to aid the process.

Each of these four clusters contain numerous roles that exist within community work. Ife reports that "community work tends to be about doing lots of things at once, and in any single activity or project a community worker is likely to be filling several of these roles, and will move between one and

another all the time" (Ife 2002, p. 231). The work requires a broad set of skills and is comprised of a multitude of roles. Ife (2002) stresses that dividing up the work by role and allocating different roles to different workers (i.e. to become a specialist in one role area, such as facilitation) will not achieve integrated community change.

Overall, this conceptualisation of inclusion work calls for an acknowledgement of its breadth and complexity, and of the skill set required to achieve outcomes within it.

### **Current Inclusion Work: What Needs to Change**

The Scope research asked respondents to identify the barriers and enablers operating in their inclusion examples. Respondents focused on the factors evident at the level of the individual with a disability (and their family), at the level of service provider (usually disability service providers), and at the level of the community with which they engaged (sometimes this referred to individual community members and at other times to groups and organisations). Additionally, respondents were asked to identify key organisational factors necessary to support inclusion work.

All respondents were able to identify successful examples of inclusion work. Frequently these examples demonstrated the complexity and longevity of the work required. Respondents identified significant barriers operating at the level of the individual (and their families); the service and staff; and at the level of community. In particular, respondents highlighted complex context of the individuals with a disability and the challenges to inclusion work that operated at this level. While trust and commitment were identified as enablers to the work, other individuals found it difficult to overcome their fear and lack of confidence. This was identified as the largest hurdle with stories confirming that it takes considerable confidence to meet new people, try new things and overcome initial fears. Many in this group were also hampered by complex communication needs, ineffective communication systems and a range of related behaviours. Additionally, almost all examples were at some stage negatively affected by health issues (mental and physical), age (at all life stages), and changing or fluctuating needs. These personal attributes were exacerbated by poor levels of formal and informal support, insufficient assistive technology, and financial barriers. This range of impediments operating at a personal level is significant and suggests a substantial level of resource requirements. However, added to these are the barriers operating at the level of service and organisation.

The following summary identifies key changes

needed in order for organisations and governments to effectively progress inclusion work, drawing together the data presented by respondents about barriers and enablers to inclusion work, and the key organisational factors required to sustain it.

### **Inclusion is Everyone's Responsibility and Needs to be Organisationally Embedded**

A lack of skilled and committed staff was the most frequently identified barrier. This encompasses both a lack of appropriate values, behaviours and attitudes as well as a lack of understanding of the change from carer to facilitator role. Two significant findings arise from the plethora of comments on this topic (including examples of staff actively preventing inclusion work). Firstly, the work of inclusion needs to be 'everyone's job' and secondly, staff roles need to be redefined and re-badged as 'community facilitator' to focus attention on what the job entails. As with Clement and Bigby (2008), respondents reported frustration with the over-focus on community presence and a lack of understanding of and commitment to participation.

Despite its breadth and the wide skill set required to do it, interviewees were in agreement that inclusion is everyone's job. Inclusion work should not be assigned to particular staff roles, leaving others to do traditional care work. As one respondent observed "we are all facilitators, it is everyone's responsibility". Inclusion work is a shared responsibility. Interviewees were clear that inclusion work needed to be a part of all support and service roles in the disability sector.

As such, inclusion work needs to be structurally in-built into organisations across all levels. An organisational environment that supports and focuses on embedding change to support citizenship was advocated as a key enabler, as was the building of relationships between all stakeholders (people with a disability, staff, organisations and communities). Staff won't change from 'carer' to 'facilitator' or inclusion worker unless they have organisational support to do so. Organisations need to systematically support and require staff to practice in this way. This includes clear and concrete practices, priorities and directions around the work, as well as skill sharing encompassing mentoring, formal and informal training, 'checking in' on staff and debriefing. This suggests a major shift and significant requirements for job re-design and skills development (particularly given a more complex understanding of the roles and skills as described by Ife, 2002). It also suggests implications for supervisors and management who need to actively require, support and evaluate

the performance of this work in all roles. Inclusion work requires advanced professional skills as well as professional supervision by people with discipline expertise. This suggests an enormous need for professional development at all levels of an organisation.

Interviewees also consistently reported on the importance of recruiting staff with the 'right' values and the attributes of facilitator or connector. Values and personality were seen as more important than qualifications. With such staff in place, it was felt that organisations can then invest in equipping them with relevant skills, such as person centred approaches, facilitation, and community development, via a planned professional development program or training support.

While the emphasis is on building-in inclusion work into all roles, given both the breadth of the work and the skills set required, there is also an argument for the resourcing of specialist inclusion staff as mentors, trainers and advisor-collaborators. Additionally, some Orientations to inclusion work, particularly Orientation three (structural change), may also lend themselves to targeted work with identified and specialist staffing.

### **Inclusion Work Requires Flexibility**

The most common theme across the interviews was flexibility which was identified as the key enabler (ie the most commonly reported) to inclusion. Respondents reported that organisational systems and approaches prevented inclusion. In one case, organisational bureaucracy prevented a partnership with a community organisation, and in others rigidity of structures such as finance and administration hindered implementing individualised support. To support people with a disability to pursue their priorities it was reported that flexibility is required across organisational processes. Supporting the staff to be flexible in their workplace, providing flexibility with time needed to do the work, or a change from 9 to 5pm hours (so that staff can better support people with a disability) were all examples given to researchers. A flexible approach to the work would harness creativity and innovation within the workplace, further enabling people with a disability to pursue their priorities in life. Resources were also needed in flexible formats and to support flexible approaches such as small funding packages that could be approved and utilised in a timely manner.

### **Inclusion Relies on Collaboration, Partnerships and Co-ordination**

Disability agencies cannot do the work of inclusion alone. It requires a combined focus with an

inter-dependent partnership with people with a disability, community members, disability services and mainstream agencies to bring about change. Consistent with previous studies, the attitudes present in the community were seen to be critical to successful inclusion work. Positive attitudes were characterised by a commitment to interact, a willingness to seek appropriate resources, and openness to flexibility and adaptation. Leadership by key individuals who championed inclusion was identified as important as were partnerships between groups and organisations that unlocked resources and support.

Co-ordination is critical in order to avoid highly atomised pieces of work all commencing from scratch and unable to effect change in systems on a case by case basis. It is also critical to break down the silo approach to disability services and supports. The organisational task now is to reduce this silo effect and set up clear communication strategies whereby people are not only aware of the important work they are respectively doing, but are also able to support each other's roles and work together for greater outcomes.

### **Strategic Planning is Needed to Manage the Breadth and Scale of Inclusion Work**

Inclusion workers need to be strategically placed across the three Orientations to systematically remove barriers and open up opportunities for inclusion to happen. Inclusion work is categorised under the three Orientations but the roles will overlap and vary according to the context and culture pertaining to particular communities and individuals where the work is placed. This is a new analysis and way of viewing the requirements of the work. It suggests that further analysis or mapping of inclusion barriers, and an identification of the resources and personnel currently targeting these, needs to be done within localities, States, or even agencies to ensure that workers are situated across this spectrum of the work. Without this, there will be critical gaps and inclusion will be stymied at the level where no resources are committed.

The work needs to be planned and developmental. It is not simply about providing a 'bridge' for an individual with a disability from their current life activities into a new set; or simply 'linking' them to a different agency or program in the mainstream community. It is not simply a 'placement' task. Whilst listening to people with disabilities and developing relationships were identified by respondents as corner-stones to inclusion work, they are not enough. The work demands are more complex and multi-layered than this if the work is to go beyond the identification of an individual's aspirations to actually achieve them. Disability

agencies and funders need to fully understand the breadth and nature of inclusion work so they can accurately and adequately staff, organise, support and resource it.

Around half of the respondents identified the need for other additional resources to support inclusion work. These included specialist psychology, therapy or planning staff, new 'community connector' positions, small amounts of flexible and responsive funding, and a wide range of assistive technology both located with individuals and in mainstream community settings. Additionally, respondents recognised that community groups were often hindered by a lack of the necessary funds to support inclusion (to fund things such as additional support staff or equipment).

Respondents identified a significant lack of time and resources to do the work of inclusion. The work of inclusion encompasses a high workload of new tasks such as building knowledge of a person's communication mode, finding funding, organising activities, attending events and building relationships. The work requires substantial time allocations with some respondents identifying the need for significant amounts of time, patience and persistence. The findings indicated that inclusion work is far more sustainable when carried out over a significant length of time. Analysis of all case studies showed that successful work spanned extended timeframes from two – seven years.

Without this broader planning and resourcing, actions are likely to result in short term achievements but no long term change, with results continually reliant on 'project' activity that is band-aid in nature rather than building-in changes that enable the action to be sustained long term.

## Implications

### *For government departments*

Identify the current resources, areas of practice, and gaps in both by mapping current investment committed to each of the three Orientations of inclusion work.

Inclusion work is critical to achieving outcomes from all government investment in disability. It requires a focus on and resources committed to all three Orientations of inclusion work. The concept of three Orientations provides a mechanism to review and map current investment, practice and gaps in both government and non government inclusion work. This systematic analysis of and attention to inclusion work is long overdue in government and is the initial piece of work necessary to commence activating the rhetoric of government policy in this area.

Inclusion requires identified investment that is long term and based on identified aspirations and areas of need.

Government needs to lead the change process that is based on strategic work to overcome existing barriers to inclusion in 'mainstream' communities and disability services. Through person centred planning requirements, the government now has a mechanism to identify inclusion priorities that are important to people with a disability and to align inclusion work to these by region, area of interest, or industry. This offers a new opportunity to invest in inclusion work across all Orientations that matches collective priorities of people with a disability. Directly addressing the barriers to inclusion in this strategic manner, requires targeted resources (human, physical and financial) that are committed for longer-term work rather than one-off, short term projects.

### Clarify the practice of inclusion work

Disability and community organisations are left to interpret 'inclusion', 'community' and 'participation' how they wish. Clear guidelines on definitions as well as breadth of the work will support clarity and greater consistency in the practice. Explicit strategies are required by government to assist organisations with good practice and to promote the importance of inclusion amongst the community sector. Inclusion work requires clearer accountability mechanisms to ensure all parties can accurately report on and evaluate the diverse outcomes (and barriers to outcomes) of inclusion investment. Such accountability mechanisms need to affirm creative and varied approaches to inclusion practice and value outcomes beyond 'presence' by supporting the longer timeframes required to achieve these outcomes.

### Actively develop cross-sector collaboration in inclusion work

Government approaches to inclusion work need to be inter-departmental and require cross sectoral collaboration by agencies receiving funding. As an inclusion leader, government needs to resource avenues for people with a disability, their families, and disability and community organisations to share examples of good practice. This exchange of ideas would generate practical suggestions for improved practice, build motivation, skill development and collaboration.

### For Organisations

The research findings of this report are based on the experiences of successful inclusion

practitioners and provide repeated evidence that inclusion work works. As such they form a basis for influencing change and promoting good and consistent practice, resulting in more positive outcomes for more people, families and communities. Systematic good practice and organisational support is essential in order to ensure that all people with a disability and their communities receive consistent support to be included and inclusive, rather than a lucky few. If organisations carry on as before, nothing will change.

Inclusion work is core business for disability agencies and must be explicitly present in organisational mission, strategies, staffing and resourcing.

Inclusion doesn't work if it's not explicitly part of the organisation's task. Prioritisation of inclusion work has implications for services, organisational strategies and roles. Inclusion work needs to be built into the fabric of the organisation from the organisation's mission, in the strategic plan and via re-construction of organisational roles. Ensure management understands, practises and promotes community development principles. Strategically place inclusion workers across the three Orientations and ensure regular interface occurs as a priority. This restructure is essential if inclusion work is going to be seriously considered and implemented as core business. Without it, other service priorities and deliverables of person centred approaches, individualised services, and quality practice will be unachievable as people with disabilities, families and carers remain unsupported in their fundamental aspirations. All planning and action needs to enable long term activity (i.e. three years or more) that is central to real and sustainable inclusion outcomes.

Resource all staff to undertake inclusion work.

Inclusion work needs to be the job of all staff as it requires consistent activity towards the identified goals of people with a disability. To achieve this, significant skills development is required for existing staff, along with targeted recruitment strategies that equally value staff attitudes and values along with inclusion skills. Professional development programs need to include community development training as a core base to build staff capacity. Staff require skilled supervision and management processes that affirm and support inclusion work. Specialist staff with advanced skills in inclusion work (possibly drawn from the disciplines of community development and social work, among others), are needed to

mentor and support the work as well as leading larger and more complex activities across the three Orientations. Organisations need to ensure they value and resource staff that enact the practices identified in the next section detailing the implications for practitioners.

Develop organisational systems and processes that are designed to be responsive to individual contexts.

Flexible systems are needed to be highly responsive to the individual contexts and aspirations of people with a disability. This requires flexible staffing hours, flexible payment and invoicing mechanisms among other system changes.

Explicitly require and resource the connection of person centred planning and inclusion work.

The disconnection between person centred planning and community development/building (seen in Victoria) must be rectified. Valuable information is collected about people's dreams and aspirations and yet this is not fed into community building strategies, or is left to the isolated planning worker to address despite being outside the job parameters of this person. Person centred practice provides vital information to ensure inclusion (community building) projects are aligned with people with a disability's life priorities. This requires an organisational recognition that inclusion work is a collaborative exercise and requires time spent in building relationships and alliances between all parties.

Identify explicit leadership and collaborative roles for people with disabilities and their families.

Regardless of the organisation's primary orientation to inclusion work, people with disabilities and their families must be consulted and supported to drive the work wherever possible. Leadership opportunities for people with disabilities and families must be opened up in all forms of inclusion work. This process will also support the work to be relevant and sustainable.

### Questions to Ask our Organisations

1. What do we understand from the terms 'community', 'inclusion', 'participation' and 'presence'?
2. In which Orientations does our current inclusion work sit? Is this adequate?
3. Are we explicitly interested in supporting people with a disability to lead a life that is important to them as defined by them (and those who know them best)?

4. Is inclusion work our core business? Are our mission, strategic plan, budget, job roles and job descriptions aligned with this?
5. Are we genuinely listening to people with a disability and their families?
6. What do we do once we have listened? Does this information guide our practice or is it overlooked and simply a process of courtesy that remains too difficult to act on?
7. How well do we know the individuals and families we are working with? Do we invest enough time with the individuals and families to build a solid relationship and gain a sense of trust? What would individuals and families say if we were to ask them these questions?
8. How well do we know the communities we are working within? Can we really say we have good relationships with the community sector? What would community members/leaders say if we were to ask them these questions?
9. Who are we accountable to in regard to inclusion? What processes are in place to ensure accountability occurs?
10. How well do we value inclusion work? Are systems in place to ensure workers can carry out their tasks as a priority and in a flexible manner? What are they?
11. How well do we support inclusion workers? What policies and processes are in place to ensure practitioners are adequately supported and encouraged to develop skills and improve practice?
12. What principles do we work by? Are all practitioners consistent in applying these principles? How do we supervise and support them to do so? Do our supervisors have these skills?
13. Do inclusion workers collaborate together? What processes are in place to ensure regular communication and collaboration occurs? Is there enough engagement with others in the disability sectors that may be doing similar work?
14. Who do inclusion workers learn from? Are they supported with mentors? What other processes are in place to ensure reflection and ongoing learning is a valued and consistent practice? What external forums could we connect with to support professional development around inclusion?

## Outcomes of Inclusion

Recent work, including this Scope research, has highlighted the significant barriers to inclusion work and helped to identify areas for action.

Clement and Bigby (2008) identify a resistance on the part of some staff to tackling the work of fostering community participation and dismantling the distinct social space which people with intellectual disability often inhabit. Clement and Bigby query what motivators would be effective to assist in this attitude shift. The Scope inclusion research may offer another motivation for this change. Respondents were asked to identify outcomes of the inclusion work they described, for people with disabilities (and their families), for services and for communities. Whilst these outcomes are anecdotal and provided by staff (not people with a disability or communities with whom they engage), they offer some useful insights into the value of inclusion.

Encouragingly, respondents found it easy to identify outcomes for people with a disability and their families and provided many examples. The most commonly reported change (reported by around 50% of respondents) was increased networks, connections, relationships and friendships. This included knowing more people, having friends and networks, and new or re-established relationships with family members. One interviewee identified that an individual had 'positive and reciprocal relationships' where there is a mutual exchange. In this case these relationships developed into a 'naturally occurring support network' around some activities.

*"J is now well connected, he has friends, networks and has reconnected with his family. J had a 40th birthday party and he had plenty of friends."*

Individuals also increased confidence, trust and independence with others valuing increased control and initiative.

*"Y has changed, she is much more self assured. She thinks of possibilities rather than thinking she has to accept whatever is happening to her."*

Around half of the respondents identified the increased skills of people with a disability as a result of inclusion. In some cases this related to increased communication skills and in others skills were specific to new activities and fields (photography, art, DJ etc). Similarly, around half of the respondents reported increased opportunities to volunteer, be a mentor or receive material gains (club membership, personal care, payment). A similar number reported increases in well being and safety directly related to increased social relationships and being known in the neighbourhood.

*'Due to the fact that C is far more involved, visible and interactive, she is better known in the community and this reduces safety concerns.'*

Finally, while respondents reported increased community presence, this was linked to a range of other benefits and in many cases was also linked to expanding social relationships. Around half of respondents discussed people going out more, having more conversations with people they know from a range of activities as their paths cross outside these activities, and having 'connections' with particular groups or retailers as a result of frequent engagement and knowledge of a shared interest. One interviewee stated the individual was 'now a valued member' of a specific community.

*'She is now more independent and confident to go out to the local shops on her own and she does her own shopping. F runs into local people at the shops that know her through art so she has many conversations with people along the way.'*

Similarly, respondents identified outcomes and changes for communities with whom people with a disability engaged, though this thinking proved more difficult for most respondents. As could be expected, most respondents were able to report improved attitudes as outcomes for community where people without disabilities felt comfortable and skilled to interact with people with a disability. Community members and organisations evidenced increased knowledge and skills, often utilising these skills beyond the initial person with a disability. In one case, community members so embraced new skills that they challenged disability service staff to achieve this level of change and more appropriately support the person with a disability.

*'The community members challenged the support staff to 'enable' people with a disability to have a go. These members were the enablers in this scenario.'*

Community organisations also benefited from expanded partnership bases (sometimes with disability agencies) that increased the sharing of expertise and equipment in mutually valuable reciprocal relationships.

## Conclusion

The Scope inclusion research has confirmed many of the findings identified by Clement and Bigby (2008). Not only is there a lack of understanding of the work of inclusion and an over-focus on achieving community 'presence' rather than 'participation', there is also an over-focus on inclusion work within Orientation 1, as a case by case 'bridging' role to place individuals in community activities. Whether this has been somewhat influenced by Victoria's emphasis on person centred approaches, and in particular person centred planning, is not clear. However, this paper proposes that governments and organisations need to step up to the larger task of inclusion as a social change project, and both plan and resource this work as such. Without such an analysis, inclusion work will be stymied as each individual meets structural barriers that no agency is responsible for addressing.

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# Some Reflections on What Might be Needed to Assist People with Disabilities to Become Authentically Included in the Community

Deb Rouget

## Introduction

This paper aims to offer some reflections on what has been helpful in PLA's efforts to authentically assist people with disabilities to become active contributing and valued members of their communities. Our reflections stem from the individuals and families we have assisted over many years who have struggled to live a "typical" life in the community. A life that is not extraordinary but ordinarily of community.

## What is PLA?

Personalised Lifestyle Assistance (PLA) is a small semi-autonomous community based advisory service/resource that was developed by families in 2003. It aims to inspire and build capacity and knowledge predominantly with people who have a disability and their families to enable individuals to have opportunities *typical of other citizens in the community*.

PLA employs a part time Manager and Assistant. It is directed by a Committee of Management that comprises of a person with a disability and families together with professionals that believe in PLA's aims and principles. In order to avoid duplicating administration resources, PLA is 'hosted' by Melba Support Services. PLA has operated on a series of non recurrent grants from the Department of Human Services (DHS).

PLA's believes that *all* people should have the opportunity to pursue a unique lifestyle in the community that is personally meaningful, relevant and intertwined typically in the community. Its core principles are authentic community/social inclusion, typical opportunities, empowerment and individualisation.

To achieve its aims and principles, PLA provides inspiration, information and education to people with a disability, families and professionals via providing theory, a stream of ideas, and practical (real life examples) that create alternatives to segregation and congregation. This is achieved through information dissemination, sharing stories, courses, retreats, a bi- annual conference and other materials such as a periodical, occasional papers and web site.

PLA also provides one to one advice to individuals/families to enable them to form a vision for a good community life. This may also include assistance to plan, implement, review and safeguard their vision. PLA places an emphasis on strengthening & building people's own skills and building informal networks around people rather than relying only on paid supports.

PLA has also assisted with reshaping disability support services by assisting people with a disability and their families to re negotiate and reorientate their relationship so that services and supports are authentically driven by the individual/family. This has resulted in a number of arrangements that are individually hosted with various services in which the person/family directs all supports. PLA has also assisted in the establishment of 3 self and family governed collectives in Melbourne (Nightlife, Living Distinctive Lives and One by One).

The following elaborates on our reflections on what might be needed to assist people with disabilities to become authentically included in the community.

The reflections are also supported by the research by Cocks & Boaden (2009) and Carver (2009).

## Maintaining Unambiguous Guiding Principles about Belonging and Social Inclusion

In a world that is filled with conflicting agendas, materialism, business, expedience and other demands, we are continually tempted to pursue quick fixes, easy options and compromise our values. Our values are at the heart of everything we do but are at risk of being most compromised. PLA has worked hard to develop and maintain unambiguous guiding principles around social connectedness. These principles are our guide or our anchor. We refrain adamantly from subjecting people to opportunities that would not be available to other members of the community i.e. segregation and congregation based on disability. One of the guide posts that families often use is to ask the question "Would this option be pursued for my son or daughter who doesn't have a disability"?

*"It's OK to want something better. You don't have to accept only what has just been offered or what has been offered in the past. As parents we need to give ourselves permission to think positively about the possibilities of meeting our son/daughters needs in a normal way – not different to our hopes and aspirations for all our children." Anita O'Brien (parent)*

It is not merely enough to have stated values and principles. They have to be lived in everything we do. It's a path that we practice but like all

others we are not perfect. We try persistently to reflect critically with humility and openness. This motivates us to do and seek better. Chris Fyffe (2008) in an external evaluation of PLA, found that not only does PLA have operating principles and values consistent with and aligned to the State Disability Plan and Disability Legislation and arguably any contemporary disability policy but, of its self is less remarkable, than the evidence that PLA is actually assisting people to live these principles.

### **Understanding and Upholding a Person's Uniqueness – One Person at a Time**

PLA believes that all human beings, although sharing similar universal human needs are complexly and superbly unique! Thus it is an incorrect assumption to say that people who have a similar diagnosis or disability want and need the same things out of life. This challenges many of the frameworks and services today that congregate people together based on disability to meet an individual's needs. Such services are not typically designed to create unique supports, one person at a time but are designed to accommodate/support groups of people who share the same label or diagnosis. Kendrick (2009) suggests that one of the major assumptions underpinning the practice of congregating people with a disability is the assumption that people who share a similar label or characteristic should, prefer or want to be with their "own kind". This assumption has an impact on how services are designed and ultimately the impact it has on a person's uniqueness.

Kendrick (2009) suggests that many service responses that exist today may be problematic to upholding a person's uniqueness because they are typically designed before the person arrive by others rather than *with* people, designed around generalised specifications rather than unique or personal ones (one size fits all), are non-negotiable in regard to individual need and variance e.g. they're often financially based on pre set assumptions that can't not be varied to accommodate personal variances, based on service related routines that do not vary from day to day and week to week, usually inflexible and rigid as to model, method & resources and lack authority sharing with individuals and families.

PLA attempts not to make any assumptions about people or begin with preconceived ideas. We do not design anything before a person arrives. Thus when people ask for assistance we have to start to get to know them and those who love and care about them. This takes time as all people are different. They have unique histories, experiences, needs, passions, interests, dreams, routines, priorities relationships etc. Therefore

the starting point with each person, their vision, priorities, lifestyle and pace will all be unique to them. No two people we assist pursue the same things.

If assisting people to apply for funding, each person's package is unique and based on their needs. Historically if people have been given standardised funding packages they all use their resources differently and uniquely and for different things. There are no pre-designed programs, timetable, activity, lifestyle arrangement or destinations in life. The essence is one person at a time arrangements rather than groups.

If people's visions and plans for the future are unique then frameworks and supports need to also be uniquely tailored. Thus what is created in people's lives is as many models of support as there are people!

### **Identifying People's Needs and Honouring all Aspects of People**

We have found that we need to honour all aspects of people, not just their disability. A person's disability is only one part of their identity and should not define their life. If disability becomes the person's defining identity then they are at risk of living, working and recreating in disability settings and their lives become defined by service routines, programs and relationships with professionals and other people with a disability.

Michael Kendrick (2009) suggests a range of universal needs that are common to all human beings i.e. work, autonomy, respect, value and reputation, social inclusion, meaning and spirituality, identity and culture, relationship, respect for and exercise of rights, financial viability, health nutrition, vulnerabilities and safeguards, learning and growth, communication, leisure, adaptive devices and transport. Incongruously although all human beings share some common human needs the way these needs are met will be complexly unique!

Once people's needs are identified and prioritised the work begins with people on identifying how their needs will be met in a typical or culturally valued manner.

### **Meeting Needs in a Typical Way: Understanding Social Role Valorisation (SRV) & Using the Culturally Valued Analogue as a Way to meeting needs**

Although a complex theory, with increasing debate as to its relevance today, Social Role Valorisation (SRV) has offered us a remarkable explanation and foundation for why people are devalued or rejected by society and how people can be accepted and valued. Wolfensberger (1998) defined SRV as

“the application of what social science has to tell us about the defence or upgrading of the socially perceived value of people’s roles” p58. This can be done through enabling, enhancing, maintaining and defending valued social roles for those at risk by using culturally valued means as much as possible (Wolfensberger,1992).

SRV conveys to us that often people with a disability are devalued in society because of a perceived difference, characteristic or identity. If a person is seen as being of low value then they are at risk of not being treated equally, not afforded the same opportunities as others in society or treated differently i.e. low quality treatment, housing, services, lack of employment opportunities, strange routines determined by staff etc. The person will also be at risk of rejection and then separated and/or exclude and denied the good things in life e.g. respect, supportive relationships, no access to the community/food/holidays or other. Once rejected or excluded from “mainstream” society people’s needs are seen as “special” or different, thus needing “special” or “professional” help to meet all of their needs. Once people are segregated from society they are denied the richness that community has to offer or the opportunities that most people take for granted.

One way of overcoming the impact of social devaluation, Wolfensberger (1998) suggests, is by assisting people who are devalued by society to develop valued social roles. “A social role may be viewed as a combination of behaviors, functions, relationships, privileges, duties, and responsibilities that is socially defined, is widely understood and recognized within a society, and is characteristic or expected of a person who occupies a particular position within a social system.” p 25.

Wolfensberger (1992; 1998) also described the Culturally Valued Analogue (CVA). This is a useful way of thinking about meeting a person’s needs i.e. what valued ways do other citizens in our society or culture meet this particular need? It may be a certain practice, pattern or custom. For example, if someone needs money in Australia they get a job in much the same way as other citizens by using their networks, word of mouth, newspapers, community ads (e.g. in shop windows), starting a small business based on their skills, volunteering to develop skills, studying etc. They do not automatically seek welfare or attend a sheltered workshop!

Along with the valued role of work comes many other valued roles e.g. colleague, contributor, friend, social organiser, shopper, wage earner, tax payer etc! The common assumption though is that people with a disability can’t work as they’re seen

as different and often denied this opportunity. Thus special work places have been developed for people who have a disability which do not offer the same richness of opportunity.

The constant question we ask in our practice is “if any other citizen had this certain need or want, where would they pursue it”? This way of thinking prevents us from thinking “special group” for people with a disability and thus helps to prevent the continued segregation and congregation of the people we assist. It has become an automatic response in our thinking which from the onset steers us to community belonging and connectedness.

For other needs the same thinking is followed – If a person needs a home they might use a real estate agent not disability services. If they need financial assistance to rent a house and can’t afford it they might find a flat mate. If they need assistance to live in their home they live with a friend or housemate. They don’t tend to live in a group home that is controlled by an agency! If they want to make friends they might join the local Rotary Club. If they have a spiritual need they go to the local Church or Buddhist retreat. If they want to learn ceramics they go to the local potter’s studio or community house. If they need to further their education they go to the local university or school and so on. For example articulating Rachel’s need for work was clearly articulated in the following manner:

*‘Rachel needs to have a paid job which is based on her interests and abilities, respectful, local and in the community (not segregated, in “special” disability settings, with other people who are vulnerable or have disabilities). The work place should be friendly, organised, spacious, not too crowded and enhance Rachel’s valued roles. Rachel wants to do something that “is challenging and meaningful.”*

There are so many opportunities in the community that we fail to notice because of thinking “disability” rather than thinking in terms of the Culturally Valued Analogue. The community is awash of prospects waiting to be engaged and taken advantage of!

Once people are in such valued roles, community members are more likely to see people for what they contribute rather than their disability or label. The practice of meeting needs in a typical manner can have many positive effects e.g. reduces social isolation and increases engagement with the rest of the community, increases positive role models, various and multiple learning opportunities to develop and reach one’s full potential, the development of a wide range of associations and friendships other than disability professionals and other vulnerable people, broadening of secondary

interests that lead to further opportunities, increased safeguards as people are known in the community, increased community support and acceptance, less reliance on paid support etc.

*'Cameron is employed part time by a local business. It is an award paying job. Recently the Manager at Cameron's workplace said that not only did he do a wonderful job but the workplace had a different feel and some staff reported looking forward to coming to work on the day that Cameron worked! Cameron's shared interest of sport also led to a weekend away with his boss and work mates to the International Cricket in Tasmania. On his birthday, to Cameron's delight, his workmates organised an autographed Collingwood Football Club jumper as a gift. Cameron's work mates were invited to his 30th birthday party. When there were job losses at his work place he was retrained!'*

It is not to say that community can meet every need but it should be our starting point to think about every need. If it can't be found in community then perhaps it a specialised service may be useful e.g. a person with Cerebral Palsy may need a physiotherapist with specialised skills however the therapy could be carried out at the local gym rather than at a special day service for people with Cerebral Palsy. In addition this is only one need. The other needs of the person could be met entirely in community.

### **Understanding & Strong Ideas of what Inclusion Is & Is Not (i.e. not a program)**

As we advance into the age of technology and materialism, it seems that community inclusion and community belonging is not just an issue for people with a disability but for all of human beings.

Often what makes it more difficult for the people PLA assists is that they have often journeyed unwittingly into an unfamiliar culture. A culture that has a heightened tendency to believe services, experts or professionals are the only way to meet one's every day needs rather than looking to their neighbour, friends, family or community to meet their needs. For example an interest in art can only be supported in a specialised art service for people with a disability.

The report "SHUT OUT: The Experience of People with Disabilities and their Families in Australia" outlines the continuing challenges for people with disabilities to be included in community life. The Executive Summary states:

*"Once shut in, many people with disabilities now find themselves shut out. People with disabilities may be present in our community, but too few are actually part of it. Many live desperate and lonely*

*lives of exclusion and isolation. The institutions that once housed them may be closed, but the inequity remains. Where once they were physically segregated, many Australians with disabilities now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard."*

PLA stemmed from the struggle of individuals and families who felt that they had been "shut out" and did not belong to the community even with countless services, strong policy direction, good intentions, aspirations and Person Centred Plans! Individuals felt marginalised, segregated, congregated and rather than being seen as citizens they were seen as clients attached to services. Often a person's every need and movement was determined by professionals and services.

Inclusion means different things to different people. Vanier (1988) suggests that community is a place of struggle and sometimes of conflict but also it is a place of celebration, joy and ultimately of human fulfilment. Historically congregate services have been built around people with a disability to protect them from the struggle and conflict that arises in community. But in doing so services often prevent the celebration, joy and human fulfilment that community brings.

PLA does not see that inclusion is a fantasy, an idealist place, somewhere you belong a bit, a choice, a panacea or a beautiful place where nothing goes wrong. Neither is it access, a program, a bus trip, a group outing to a park, "special" groups for "special" needs at the local neighbourhood house or time filling activity. It does not view social inclusion and belonging as a need only of people who have a disability but for all community members.

In ordinary terms "inclusion" is what the human race wakes up to everyday. It's our neighbours, families, schools, associations, friends, businesses and governments. It's an intricate web of experience and opportunity where we belong, learn, love and grow from the moment we are born. It's very "ordinary" and very familiar.

Wills and Jackson (1996) suggested that inclusion in regard to mainstream schooling includes being physically included, socially included and included in regular curriculum. Thus, social inclusion is more than physical presence – it's also a sense or feeling that you belong, are welcomed, connected, have something to offer or reciprocate and are surrounded by a range of relationships other than those which are paid or based on diagnosis. Janet Klees (2005) suggests that we can't force relationships to happen but we can build a context for relationship to grow and

flourish with other community members. Thus enabling and supporting people with a disability to also experience, contribute, learn, problem solve and belong to what is good and difficult about community, can only happen through every-day or typical opportunities. If other citizens cannot participate on equal terms in an experience then we believe it is not genuinely “inclusive” or “of community”.

### **Finding People’s “Hook” into Community Life**

We have found it important to discover what might “hook” people into community life. This is done by discovering and harnessing people’s unique interests or abilities. For example what is the person passionate about, what makes the person “tick”, what gets the person up in the morning, what does the person enjoy most, what is the person good at doing etc. Once a person’s “hook” is found it offers an opportunity for the person to share their common interest, cause, desire or skill with other members of the community. Once people share their interest it also provides an opportunity for people to get to know each other in terms of the interest. In addition if people contribute their skill then others see the person as having ability rather than disability. This highlights that people are more than their disability. Fear of the unknown often subsides as people see people as having interests and skills not that different from their own.

*‘Lauren was passionate about TV and soap operas. Her passion was her “hook” into community life. It was harnessed by her family and she became an usher at a large theatre in the city. This was a great opportunity for Lauren and her self esteem and skills began to flourish. However her family really wanted her to belong and develop friends at her work place. Being a Melbournian Lauren is also passionate about football. Her family then used her passion for the Kangaroo’s Football Club to “hook” her into her work place. They discovered many other passionate football followers! Lauren then went on to attend various football matches with a co worker who even went to the Footy Show with her!’*

### **The Power of Positive Expectations and Assumptions about People**

If one is surrounded by positive expectations and assumptions then they will have a chance to live up to them. Alternatively if they are surrounded by negative expectations and assumptions then they will live up to those too! This is not only about people with a disability but also fellow community members.

Positive expectations and assumptions and high

expectations about people are vital to imagining better as it frees one up to countless possibilities i.e. believing that *all* people seek happiness and fulfillment; have the ability to learn, grow and develop regardless of their age or disability; can love and be love; are equally as important as each other; have strengths and weaknesses; can contribute and become valued; belong to the community; live in their own home with a range of supports.

### **The “Right” Support**

Many of the people we have assisted have complex disabilities. Thus they need personally tailored support to participate in the community. Support workers that have been engaged are more like social networkers or community connectors rather than “Disability Support Workers”. They need to be able to not only research and know the local community but keep their eyes peeled for opportunity and nurture possible relationships and friendships.

Those relationships which have flourished have taken intentional effort. For example invitation, building moments for reciprocity e.g. giving a person a lift to art class, collecting a person’s mail while they’re away, encouraging and enabling community members to support the person (even in small ways), sharing secondary common interests such as Cameron had with cricket. This gradual and thoughtful work of drawing community members into people’s lives will not just happen by chance. It’s a skill that is vital but is not always fostered or recognized and fostered in support workers.

### **Being in the Driver’s Seat: Control & Directing One’s Own Life & Supports with Assistance Support From Family &/or Other Trusted People**

PLA believes people should determine their own lifestyle and if people require support to do this then it needs to respond in a way that is enriching, life enhancing and supports their decision making. This means that people should have choice over where they live, who they live with, what they do, where, when and how etc. People should also have say-so over resources and supports if required. Although this is quite complex for people with communication difficulties they can generally let people know in some way what things, people or places annoy or delight them. The art is in tuning in to people! It is also about engaging and harnessing the knowledge and strengths of those who love and genuinely care about them.

However, PLA avoids defending the choice of segregation or congregation of people with a disability. Until people have had the opportunity

to pursue a typical life of inclusion the choice of segregation/congregation is not a choice but one of limitation based on a set of assumptions about what people want and need and often an inability to think beyond such arrangements.

Most people PLA has assisted have experienced a lack of authentic control over their life and supports. For example people were unable to determine what they did through the day, where they lived, who they lived with, selection, direction and scheduling of support workers amongst many other things. They also lacked knowledge or control of their funding budget. Predominantly such decisions were made by services. As a result people had many restrictions placed on their lives or a limited menu of options.

At a systems level, Fyffe (2008) states that the outcomes of PLA are impressive as it places individuals and families in the driver's seat and reduces the demand on services and government by reshaping the locus of control from services and DHS to individuals and families, renegotiates relationships and expectations and has assisted people to become more resourceful and to see the value of informal/natural/community supports rather than see funding as the only solution to a good life. In addition Fyffe (2008) states that PLA has also had an impact on re-orientating services through the development of individual and family governed collectives, hosting arrangements with traditional providers and assisting with the identification and engagement of natural and informal supports.

The shifting of the locus of control from services back to the hands of people themselves has predominantly been achieved by PLA through "recrafting" traditional congregated, program, centre based or service driven decision making processes. One method has been through assisting people/families to establish Individual Arrangements in which the person (with the assistance of their family/advocates if necessary) is empowered to make decisions over their own lives. To achieve this PLA has assisted people to negotiate an agreement with a service provider to "host" their individual funding. In this arrangement the service delegates conditional authority to the person and family to direct their supports and resources and make decisions over their life. The service takes care of the administration requirements and other components of importance as requested by the person. Such delegation, although having conditions that are mutually negotiated and agreed upon (e.g. meeting legal requirements of employing staff, duty of care, reporting on funds etc), means that people have high degrees of transparency over the use of their funding and authority to use their resources in

a personally tailored manner that meets their needs within funding guidelines and other legal limitations. It also means people are able to chose what they do, when, how and who with. This includes selecting and directing support workers if necessary. An additional benefit is that people have not had to operate a "business" to have their needs met as the agency takes care of tedious administration requirements. Melba Support Services Inc in Melbourne, is an example of a service that has hosted such arrangements with individuals and families for nearly 10 years.

Another method PLA has used is to assist people and families is to create consumer or family governed collectives. Such examples are a means in which people and families who share similar values (of individuality, empowerment and typical pathways) come together in a collective. Collectives have often developed from people coming together to solve a problem or from a lack of service options. The advantage of a collective is that although getting on with their own lives, people have the support of each other, can share some resources e.g. a shared coordinator, knowledge, information and guest speakers etc. Members often inspire and support each other in a manner that is unlike typical service provision. Examples of collectives initiated with the assistance of PLA are One by One, a family governed service to enable its members to gain the support needed to live personally tailored community lives; Living Distinctive Lives, a family governed collective to enable its members with disabilities to live in their own place away from the family home; and Nightlife, a consumer governed flexible, on call night-time service for people who live in their own home. These collectives also have a "hosting" arrangement with a service provider who delegates conditional authority to the collective in regard to day to day operation, membership, resource allocation, staff etc. The benefit of such collectives is that people are genuinely empowered at both an individual level and at a service design and implementation level, while gaining assistance from a host agency in regard to administration. Collective membership can also be a useful safeguard to ensure what is being provided is actually needed and wanted. The collectives although useful to people and families are not for everyone. People and families who join them need to be able to work together and share the same values.

### **Some Thoughts on Safeguarding and Sustainability: Balancing Formal and Informal Supports**

Individualisation based on costly paid supports is not only unsustainable but does not enrich people's lives in freely given relationships that

safeguard people. Individuals with disabilities can be extremely vulnerable if the only supports in their lives are paid. Paid supports are problematic and can be more prone to disappear as their primary motivation is financial remuneration.

Fyffe (2008) argues that PLA has assisted people and families to see the value of informal/natural/community supports rather than see funding as the only solution to a good life. By building people's awareness and motivations to gradually and thoughtfully build unpaid supports, people have not only had the opportunity to build a wider network of friendships and associations but also build a more reliable safeguard around their lifestyle that is not paid.

Another vulnerability of people with a disability is what happens when their family is no longer around. Fyffe (2008) found that PLA has assisted with changing risk by assisting families to answer the question "what happens when I die" through Circles of Supports. Ward, Rodgers and Lys (2007) describe Circles of Support as a group of unpaid citizens who come together to support and share a relationship with a person who is vulnerable because of having a disability. For many individuals Circles of Support have been an intentional strategy of PLA to draw unpaid people into people's lives to think about and safeguard their vision. Circles of Support require good facilitation and clear articulation of purpose, roles and responsibilities. Circles of Support have been useful to people but are not a magical answer. They take intentional thoughtful assistance, perseverance and good values based facilitation. However often Circles of Support can increase links to community. For example one member of Warren's Circle of Support goes to the gym with him, another takes him to Salvation Army Band practice every week and another has helped him with contacts to exhibit and sell his art work.

### **Good Community Lives Don't Necessarily Cost More when the Right Supports are in Place**

As we live in a climate of scarce resources, PLA has a philosophy of thinking "how could we do differently" with available resources. Resources are never our starting point but once we assist the person's to develop their vision, it is then a matter of assisting them to tailor their resources in a different manner. People often save resources via hosting arrangements as they avoid costly overhead fees. As people seek support from the community and build in informal supports and relationships they also become less dependent on paid supports. Thus the staff people employ need to be good community connectors who can research local communities, discover

opportunities, foster valued roles and encourage and foster relationships between people with a disability and other community members.

*'Originally Cameron received a Support and Choice funding package to support his vision of finding work and living in his own place. Through a hosting arrangement Cameron and his family employed a job and community seeker. Six years on he is now employed by a local business and supported at his work place by his co workers. He is also supported to live in his own place with the support of a housemate of his choosing (who receives free rent in lieu of support). His funding package is now only approximately ¼ of the original package and significantly less than the cost of living in a group home.'*

### **Capacity Building & Exploration & Consideration of Options through Value Based Training, Mentoring & Networking**

We have found that one of the greatest catalysts for creating change in ourselves and others is through building the capacity and knowledge. Often people with disabilities, families and professionals can't imagine or see past the current way of doing things. Thus they continue to walk the same path unaware that a different, more liberating and inclusive path might be possible. Often when people become discouraged they may become dismissive and thus even less likely to seek a new path. People need to be inspired, informed and assisted. We have found that it's more likely that when people see that something can actually be done that they will actually believe it to be true.

*"Many thanks for a great weekend – very inspirational especially the realisation that even families who struggle with severe disability have achieved what seems to be impossible. Also the wealth of practical knowledge & the realistic informative way it was delivered – a building of layer upon layer which I felt catered to everyone's interests in the room, so our thanks again. I have worked out an action plan in my head & I hope you don't mind if I briefly run it by you – I would appreciate any feedback you may have & assistance." (SE – parent from Community Vision Building Retreat, 2009 )*

Such capacity building investment needs to be multiple and frequent. PLA has used a number of methods to build people's capacity as one method on its own is not enough. We have found one of the most powerful ways of inspiring people is when individuals and families share their own stories of community belonging and connectedness. Fyffe (2008) found that PLA has assisted individuals, families and service providers to "think differently

and re think" with an emphasis on assistance and examples.

People's personal stories of struggle and achievement bring such richness and truth that is difficult to dismiss.

*"We really enjoyed it [the retreat] and it gave us the opportunity to speak with other families in similar situations and with similar ideals... [it] also gave Chris[husband] and me a rare chance to talk together and mull things over on our minds, not that we got things sorted, but we got things STARTED...the highlight was listening to the personal stories, and I dream of the day when we can tell W's story." (LC- parent from Community Vision Building Retreat, 2009)*

*"I found the 2005 One Person at a Time Conference inspirational, a catalyst for some significant changes in thinking and planning around our 21 year old daughter 'K's' life who has significant multiple disabilities. One of many direct benefits since has been the formation of a Circle of Support around 'K'. The Circle has been successfully active for over 18 months now and has added fun, community, complex planning and many practical benefits for 'K' and all involved. 'K' had some challenging health issues during this time and the support from the Circle also proved invaluable. We have now become members of Living Distinctive Lives which was initiated with the assistance of PLA. This enables planning for 'K' moving out of the family home into her own place which is based on her personality, passions and needs. The shift to planning around 'K's' dreams instead of being paralysed into inaction by the lack of suitable services has been very liberating". (B.S)*

Capacity building should be offered through a range of ways but the underlying factor is that the methods articulate the multidimensional values of uniqueness, community belonging and connectedness and empowerment. Fyffe (2008) noted that PLA builds knowledge and informed choice through training and education events, has encouraged and supported significant lifestyle changes for people, supports the personal development of individuals and families (by increasing confidence, leadership roles and building informal support so people do not feel alone or isolated e.g. people become part of a larger local/national/international network or through localised/personalised supports such as Circles of Support).

Following is an outline of the methods used to build capacity in people with a disability, families and also professionals.

- Values based trainings such as Social Role Valorisation

- Seminars for individuals, families and professionals on particular topics e.g. Connecting to Community; A Home of My Own; Circles of Support; Optimal Individual Service Design, Ethical Leadership, When Dreams Become Reality, Consumer & Family Governed Services
- Family Series on Community Vision Building
- Family Retreat on Community Vision Building
- Bi Annual "One Person at a Time Conference"
- Networking and connecting individuals and families who are just starting out with those who have gone before who can provide good sound leadership, ideas and successes
- Investing in individual and family leadership e.g. national and international networks; sponsorship of visits or attendance at international conferences; developing individuals and families as speakers
- Distributing reading material
- Development of a values based periodical
- Conversation!

PLA makes a strategic commitment to offer capacity building to individuals with disabilities and families as such opportunities are often only available to professionals.

### Opening People up to Dreaming

Once people are inspired we have found that people often ask "where do I start"? Thus people often need assistance to develop a clear vision for the future. This often involves freeing people up to dream about their own life and letting go of the limitations. This begins the process of imagining and thinking about the life they would optimally like to live. It is important not to start with funding, available services, money or past experiences. Dreaming is not about fantasy but opening up possibilities and imaging a good life. Many people dampen people's imagining or dreaming as being unrealistic i.e. it's only possible for certain people. However, often the essence of a dream is quite possible.

Often when people get the chance to dream they really want a life with similar opportunities to other citizens' i.e. to get real work, live in their own home, have friends etc. Such dreams are realistic as we witness people achieving such dreams every day. Often we have found its not people's disability that limits them but rather the restriction imposed by many services and systems. So perhaps the real question is do we believe it's possible and do we have the creativity,

flexibility ability and stamina to craft the supports people may need to achieve their dream?

Warren, for example, had a strong interest in the police force. Some may have viewed his interest as an obsession and the congregated service arrangements originally supporting him stifled any advancement on his aspiration. However, by enabling him and supporting him and his family to dream, Warren's interest was harnessed into what has been a life fulfilling dream that was once thought of as unachievable.

*'After spending many years in disability settings, Warren's family came to the realisation that authentic change was needed for their son and that would only happen if community members became involved in his life. The journey started in 2005 after his mother had been to an event hosted by PLA. With some assistance from PLA and Living Distinctive Lives, Warren's family began to create a vision for a typical, yet unique life for Warren that is lived in community, and that focused on his skills, abilities and passions. To ensure his inclusion his family believed it was important not rely to on human services to do the asking, so claimed back authority. Warren moved out of a group home and now lives in his own place with the natural support of housemates. Rather than attending a day service for people with a disability he now enjoys a rich community lifestyle that includes volunteering at The Police Museum, St Vincent's Hospital, The Salvation Army Café, membership of a gym, contributing to his church, and pursuing his interests in art.'*

We have found that a dream may begin with a few moments. It then has an anchor to gather momentum. The path seems clearer and thinking differently about people and community becomes a natural evolution. It also suggests that anything is possible and people can have a better life.

### **Articulating a Clear Vision for the Future**

PLA has found it important to anchor people's dream into a vision statement so it remains on track. This is often done through trying to encapsulate the dream in a few words by being precisely descriptive! For example the following is Warren's vision statement:

*"To have the opportunity to be on the natural pathways of life, in valued roles that make sense for me. This means I will have the individual assistance to be myself in typical roles, and be enabled to have access to life conditions which are at least as good as the average citizen" (Warren's vision statement, 2009)*

This helps to steer all that is done and acts a point to check ideas or opportunities. It becomes a guide for further action. Thus if an idea is raised

e.g. a work opportunity in a segregated setting it is avoided as the experience is not ratified by the vision statement.

### **Staying with People over Time**

In our lives we rush from person to person, task to task, meeting to meeting hoping that within an instant or a few months we will have a quick fix or a solution to people's lives and it seems that genuine inclusion in the community has eluded us. People and communities are an intricate web of uniqueness, complexity and information. It is an impossible task to "get the job done" in a few months as much of the detail around people and who they are and can be is unseen and unknown by a fleeting visitor. If we are going to connect people sincerely and genuinely to the community and build typical lives then we must be committed for the long term. This does not always mean people, families and communities will need the same intensity of support as their skills will develop and strengthen. However as life throws it challenges and changes, people need champions to be *with* them over time.

### **Conclusion**

Our learning about community would not have been possible without the efforts of the individuals, families and professionals involved in the community living movement. They not only dreamed of an ordinary life typically abound in community but have worked with vigorous determination over many years to make it a reality. Our work is not a panacea but we have found some key ingredients that are helpful i.e. maintaining unambiguous values and ethics about social inclusion, inspiring and educating people with information and "real" life stories and giving them assistance over time to craft a unique lifestyle. We know that it is possible and we dream of the day we will not have to argue and write about what should naturally occur just because you were born!

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# Developing Community Participation: an ABI perspective

Janet Stumbo, Tom Worsnop & Cath McNamara.

## Introduction

Research literature on community participation for people with acquired brain injury (ABI) is minimal. What little there is focuses on people with traumatic brain injury (TBI). This paper therefore draws largely on anecdotal evidence, obtained through lived experience of ABI and learning gained through working with people who have an ABI.

## Complexity of ABI

One of the main challenges in looking at participation for people with an ABI is the wide diversity that this entails. Severe brain injuries (frequently called 'catastrophic') can refer to high level physical, communication, behavioural and cognitive changes, dependency for all ADL (activities of daily living) and social interactions, and frequently concurrent issues such as substance abuse, inappropriate accommodation and family breakdown. Mild to moderate ABI can mean a person does not present with any apparent disability at all, and is often referred to as a 'hidden' disability. There is, of course, a spectrum of presentations between and around these two extremes.

Cognitive and communication barriers resulting from ABI present particular challenges to community participation that are somewhat unique to ABI. This is where there is probably a particular ABI perspective that differs from the range of common challenges facing people with disabilities, chronic health conditions and other groups experiencing community exclusion.

The first point in recognition of difference is because of the 'acquired' nature of the injury, and then the additional complexity introduced where communication or cognition (thinking) injury means the capacity to process the experience of change is affected. In contrast to 'intellectual disability' the issue for people with an ABI is accessing pre-injury intellectual capacity where the 'access pathways' have been disrupted. This is different to supplementing ongoing intellectual development, which may also be a feature of ABI.

This is especially so when the injury has occurred in childhood or youth. A frequently cited example of an inappropriate approach to support post-ABI is where a young person is being considered for school disability supports,

and their intellect is equal to their peers on initial assessment. Difficulties arise over time where new learning is affected by cognitive hurdles such as memory loss, or poor planning, and the young person progressively slips behind their peers. Interventions at early stages will assist in accessing the learning capacity that exists, but often it is not until a consequent assessment indicates a lowering of intellectual results, that interventions are funded.

People with an ABI consistently report their need to come to grips with a change in their 'identity, recognising that they are the same person, but different as well. Concurrently, family (in its broadest definition) also have to understand this process as well, particularly as it relates to changes in the capacity to continue a family role, e.g. 'bread-winner', older sibling or parent. There are also people without family support who have to do this on their own, without the useful reference points that family often provides. The process takes 'as long as it takes' and that frequently needs to be measured in years rather than months or weeks, as would a physical injury.

## Obstacles to Participation

As with other disabilities, people with ABI come from different backgrounds and have unique personal histories and the communities they are trying to re-engage with will differ according to those backgrounds and histories. However there are some common themes coming through from people with ABI about the obstacles they face trying to re-connect. These include:

- "Crushing of hope" by medical professionals is an all too common experience, particularly for people who have sustained severe brain injury. People with ABI and their families report being given the worst possible prognosis and little hope for any substantial gains. This is most vividly reported about the early post-injury period however often persists beyond this. Maintaining hope, while often labeled by medical professionals as "being unrealistic" or "in denial", is seen by people with ABI and their families / supporters as one of the major factors enabling people to begin and persist with the effort to re-engage with life.
- One of the effects of brain injury may be impaired capacity for insight. While stressing the importance of retaining hope and high expectations, it will also usually be necessary for people with ABI to make adjustments for changed abilities. Impaired capacity for insight can make it more difficult for people to see the need for adjustment in expectations and/or behaviour.

- If rehabilitation remains focused on physical and / or cognitive gains and fails to move into the realm of social participation this will affect the individual's capacity to generalise their rehabilitation gains to real life (discussed further below).
- Negative community attitudes, ignorance and intolerance are clearly obstacles for all people with disabilities in achieving genuine community participation. ABI is still very much a "hidden disability". There is limited awareness and understanding, both within the general public and parts of the disability sector, about the range of effects / impacts of ABI and the nuances of cognitive and behavioural disability that may be associated with ABI.
- Follow-up studies of people with traumatic brain injury indicate significant social isolation and negative effects on relationships for people with moderate to severe TBI (Eames et al, 1996; Brzuzy & Speziale, 1997; Olver et al, 1996; Winkler, 2002 cited in Sloan, Winkler & Callaway, 2007; also Douglas and Spellacy, 2000 cited in Douglas, Dyson and Foreman, 2006). Cognitive and behavioural effects of ABI (e.g. lack of social awareness, disinhibition / lack of control, aggression) can have a profound impact on the mutual social engagement needed for genuine community participation.
- People with ABI make up a significant proportion of the cohort of younger people living in isolated accommodation settings such as residential aged care (RAC) and Supported Residential Services (SRS) in Victoria. For example, of the 105 people initially involved in the planning process for the 'My future my choice' initiative, 58% had an ABI (Winkler, Sloan & Callaway, 2007). Difficulties in achieving community participation are compounded by this type of accommodation setting.
- People with ABI are also significantly over-represented in the prison population. Recent work commissioned by Corrections Victoria indicates that 60 – 70% of people in correctional facilities in Victoria have an ABI. It seems that this is becoming a de facto accommodation service for many people with an ABI. While the highly structured environment may suit some people in terms of managing some of the cognitive and behavioural difficulties associated with ABI, release from prison, usually into an un-structured and un-supported environment, can prove too great a challenge. Re-offending and further imprisonment are often the end result.
- Assisted community participation (including individualised support) may significantly assist with social integration / community participation of people with severe ABI (e.g. Douglas, Dyson & Foreman, 2006). However unless people sustained their brain injury through a road transport or work-related accident availability of funding for such support is severely limited. As highlighted by Shut Out, the report of the National Disability Strategy consultations, major reform is needed to achieve an adequate funding pool for individualised support based on level of need.

### **Community Participation for People with an ABI**

Four areas together support community participation for people with an ABI, and all need to be in place:

- A comprehensive therapeutic rehabilitation system that offers the skills and techniques for the re-gaining of capacities lost from an ABI. Two factors of particular importance are the attitude shown during this phase (one that provides hope, is realistic but is not pessimistic, negative and based on a fear of litigation) and a focus on social skills in the person's environment;
- 'Safe places', from which individuals can venture out from their rehabilitation process, to test themselves with their changed identity, capacities and relationship to the world. Frequently this requires peer support, where people with an ABI can find others who understand their experience, and can assist in normalising their experience;
- Individual steps into the world that require support but ultimately need to be 'self-directed', allowing for dignity in risking 'hiccups' or failures, taking away the protective systems and allowing the 'time it takes' rather than imposing timelines;
- Building the capacity of the community to understand and include people with all disabilities. While not explored in this paper, this is an essential element in the inclusion of people with all disabilities as full citizens.

Supporting community participation for people with an ABI therefore needs to account for many concurrent areas of work.

### **Rehabilitation Framework**

A rehabilitation framework is a key concept in thinking about how people with an ABI get re-involved in their communities. This incorporates two key ideas: a medical concept involving targeted

allied health support and other ‘therapeutic’ interventions, and another concept that involves ongoing social re-engagement activities. The intensive phase after injury, where acute conditions often require substantial medical interventions, give way to rehabilitative frameworks, and these to community integration systems, and ultimately to self-management. Maximising opportunity for citizenship and community participation, while often incorporating therapy oriented programs, focuses on re-learning a role in family, community and location. This is a lifelong process and takes place in the ‘real’ world. The process is neither linear nor easily predictable, despite the wealth of knowledge and research that has been done into the recovery of the brain.

Overall evidence seems to indicate that the earlier the introduction of life goals back into a person’s routines, rather than goals that are only therapeutically-accurate, the better the recovery potential. And it is also clear that every individual’s recovery process is unique and is built upon a whole range of pre-injury<sup>1</sup> skills, connections, family supports (or lack of them), and is highly aligned to the age when the injury was received (paediatric, juvenile, and adult injuries are very different in the way they effect recovery patterns).

The rehabilitation framework is not the same as a developmental framework, which has been the basis for much of the development of ‘Disability Services’<sup>2</sup> although the particular supports engaged may be similar. It is not adequate to assume these two approaches are the same. If effective community participation is the goal, anecdotal evidence shows that using developmental concepts has not been a success for people with an ABI. It is like squeezing round pegs into square holes.

The key features of a rehabilitative approach are:

- The restoration of capacities lost at the time of an ABI and acknowledges the person’s pre-injury identity and experience;
- Planning for lifelong improvements in abilities (no matter how incrementally small);
- Shaping an encouraging environment, with supplementary aids and tools (eg memory prompts)
- Addressing the onset of delayed depression (frequently 2-5 years after injury)(Douglas and Spellacy, 2000);

- Addressing post-traumatic responses, in the individual and his/her family and carers;
- Family centred where possible (because family breakdown is a frequent outcome)
- Encourages new identity exploration, where previous roles (eg breadwinner, professional etc) are unable to be continued.

The ‘provision’ of services to encourage community participation may be an essential element in the recovery of capacities lost through an ABI. An individualised approach to this work recognises that each person with an ABI will need a tailored approach to maximise his/her opportunities. However, we are social beings and our identity is in relationship as much as it is individual, and isolation is frequently reported as an outcome for people with an ABI. Re-building a life after a life-changing event like an ABI involves a complexity of personal goals and access to peers where exploration of a new identity can be safe, and where explanations are unnecessary (a particular challenge for those whose communication or cognitive capacity has altered significantly as a result of the brain injury).

### **Some Current Initiatives Encouraging Community Participation by People with an ABI**

While the ABI specific and broader disability service system continues to develop, a range of initiatives are underway to find environmental and organisational ways to allow people with an ABI to steer their own course of social rehabilitation:

- *Self advocacy*  
Brain Injury Matters Inc (BIM) facilitates self-advocacy and community education for people living with an Acquired Brain Injury (ABI). BIM aims to help people living with ABI to realise potential for a full life within a supportive community and increase community awareness about ABI. BIM has links to regional groups including BrainPower in Port Phillip and WESABI in the Western region.
- *Creativity and participation options*  
OMABI was a group created at BIM, joining the ancient meditation mantra OM with the acronym for acquired brain injury. It provides performance and participation opportunities using music as a medium. Sessions explore

<sup>1</sup>The medical term ‘pre-morbid’ is a technically accurate terminology, but also has unfortunate overtones. Significant factors in rehabilitation after ABI are the capabilities and life goals and achievements prior to injury. These can provide the basis of a strengths-based approach to recovery. However they also present the person with a brain injury / their families with difficult comparisons between what was and what they feel the limitations might be in the future.

<sup>2</sup>Under the recent Disability Services Act 2006 in Victoria, the focus of Disability Services in Victoria has intentionally broadened public sector service delivery to incorporate a wider group of disability types including ABI. This has replaced the specifically targeted Intellectually Disabled Persons’ Services Act 1986 and the Disability Services Act 1991, which outlined principles but had ‘fewer safeguards and less regulation of supports and services’ for other disabilities.

improvisation where the creative input of participants is both invited and encouraged in the development of new material.

Ambient Orchestra, an initiative to provide an artistic program that aligns with the emphasis placed on self-determination and choice, social inclusion and increased recreational and vocational opportunity in The Disability Act (2006), National Arts and Disability Strategy and The Victorian State Disability Plan 2002-2012. Objectives are:

- to provide a forum in which individuals are empowered to explore their own artistic voice
- to promote collaboration and musical awareness between the participants
- to foster artistic collaboration and social inclusion between participants and artists/musicians from the wider community
- to provide a results-based opportunity for participants in working towards presenting music of enduring quality to the public.

- *ABI Neighbour-Rings*

Initiated through an innovation grant from the Department of Human Services, this project aimed to look at the feasibility of adapting the Key-Ring model in operation in the UK for people with an intellectual disability, to the needs of people with an ABI.

The momentum for this initiative came from the experience of case managers in the Melbourne Citymission ABI Unit, who were increasingly frustrated by the lack of appropriate accommodation opportunities for people with an ABI:

- whose level of support needs meant they could not manage safely and independently with available supports through disability services or HACC services, in public housing stock, or
- whose support needs were not prioritised high enough to qualify for the more intensive supported housing models (e.g. CRU) available through disability services or similar.

Many were being forced into unsuitable aggregate living in SRS and similar arrangements that did not provide a rehabilitative environment or opportunity.

'Neighbour-Rings' are groups of people with ABI living within easy distance of each other in the community. These people have required substantial support to pursue individual lifestyle choices. The Neighbour-Ring creates partnerships outside of traditional 'disability

service' models, so that participants can actively participate in the local community close to their homes. Participants assist each other to pursue social and other activities, to achieve goals, and to become an integral part of their community

- *ABI Learning and participation group*

This group was established in 2004, using a community development framework, and facilitated through the community development worker at Hartnett House and the Neighbour-Ring Coordinator. The group has evolved over time and now operates out of the Compass Clubhouse in Northcote. It meets monthly, and currently has regular membership of about 30 people. The group does not have dedicated resources, but is supported through the ABI Services Unit and Melbourne Citymission for basics like meeting space, administrative resources and a meal.

The original goal of bringing together people with an ABI who are looking for opportunities beyond accessing services, by providing a framework for building confidence, re-learning skills and testing out capacity from a 'safe' base still remains strong. Further goals for the group are self-managed, with facilitation now provided through the Neighbour-Ring coordinator and the Compass Clubhouse facilitator.

- *Compass Clubhouse*

Piloted using a small philanthropic grant in 2006, and the Transport Accident Commission, and then through a grant by the Lord Mayor's fund in 2007/08, this initiative provides a more substantial opportunity for people with an ABI to move from support and service emphasis to developing independence in life goals, with a particular emphasis on 'work-ordered' days. Current operation is three days per week, with the following work groups operating:

- Administration, which includes membership processing, newsletter and event coordination
- Catering group, which provides both in-house meals for members who attend, and for events such as the recent open day held in brain Injury Awareness Week;
- Gardening group, which now supplies herbs and vegetables for the catering group, and also supports skills development
- IT working group which is offering a range of opportunities to learn computer skills and also supports the IT system development.

Compass Clubhouse is part of the International Brain Injury Clubhouse Alliance, which was founded in 2004, as a collaborative network of Clubhouses that serves persons with brain injury and stroke through the use of the Clubhouse Model. 'A Clubhouse is a community of people who have sustained devastating life altering events and need the support of others who believe that healing is possible for all'.

Sustainable funding remains a challenge, as the Clubhouse model does not fit with any of the activities currently funded through government (although there are mental health clubhouses in operation elsewhere in Australia).

### **Socio-medical Model for the Care of Young People with Severe Acquired Brain Injury**

This model of partnership has been developed from eleven years of experience of caring for Chris Nolan and eight other young people with ABI accommodated in a residential aged care facility. They are representative of a small but very vulnerable group of young people, mostly living in nursing homes, who have similarly complex care needs due to their narrow margin of health. Their care therefore requires specialised knowledge of health crisis management, together with knowledge of how the brain responds following severe injury. All care needs to be planned, co-ordinated in partnership with others, including family, and put into effect by staff with relevant specialist knowledge and experience. The model in practice provides an integrated therapeutic, rehabilitative, restorative environment.

In the socio-medical model of partnership people with severe ABI are regarded primarily as social beings. The philosophical underpinning of the model comes from the view that we are all persons, not in isolation from each other, but in community. An appropriate environment supports and fosters each person's communal place in the world. The partnership model allows for staff, people with severe ABI, families and friends to belong to the one community – it is a reciprocal relationship also involving the wider community.

Many people with severe ABI are unable to articulate their own needs, wishes, dreams and hopes; they depend on others who know them well, to be their 'proxy' – not to speak for them but to journey with them. Participation in their 'care community' and in the wider community will necessarily involve active support from an interdisciplinary, fully integrated and non-hierarchical team. (The 'What Does Chris Want' Group, 2007)

There are also a number of broader disability programs that have been successful in providing skills in community engagement and participation for people with an ABI. These include:

### **Building Better Lives**

This was established by the Summer Foundation to 'change human service policy and practice related to young people in nursing homes (YPINH)', utilising a range of strategies to influence health, housing and disability services policy and practice related to this target group.

- Young People Get Active (YPGA) is a social support group for people with disabilities who are either living in aged care or at risk of admission to aged care. The Summer Foundation is working with YPGA to obtain funding to develop a framework, governance structure and partnerships to ensure that the network is directed by people with disabilities and sustainable.
- The Building Better Lives® Ambassador workshops aim to engage and support a representative group of young Victorians in nursing homes or at risk of admission to nursing home to get involved in systemic advocacy

### **Leadership Plus**

The Leadership Program accepts people with a variety of disabilities who demonstrate through a selection process that they have leadership potential. It offers participants the opportunity to talk to a cross-section of community leaders, to hear their frank opinions and concerns, and learn from their experiences. It allows participants to exchange ideas and work together through a year-long program. The program is accredited through RMIT TAFE (competencies in 6 Units of the Diploma of Community Education) and delivered jointly with Leadership Plus.

### **Conclusion**

Community participation for people with ABI requires a community with enough awareness about ABI to enable understanding of the cognitive and behavioural impacts and required adjustments. A social rehabilitation framework operating within the person's own environment is also a key factor. Most importantly, the energy and engagement of people with ABI themselves, both in their own re-connection and in creating peer-support opportunities, provide the foundation for genuine community participation.

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## Appendix A

### Case Study: An ABI perspective

**Abstract:** Acquired brain injuries (traumatic brain injuries) change people's lives beyond recognition. The case presented here encompasses 25 years in the rehabilitation of one woman who has reinvented herself to meet all the challenges of living with brain injuries successfully. Dr. Stumbo brings you her story as an example of what is possible with motivation and unbiased access to all the allied health professions.

**Introduction:** Each and every human brain on this planet is unique, modified in structure and function by virtue of all of that individual's experiences and education. One cannot make generalizations about recovery and rehabilitation from acquired brain injuries. Every individual is different; every brain injury is different; every course of treatment and the rehabilitation required is going to be different.

The human brain and mind it creates is the most complex thing in the known universe. Neurosurgeons are revered specialists in surgery of the CNS. They are not interested and often have no knowledge of the person attached to that particular brain. To allow them to set the course

of their survivors' subsequent rehabilitation is disgraceful. One medical specialist cannot expect to service all of the damaged mind's needs. To be successful ABI/TBI rehabilitation must remain multi-disciplinary and must be facilitated to access all of the non-traditional medical specialties.

We are going to need the whole range of allied health professionals to rehabilitate our damaged brains. Human brains are plastic enough to change and adapt throughout adult life. It can be done; but not without chiropractors, speech pathologists, physiotherapists, clinical psychologists, occupational therapists, learning disabilities specialists, behavioural optometrists, vision therapists, Feldenkrais practitioners, case managers and even general practitioners. You are also going to need the whole-hearted, optimistic participation of the injured individual, himself, because he is the only person on this planet who can change his brain (Doidge, 2007). Brain injury rehabilitation can be as complex as any human being.

This presentation describes the impact of the established medical professions and the various allied health professions on one individual's remarkable rehabilitation.

**The case:** In June 1984 Dr. Janet Stumbo, the local veterinarian, was pulled all but dead from the wreck of her car wrapped around a tree in Tura Beach, New South Wales. No one expected her to survive that night. She did survive. Dr. Stumbo was released from Royal Canberra Hospital in September that year totally blind in one eye, partially blind in the other, and in continuous pain, which she was told to expect to suffer for the remainder of her life.

Not offered rehabilitation by the professionals at the hospital, shut out by her grieving husband, and never allowed to return to her home: Dr. Stumbo was forced to turn to the opportunities she could find in her former and future communities of:

- Clients and friends – for love and support.
- Former classmates from veterinary school in Melbourne- returning to
- work as a veterinary surgeon after six months of supervised trials.
- The university in California where she earned her first degree
- Finally returning to Melbourne to live in her last Victorian neighbourhood, across from her own veterinary faculty.
- Men and women of the Wyndham Rotary Club
- Toastmasters International members of District 73.

## Discussion

It was two years before she found a chiropractor to relieve her of that headache. Two years before any effective rehabilitation could proceed. Once Dr. Stumbo started cognitive rehabilitation with a speech therapist, she drove her own rehabilitation towards return to veterinary practice.

Because her life was totally disrupted these rehabilitative efforts and professionals occur in Victoria and the ACT in Australia and California and Washington in the United States. A significant factor is that this individual kept up with intense efforts at her own rehabilitation in spite of her consistently hopeless medical prognoses. From what the neurosurgeon said at that time, it was obvious that it had already been determined that her brain was too badly damaged to salvage. This is the all too common scenario for the majority of brain injury survivors leaving hospital to face their savagely altered lives. Any motivation most of these victims may have mustered is crushed by their neurosurgeons insisting that they KNOW, no matter what the survivor does, he will not improve.

Starting out ignorant of her need for rehabilitation, she had to stumble into it herself. It would take a remarkable individual with a set of amazing attitudes to overcome that negativity and pain to accomplish any kind of rehabilitation. And so it did.

She returned to Victoria in 1992 to train for and pursue a second career more within her present capabilities. It was at that time she was sent to the CRS. After days of neuropsychological testing the consultant Neuro psychologist confirmed the conclusion it had taken her years to arrive at: she was no longer fit for veterinary practice. Her biggest disability at this time was due to loss of interpersonal skills – those frontal lobe executive processes so often damaged in car

accident survivors. The rehabilitation specialist there suggested she go home and watch TV sitcoms to see how people related to each other. She had to teach him about cortical blindness! Worse than that the show he thought would be best to watch was the Simpson's – a cartoon about a dysfunctional family headed by an alcoholic with brain damage. Unbelievable.

This high functioning, intelligent individual still had to turn to her community for effective rehabilitation. In this new community it was a Rotary club that came to her rescue. Thinking interactive interpersonal skills training would have to be better than watching television she joined when invited by this group of community-minded men. She made this a positive and successful interaction by being straightforward and willing to pitch in and help them in every way she could.

## Conclusion

It was this mature, intelligent, well-educated doctor's former communities that offered her the hope: friendship, love, and chance to work again that allowed her to recover and return to a useful life. On release from hospital she was nearly blind and in continuous pain. Now, 25 years later, seeing 6/6 with each eye, having earned a Master of Science degree, she has successfully created a new career as a published writer and speaker. If you want to examine the gory details: the course of her rehabilitation is chronicled in *Endless Journey*, first edition published in 1998, second edition published in 2006.

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## **The Pearl in the Middle. A Case Study of Social Relationships with an Individual with a Severe Intellectual Disability**

*Hilary Johnson, Jacinta Douglas, Christine Bigby  
& Teresa Iacono*

In an increasing fast paced electronic communication driven world, people with limited abilities to communicate maybe isolated and under resourced. These people, who may have additional physical and intellectual disabilities, frequently experience a lack of community acceptance. Various pieces of legislation and policies have been enacted to encourage the inclusion of marginalized groups, particularly those with disabilities (Department of Health, 2001; Department of Human Services, 2002; Lecompt & Mercier, 2007). The drive to strengthen a sense of community belonging is worldwide and some successful approaches such as “involving all neighbors” to include people with disabilities have been demonstrated (Carlson, 2000). There has been a growing recognition that for people with disabilities to feel included, there is a need to develop and maintain social networks in order to gain a sense of personal connectedness and being part of a community.

People with intellectual disabilities comprise 3% of the population (Wen, 1997) and many experience difficulties with communication (Australian Institute of Health & Welfare, 2003). The more severe the intellectual disability the greater the likelihood of other associated disabilities such as limited speech (Arvio & Sillanpää, 2003). People with severe or profound intellectual disabilities fall along a spectrum of communication ability, from non-symbolic (i.e. unable to use words pictures or signs), to limited linguistic (i.e., some ability to combine symbols flexibly) (McLean, Brady, & McLean, 1996). Even individuals with limited linguistic skills predominantly use informal means of communication such as body language, gesture and facial expression. People with limited formal communication are often ignored and denied opportunities to participate in community life. In order to communicate effectively, these people need good communication partners to scaffold and support communicative interaction.

Until the 1970's most adults with more severe intellectual disability lived in large congregate care institutions but are now living in the community, often in small group homes. Small group homes comprise 4-6 people with an

intellectual disability who are supported by paid staff. Many of the residents attend segregated day centres with community visits (for example shopping, bowling or visiting parks). The move from large institutions to living in the community has not automatically resulted in making new friends or social inclusion. Concomitant with moving from large congregate care facilities has been the transition from a medical model towards a social model of service provision. An essential element of the social model required support staff to accept each person with a disability and celebrates that person's strengths (O'Brien, O'Brien, & Mount, 1997). Coles (2001) suggested this change has proved the most difficult for staff supporting adults with limited communication particularly where support staff are providing opportunities for community engagement. The barriers of segregation and institutionalization still remain for people with severe and profound disabilities; their relationships are usually limited to family, paid workers and sometimes other people with intellectual disabilities (Kennedy Horner & Newton, 1990).

Social networks for people with severe intellectual disabilities are often small in number. Robertson et al (2001) stated those people living in community residences had networks with a median of six network members and a range of 0 to 20. For some people their social network was entirely comprised of paid staff. Paid staff have sometimes been discounted as being part of a social network as their presence, although frequent, has not been voluntary. However positive outcomes from staff and client relationships have been reported in the research literature. Some paid staff have reported working in the same house for years and enjoying spending time with residents (Forster & Iacono, 2008). In a study by Newton, Olson & Horner (1995) paid staff members sought to maintain relationships with residents after leaving the workplace and visited or took them out regularly.

However social networks that rely solely on paid workers can be unstable due to a high turn over in staff (Hatton, Rose, & Rose, 2004). In addition staff members may not always be good communication partners as they have been reported to demonstrate difficulty in recognizing non-verbal behaviours (McConkey, Morris, & Purcell, 1999) and have indicated problems in adjusting their communication style to meet the needs of the people they support (Purcell, Morris, & McConkey, 1999). Light (1988) stated the purposes of communication are to share information, get needs met, to fulfill social etiquette and for social closeness; however as requests and directions often dominate support workers interactions the social interaction functions of communication maybe limited.

The role of communication in contributing to the quality of the relationship is not fully understood but it is generally recognized that the quality of personal relationships is more important than the quantity of relationships (Morgan, Patrick, & Charlton, 1984; Newton, Horner, Ard, LeBaron, & Sappington, 1994; Newton et al., 1995). The amount and types of social support provided in a relationship is indicative of the quality of the relationship. Social support is underpinned by a notion of giving and receiving, a concept of reciprocity that comes from exchange theory (Wellman, 1981). The role of reciprocity in relationships has not been extensively explored in the social networks of people with severe intellectual disabilities. Robertson et al (2001) in a large study of over 500 people with intellectual disabilities stated it was unusual for these adults to provide support to others or to demonstrate reciprocity.

Smaller studies that have taken qualitative approaches to investigating relationships between people with very limited communication and their social network members have begun to demonstrate the existence of reciprocity (Bogdan & Taylor, 1998; Dennis, 2002; Newton et al., 1995). The components that encourage reciprocity in a relationship has not yet been determined nor whether a style or mode of communication maybe a facilitator. Bogdan & Taylor (1998) analysed over a 100 interviews comprising staff family and friends and emphasised an important perspective of seeing the *humanness* in people through (1) attributing thinking to others, (2) seeing individuality in others, (3) viewing the other as reciprocating, and (4) defining a social place for the other. The authors emphasised the person centered approach of their networks members and found this impacted positively on the relationship. They suggested accepting, reciprocal relationships were formed where the networks members were either family, had religious conviction, believed in the principles of social justice or became friends through having fun together (Taylor & Bogdan, 1989)

Newton et al. (1995) confirmed the ability of people with severe intellectual disability to participate in reciprocal relationships, through interviews with fourteen people who chose to be ongoing social network members for people with limited communication skills. Some social network members discussed how they felt appreciated by the person with an intellectual disability. One member commented that she could unburden herself because her friend had "no compulsion to fix things" (p. 389). The authors discussed the fact that that network members commented on the differences in communication modes, but this

did not seem to impinge on the closeness of their relationship.

Dennis (2002) analysed data from focus groups comprised of staff members identified as good communication partners. She found that communication partners' personal beliefs and values in recognising the importance of communication were important to successful communication. These partners attributed their success to having a strong belief in the communication abilities of the person with a disability, a commitment to the person, respect for idiosyncratic ways of communicating, an awareness of their own personal attributes and limitations, and an ability to change themselves. These communication partners embodied the tenets of person centred practices.

The research literature does not adequately describe the communication skills of people who are symbolic but non-linguistic: that is, those who use conventional symbols, such as spoken, signed or pictured words, but do not combine them in linguistic units. From the limited published information on the social network of these people it cannot be assumed that their aspirations are the same as for people with milder intellectual disabilities who have more advanced communication skills. Advanced communication skills allow a person to engage in conversational interactions around a diverse range of topics which may provide the basis of shared interest for relationships to develop. Little is known about the composition of the social networks of individuals who are non-linguistic, the role of communication in those social networks, how relationships are developed and maintained and how social support functions. If community inclusion is an important goal for all citizens then it is imperative to better understand the communication of people with severe intellectual disability and how social relationships are initiated, maintained and developed.

This paper describes the communication of an adult with a severe intellectual disability who is a symbolic but non-linguistic communicator and how her communication is perceived by members of her social network. In doing so it seeks to answer these research questions; (1) what strategies are needed to identify preferred social network members? (2) What modes of communication does the adult with a severe intellectual disability use? (3) In what way does the ability of the network members to interpret the communication of the adult with a severe intellectual disability determine their relationship? This data was collected as part of larger PhD study.

## Method

### Design

As little is known about the communication and social network of adults who are non-linguistic, a qualitative approach to data collection and analysis was taken. Qualitative methodologies are appropriate to use when trying to understand an area about which little is known (Morse & Richards, 2004; Strauss & Corbin, 1990). Grounded theory methodology was chosen as it provides a way of understanding complex human phenomena, with the resulting theory grounded in the issues that people perceive as important in their lives (Mills, Bonner, & Francis, 2006). Grounded theory also represents a rigorous approach to extracting meaning from participants' experiences (Schwandt, 2007).

Glaser & Strauss (1967) originally developed the grounded theory approach to collect and analyse data that incorporated a symbolic interaction framework. The focus of symbolic interaction is on understanding the shared meanings that emerge from interactions. Strauss and Corbin (1990) further developed grounded theory analysis by utilizing detailed coding systems (Charmaz, 2006). A central feature of grounded theory is that data collection and analysis occur simultaneously, where the data are compared and contrasted using a *constant comparative* method. In addition, grounded theorists emphasise the centrality of *theoretical sensitivity*: that is, the way data are handled, coded or questioned is about developing theory, which questions and opens up new possibilities. Data continue to be collected and analysed until no new categories or concepts can be garnered and saturation is reached. Charmaz, (2005), formerly a student of both Glaser and Strauss, has maintained the basic tenets of grounded theory but differed from Glaser by emphasising the importance of a constructivist approach. The constructivist approach acknowledges the importance of a subjective reality and the role of the researcher in developing meanings. Researchers who have taken a constructivist grounded theory approach have examined how people establish meanings, why they establish those meanings; furthermore they have included the researcher as an integral part of the process, a co-producer and verifier of meaning (Charmaz, 2000).

A grounded theory approach that is based on symbolic interaction framework and includes a constructivist approach is suitable for research in the area of communication where little is known (Skeat & Perry, 2008). The data presented in this paper consists of observations with one participant and her social network compared and contrasted with information from interviews. The

data (interviews and field notes) were entered into Nvivo 8, coded line-by-line and examined for *invivo* codes (descriptive terms used by interviewees). These codes were then re-examined in a process of focused coding as the data from each interview and field notes were compared and contrasted. Saturation was reached when no new categories emerged. As data collection and analysis is in progress for other participants the development of a theory is not yet complete.

### Ethical Approval

Ethical approval for the study was granted through La Trobe University's Human Ethics Research Committee and Monash University's Standing Committee on Ethics in Research Involving Humans. Informed consent was obtained on behalf of the participants with intellectual disability from their next of kin, and directly for the participating support workers and participant's family.

### Participants

The participants included a central participant and that person's social network. Sandra (pseudonym) was identified as having a severe intellectual disability and being a symbolic but non-linguistic communicator by a staff member from a Day service in Melbourne. A consent form to participate in the research was completed by her parents. The selection criteria for the central participant were being aged over 18 years with a severe intellectual disability, independently ambulant, living at home or in a non-government group home and having contact with one or more family members. The latter criteria ensured the participant would have long term contact with some unpaid members in the social network. Communication criteria included adequate hearing for speech (to ensure any difficulties with understanding speech were due to cognitive issues not a hearing impairment), an ability to recognise photos and pictures, the ability to expressively communicate with less than 50 words/signs and to be non-linguistic (unable to flexibly combine symbols).

The definition of what constitutes a social network member in the research literature have included (a) people who are important or really liked by the central participant (Forrester-Jones, Jones, & Heason, 2004; Kennedy, Horner, & Newton, 1990) or considered important right now (Antonucci, 1986); (b) those who have had recent contact, such as seen in the last week (Renblad, 2002) or two weeks (Newton, personal communication, August 7, 2007) or been in contact in the last month (2001); or (c) people who have a special bond or provide social support (Krauss & Erickson, 1988; Krauss, Seltzer, & Goodman, 1992). Some social networks also have exclusion criteria, such as excluding

paid staff (Dagnan & Ruddick, 1997). For this research the author adopted four qualifiers for people to be termed social network members: (1) people whom Sandra could name when not in her presence, (2) people with whom interactions were positive and in which Sandra showed pleasure, (3) people with whom an interaction/activity had lasted more than fifteen minutes (Newton, 2007 personal communication), and (4) people who had known her for several years. Each person needed to meet a minimum of two criteria to be deemed a social network member.

In addition to observing interactions the researcher asked the family and day centre staff to identify people important to her. The family identified one ex-support worker who was in occasional contact (a couple of times a year) with Sandra. However this person was only available for a phone interview. This person, nominated as a friend and who met criteria was the only person not interviewed or observed with Sandra. Some of the Day support workers suggested peers who liked Sandra or with whom she had shown pleasure. There were only two peers who met the criteria of a social network member.

### *Procedure*

The initial meeting with Sandra occurred in the Day service where the researcher was introduced to her while Sandra was making a sandwich for her lunch with a disability support worker (DSW) in the kitchen. Once lunch was made, she was observed during interactions in the lunch room. After lunch an attempt was made to engage her in completing a formal communication assessment—the Peabody Picture Vocabulary Test – III (Dunn & Dunn, 1997) – but after pointing correctly to a couple of test items she lost interest. Subsequent attempts received a similar response and the test was abandoned. Her program file contained copy of the Triple C (Bloomberg & West, 1999) that had been completed two years previously while she transitioned from school to the Day service. The assessment indicated she was at an advanced symbolic stage of communication. This assessment and the initial observations indicated Sandra reached the criteria criterion of being non-linguistic for inclusion the study. A subsequent discussion with the program manager identified Sandra's timetable and the activities in which she participated. As Sandra refused to leave the centre for community based activities all programmes were centre based. She was willing to participate in only two centre based activities and when not in one of these programmes she sat in the lunch room which was located outside the room in which she was based. Here she had a view of everyone moving around the centre and there were many opportunities for interaction.

Participant observation occurred in the lunch room, when she was cooking in the kitchen, and during programme time in her group room. Engagement with her depended on her mood and interest in the interaction. A total of 10 hours was spent observing on 13 separate occasions. In addition a video of a program in which she participated was viewed.

A meeting was organised at her home where the study was discussed with Sandra and her parents. A worker from a behaviour intervention support team also attended. Her parents provided reports from an educational and developmental psychologist when Sandra was 12-years-old. The reports were based on observation, interviews and formal assessment and concluded she had a severe intellectual disability and a moderate Autism Spectrum Disorder (ASD). Sandra was also diagnosed with epilepsy when 3- years-old and still experiences seizures.

Her parents outlined her weekly timetable in order for the researcher to organise to attend her activities and meet frequent communication partners. Over the last year Sandra had been reluctant to leave the house and all social activities were house based. A total of 21 hours were spent observing Sandra at home on 13 separate occasions. At home she spent the majority of her time watching TV –either in the front room, or in the back room located in the kitchen. She also had a TV in her bedroom but rarely chose to go in there.

Observations occurred over a five month period. During that time members of her social network were identified and interviewed. The aim of the interviews was to supplement the information gained through the participant observations and understand the social network member's perception of Sandra and their relationship. Interviews ranged from ½ an hour to 1.25 hours and utilised an unstructured format. The interviews opened with the question "Could you tell me about your relationship with Sandra and how communication in this relationship occurs?"

The interviews were digitally recorded and later transcribed. One of the interviewees who had an intellectual disability had difficulty with the unstructured format and pictures were used to clarify responses and keep attention to task. Individual photos of social network members who were interviewed were presented to Sandra and her reactions transcribed.

### **Results and Discussion**

After analyzing the data a time was set aside to provide feedback to the Day Support Workers (DSWs) and family (during the regular staff meeting time at the end of a day). A time was

also offered to the parents during which Home Support Workers (HSWs), family and Sandra could be involved. A person centred approach was utilised that looked at portraying Sandra's strengths and abilities. This approach emphasised the different roles she played and how she used her communication skills and engaged others. Sandra's communication included the use of facial expression, body language, touch, objects, gesture, key word signs and spoken words and these modes varied in frequency across the roles. Her communication modes fulfilled three main purposes. These were to get her needs met, to share information (mostly about other people) and for social interaction and social closeness. Analysis of the data suggested three major aspects as to who Sandra was, which were captured in the roles of the 'lioness', 'anxious child' and 'entertainer'. The term lioness was an in vivo code suggested by a DSW but underpinned in transcripts of interviews with terms such as "track" and "lunge". The anxious child was observed by the researcher at the day centre and the term "anxious" appeared repeatedly in the interviews. The entertainer role arose from the enjoyable times experienced by all in her network.

As a lioness she exerted control on her personal belongings, her personal space and her relationships. She communicated this control predominantly through informal means such as the use of objects, her body movements, facial expressions and touch. One of the objects which was central to many of her interactions at home, was the TV.

*"It can also be pretty frustrating because she occasionally swaps channels, turns the volume down, turns the volume up. I mean she likes to, I think that's sort of a bit of a power thing with her (family)"*

Sometimes she used words such as "wait" (which meant stop, don't do anything) and "go away" used to terminate or signify impending anger. Sometimes she would also say "hand hand" as if she wanted to hold it but as you came close she would sometimes reach out to strangle your neck. Her powerful lioness presence was evident across both environments. Her social network partners observed her facial expression and body language carefully while noting her speech and tone of voice. At the Day centre those who did not know her well avoided interactions.

*"She's a private person and um she has her reasons if she doesn't want you in her space, if she wants to bring you into her space. Yeah we have a fairly good sort of um relationship but I am always a bit wary." (DSW)*

Her need to control appeared to be also driven by a high level of anxiety. The word anxious was

used by one of the DSW when asked to describe Sandra in one word. Sometimes Sandra's anxiety appeared to be overwhelming and she would seek others to help. Here she became child-like reaching out for comfort and was visibly distressed. Her anxiety was usually communicated through her body language, facial expression speech and tone of voice. As her anxiety levels varied from demonstrating her vulnerability and desiring comfort to lashing out when others came close, social network members commented on how this was not always easy to interpret or understand.

*"So there things where she sort of does this, and I mean a lot of people will look at that and get confused because she sort of tenses up and shakes her hands and I know immediately that that means she's anxious or a bit worried, that kind of stuff and a lot of other people that haven't met her very often sort of get a bit (family)*

*She does get very anxious and, for reasons that probably you're very aware of too. You want to minimise that anxiety. And sometimes because her dad was away, I think that that might have added to the anxiety. But she was constantly repeating, "Mum, Dad, home, home," you know like, and she does that quite often." (HSW)*

The words she used when she was anxious were sometimes difficult to understand and sounded like she was using a language other than English. These were sometimes used in fun situations but also present when anxious and could indicate an escalation of her anxiety. One of the DSWs noted her mood could be complex to interpret and suggested a need to intervene.

*"I don't know whether it's anxiety or something I don't know what's going on with her, but um yeah I just try to redirect her into thinking something else she goes "farfar" bizarre gibberish words she says." (DSW)*

Although Sandra's behaviour could be both puzzling and frightening, network members commented on the fun they could have with Sandra. Sandra's third role was that of an entertainer. In this role she played a mimic, copying accurately peoples' facial expressions and subtle nuances, she would repeat words, sometimes sounding like a broken record, she could be outrageous and outgoing, dancing energetically. Although she used speech, her range of facial expressions and body language conveyed powerful messages. She reached out to people by mimicking them and playing games. One of the support workers noted, "Well I touch my lips a lot and I haven't noticed that I do that and now every time every Tuesday Sandra is going "mmm" and that's exactly what I do."(HSW) This ability to mimic and share was seen as a positive skill and was valued by network members. Mimicking was often relationship

building as the network members felt Sandra was individualising her responses. Mimicking also provided some safe ground to interact.

*“And also more on a sort of one to one level of communication, because you’re communicating through laughing and watching something together as opposed to try and have direct dialogue which is impossible. So it probably makes her feel a little bit better because you don’t need to have a thousand words, you can just laugh and make faces.” (family)*

Mimicking also included repeating words and these could result in enjoyable interactions. Her father explained

*“So if I’m here and she wants attention it’ll be “Dad, Dad, Dad” and it really won’t stop until you go up there, and she’ll say “sit, sit, sit” and you sit there for a while. Then she’ll say “talk, talk, talk”. So you sit down and say “what do you want to talk about” and she’ll go “talk”, and you go “what do you want to talk about and she’ll go “talk”. I say “do you want to talk about school” and then I’ll say something like “Katie’s a good friend” and she’ll go “friend.”*

Sandra’s behaviour was also seen as outrageous and defying convention. A HSW commented on the enjoyment she experienced witnessing Sandra’s behaviour.

*“She does what we would all love to be able to do and that is punch the person in the face who just stole your car park, or take your pants off when you’re hot and just sit there and not give a toss, stick your finger up your nose or scratch your backside in public or your front bits or whatever ... she does and then things like when she does dancing and then she comes home she just cracks me up.”*

Sandra’s limited verbal communication did not limit her interaction with people. However reading her mood and understanding her communication was vital to the safety of the network member and affected the mode and frequency of their interactions. A family member stated she was the “barometer of the household” and on entering the house visitors would be warned when the lioness role was active. Social network partners learned to read the nuances in her behaviour and react accordingly.

*“its easy to be a little bit wary of Sandra I suppose, and I started out that way. So I started making sure I got a smile out of her and a sort of friendly response before I would approach her.” (DSW)*

The Day Service presentation was attended by twelve support staff and a program manager. Only three of her social network DSWs were there as others were driving buses, absent from work or doing other tasks. All who attended responded

very positively and robust discussion ensued with suggested strategies to increase and improve interaction. These suggestions included increasing possibilities for short interactions and capitalising on her interest in certain people by assisting her to help at the Reception desk so she could be part of everyone arriving and/or leaving the centre. One DSW, although agreeing with suggested strategies, stated he could not greet her several times a day as greeting a person once was all that was necessary. A few staff members acknowledged the identification of her roles helped them understand her behaviour, particularly the lioness role. One staff member reported how the presentation had helped her to really know Sandra.

### *Social network*

Sandra’s social network was identified using the previously described criteria. In addition photos were taken of the fourteen members of Sandra’s social network. The photos were intended to provide a method by which Sandra could indicate preferences of people in her social network and confirm or deny the proxy report. The social network identified by the researcher was either through observation of Sandra and her interactions and/or suggested by people who knew Sandra well. The network consisted of four immediate family members, three HSWs, five DSWs and two peers with an intellectual disability. Two additional peers were suggested to be people Sandra liked but she showed very little interest in either of them. The photos of family and HSWs were presented to Sandra in her home and she appeared delighted, as demonstrated by going through the photos and naming people excitedly. Most of Sandra’s spoken words consisted of proper names and she often named people when she saw them or heard their name. The next week photos of DSWs and peers were added. She was again very excited. After a couple of days she stopped taking the photos to the Day centre. However her family reported she brought them out at home to show strangers and friends of her brother. As she went through these photos the warmth in her tone of voice indicated those people she appreciated most. After a few weeks she stopped naming all the photos and concentrated on a few, her parents, her brother, one home support worker and sometimes her two peers. This activity suggested these six network members were the ones with whom she felt the closest.

Her home social network was relatively stable. Three of the family members lived with Sandra and had known her all her life while the fourth (Sandra’s brother’s partner) had known her for less than ten years. The HSWs had known her from less than one year to over ten years, one of them having met her when she was small and

then worked with her most of her life and another having worked with her when younger, left to have a baby and then returned. The DSWs had known her from one year to three years and her peers from less than six months to three years.

Although some support workers stated Sandra preferred males only eight of her network were male. Eight of her network saw her daily so interacted frequently. The social network was dense with most people knowing of each other but only Sandra knew everyone. The DSWs at the centre did not know the HSWs and not all of the DSWs knew the parents. One of the DSWs was a bus driver and had briefly met some of the HSWs.

Of the two peers, one had only known her for a few months and was very part-time. He stated he was merely helping the staff with lunches and showed some concern about Sandra's aggressive behaviour to others. From his interview responses it appeared Sandra's interest in him was not reciprocated. The other peer who had known Sandra for a few years seemed to enjoy being with her. Sitting with Sandra entailed sitting in an open lunch room in the day centre where there was a lot of interaction and this may have increased the enjoyment factor. His communication was difficult to understand but he seemed to enjoy talking and Sandra did not interrupt. When asked what he liked about Sandra he responded "just talking". The staff supported peer interaction with Sandra by giving each of the peers a role, such as helping out with her lunch. This support meant that the peers received additional positive attention from the staff. Sandra could sometimes be encouraged to join in a group activity if one of the two peers also attended.

Although Sandra had limited communication and could physically attack people, people were still attracted to her and reciprocal social support was identified from analysing the network member interviews. Individuals in the network reported receiving from Sandra a feeling of enjoying her company, love, personal satisfaction, and feeling fortunate. Taylor & Bogdan, (1998) considered the first three elements to be part of an accepting relationship. The first two elements – enjoying her company and receiving love – were seen most often in the home environment where Sandra appeared the most comfortable.

The feeling of having fun and enjoying keeping company emerged from Sandra's ability to entertain and play games whether it was mimicking another's movements, repetitive word games, dancing wildly or copying the wrestling on the TV. Her sense of humour and fun was infectious.

*"When she's not being a pain in the arse she can really brighten up a room. Like sometimes when she comes home from school and she's been doing dancing or disco or whatever, probably popping around and I'll come out and she'd be lying on the floor trying to do a dance move or stretching or you'll come out and she'll be sort of listening. She'll be sort of thundering backwards and forwards and it's just, she has a real freedom."* (family)

Her ability to demonstrate love was identified most clearly by family members.

*"I just love everything about her. I love her sense of humour. I love her affection towards me. I just love the way she looks, you know, how she looks at me sometimes."* (family)

Her mother recounted an incident to emphasise the delight she had in her daughter. It concerned an integration aide (Ben), Sandra had had at school for several years. Ben had a partner, Sue and they would visit Sandra. Sandra used to walk with them but always between them, Ben then Sandra and then Sue. "She's really telling him what your place is, this is how I am, the pearl in the middle."

Support workers from the home and day centre reported feeling personally satisfied working with Sandra. Partly it was the challenge of supporting Sandra and a feeling of achievement when mutual respect was accorded.

*"So yeah, I really find sitting back and watching her how she does look at certain people or how she responds to the way people talk to her and all that and yeah I do get something out of her. I do actually enjoy the shift."* (HSW)

Another said "Like when we're dancing and stuff it makes me feel that I've made a difference to her day" (HSW). A third HSW commented on the positive response she received from Sandra on showing her new baby "she prefers males. So to be able to be like that with her is actually I guess quite a privilege to think I've actually broken down that stereotype."

However the challenge of supporting Sandra also made some of the network reflect on their own lives and commented on how grateful they were not to have this challenge (a child with a disability) in their own family life.

*"There with the grace of God goes I, I have two sons, I have five grandchildren and I look at her and the others and I think well it was only one gene that perhaps caused her to be this way, it could have been my kids. So I consider that I am very blessed in that respect."* (DSW)

*It also gives me a reality check that how blessed I actually am to have a child of my own and how*

*very lucky I am to do that. But it also you know because I work with lots of people's other children and it just gives me a really good reality check that, you know, some people do it really tough and have to strive really hard".(HSW)*

## Summary and Implications

Facilitating community inclusion with people with severe intellectual disabilities presents with complex issues. Finlay, Antaki, Walton & Stribling (2007) stated "inclusion is not just being in public spaces but is also about respectful, mutual exchanges between individuals, which are rewarding for both parties" (p.532). This statement suggests developing an individual's supportive social network can assist with the processes of inclusions. This case study of Sandra highlights the centrality of communication issues in both the development of a social network and understanding how it is sustained. Sandra is an adult with a number of labels, severe intellectual disability, autism spectrum disorder, seizure disorder, non-linguistic communicator and challenging behaviour. Beyond the labels is a woman whose spirit, actions and emotions engage others. Currently Sandra has chosen to limit the public spaces in which she participates in order to feel secure but has clearly initiated maintained and developed reciprocal relationships with family, support worker and peers.

Her network, excluding family, consists predominantly of paid and domain specific relationships. She is seen by those who know her as an attractive person and one with whom interaction can be challenging, but is valued. Her relationships at home are the most stable. Two of her home support workers have supported her for several years, both returning after work breaks. One HSW reported she could not see a time in her life without Sandra being present. This same HSW also attended some family functions primarily driven by her interest and connection with the family. This commitment to support the family was also echoed by some DSWs.

A consistent approach by the people in a network can facilitate familiar routines, lessens anxiety and promotes opportunities for interaction. Attending a day service allows a large number of possible interaction opportunities, often brief and repeated. Some but clearly not all of these may result in the inclusion of new members in a person's network. Conversations are often not conventional in form but they provide satisfying interactions for both parties. It is expected that experienced staff will facilitate interactions between new staff and the people they support as well as facilitating peer interactions between them. However staff do not routinely share the way they co-construct

successful interactions with each individual person with whom they work, and may be unaware of their own skills, or that their modes of interaction differs from those of other staff members. Sharing knowledge about the constituents of successful social interaction with an individual is dependent on the opportunity for discussion between network members from different interactional contexts. As successful interactions underpin possibilities for relationships, it seems critical to take the time to analyse their nature. This requires opportunities to share knowledge and reflect on interactional practices which may also produce more and varied opportunities for social engagement. In services where there is turnover of staff, or limited time for regular staff meetings, there is a danger that knowledge about individuals' interaction preferences may be lost when network members leave.

Understanding and learning to interact with a person with a severe intellectual disability requires time, relinquishment of control, a focus on their interests and a commitment to the interaction. The type of communication exchanges that are satisfying for people with a severe intellectual disability are mainly social exchanges. Where support workers focus on pursuing social interactions, they can develop enjoyable relationships and find personal satisfaction in their work. Although service co-ordinators may try to match staff with particular individuals, group programs may mitigate away from this. There is a considerable focus in day services on programmed activities; however the elements that contribute to having a good day are more likely to be embedded in the interactions between network members. These interactions are more important per se than the programmed activities, although the activity does provide a joint focus within which to share time.

Spending time in the community may not be the best option for all people with an intellectual disability. People like Sandra clearly benefit from frequent and brief interactions with a range of known people in secure and more predictable environments. Given that paid and family network members find satisfaction in relationships with people like Sandra there is no reason to suggest that others may not also enjoy their company. This opens up possibilities for extending peoples' networks by introducing unpaid community members which could occur in familiar rather than unknown community environments. The lessons learned from getting to know Sandra can be applied to extending her network and that of others with severe intellectual disability. Central to successful interaction with Sandra is an understanding of her communication, the roles she takes and ways she chooses to interact.

Existing networks members, if given the chance to reflect on their interactional knowledge are an important of such information that can be shared with new potential network members. Critical to building new relationships is providing new network members with an understanding of who the person is and ways to support communication from which they can develop and derive their own unique positive interactions.

Current networks are often domain specific e.g home support workers, day support workers, and attempts could be made to strengthen the support for an individual outside the family by setting up circles of support (Falvey, Forest, Pearpoint, & Rosenberg, 1994). Circles of support include people who know the person with a disability well but also offer opportunities for introducing new people into the network who may not have a paid relationship. This study provides some important insights into how this process might be supported. Service organisations could take a more direct role in person centred planning to promote relationship building. Inclusion is more than promoting activities that engage people in public spaces and community settings. Rather it is the development of a rich personal network that, in the end, will facilitate the inclusion of people with severe intellectual disabilities.

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# More Than Just Places – It's About People

Daniel Leighton & Ralph Hampson

## Introduction

The Victorian Government is committed to developing a stronger and more inclusive community. However, changes to the *A Fairer Victoria* policies over the past 5 years have made that goal more difficult for people with an intellectual disability as the policy focuses on place based disadvantage rather than a recognition that for people with an intellectual disability disadvantage continues to exist in all communities.

In March 2005, the Victorian Government released a position paper, *Challenges in Addressing Disadvantage in Victoria*. This paper outlined the nature, extent and distribution of disadvantage in Victoria. It identified the barriers and circumstances that prevent individuals from fully participating in social and economic life. This led to support for a 'coordinated approach involving all levels of government, non-government agencies and local communities'.

In the first *A Fairer Victoria* statement, the Government committed to investing \$119.5 million to make Victoria:

*... a more accessible place for people with a disability, improve housing and respite options, better protect the rights and interests of people with a disability and create more flexible support packages to give people with a disability maximum choice and opportunity in the way they live their lives.*

While the stated policy of the Victorian government is to make the state a more accessible place for people with a disability, no specific funds were allocated to achieve this goal. Rather commitments were made totalling \$75.2million over four years to "continue to lead the way in building stronger communities, targeting our investment to help communities with high levels of disadvantage". The focus of the investment was on disadvantaged place based communities with the goal being to create strong, active, confident and resilient communities that provide a network of support to the people who live there, and also have a voice in the matters that really matter to the community. People with an intellectual disability are assumed to be included in this community development approach. *The Victorian State Disability Plan 2002-2012* has as one of its primary goals:

*... strengthening communities so that people with a disability have the same opportunities as all other citizen of Victoria to participate in the*

*life of the community – socially, economically, culturally, politically and spiritual.*

With the increasing focus on place based disadvantage the risk is that the disadvantage faced by people with an intellectual disability who live in what are deemed 'advantaged communities' will be given less attention or perhaps ignored.

Jewish Care Victoria (JCV) fully supports the Victorian government commitment in seeking to create 'strong communities'. As a leading provider of disability services, focused on supporting the Jewish community, we are recognised as being at the cutting edge of service delivery. Jewish Care's services include individual support, transition for young adults, schools integration, respite and supported housing options for adults with disabilities; but as a service provider how do we engage in a "coordinated approach involving all levels of government, non-government agencies and local communities" to create and fund services to support people (as well as provide affordable housing) in places that aren't experiencing disadvantage? JCV is acutely aware of the need to work in partnership with our service users so that wherever possible they can be engaged with mainstream services which are located in the community in which they live. Within the current policy context this is challenging, and this paper explores the issues JCV has and continues to face.

## Community Engagement

Verdonschot, de Witte, Reichrath, Buntinx and Curfs (2009) reviewed the literature to identify what was known about community participation of people with an intellectual disability. Their findings provide a useful backdrop for later discussion. Reviewing the literature for a 10 year period from 1996-2006 they identified twenty three quantitative studies that met their criteria for inclusion. It was clear from their review that there is little known about community participation of people with ID.

Their review concluded:

*... one conclusion can consistently be drawn from the review: people with ID living in community settings participate more than people living in segregated setting, but their participation level is still much lower than non-disabled people (Verdonschot et al, 2009:315).*

Interestingly they also reported that the studies reviewed varied in their definitions of 'community participation', that most did not locate the work within a clear conceptual framework and methodological quality and methods varied greatly across the studies.

One of the key challenges faced by service providers wishing to support people with an

intellectual disability in the community is the lack of a durable and sizeable personal social network. Utilising the domains of the International Classification of Functioning, Disability and Health, the average number of people in the social network of someone with an ID appears to be 3.1, with one of these being a member of staff. In reviewing the literature, Clement and Bigby (2008:264) note:

*People with intellectual disabilities, whether they have a history of institutionalisation or not, typically have small and highly restricted social networks characterised by interactions with co-residents or co-participants in day programs, immediate family members, and service workers who are paid to support them.*

Exploring how the Victorian Government policy 'building inclusive communities' the authors followed the lives of five people with severe ID who had been relocated from institutional care to a new group home in the community. The study demonstrated that the group home created a community presence, rather than participation with the non-disabled community. The authors note that unless staff and families are convinced of the veracity of this goal they may not work towards achieving it. Further they note that the debates regarding the definition and conceptualisation of 'inclusion' are ongoing and multifaceted.

A study undertaken by Alphen, Dijker, van den Borne and Curfs (2009:750) considered the opinions of 39 people with ID who lived in neighbourhood housing facilities. The authors identified five key themes in relation to neighbouring: superficial neighbouring; involved neighbouring; feeling at home; the organisation; and formalisation of relationships; and apprehension towards interaction. They report that the experiences of neighbouring are much like those of non-ID people, most knew some neighbours and greeted them, and some exchanged favours. There were a distinct group who seemed relatively unaware of their neighbours. One interesting result was that "neighbouring that moved beyond the superficial more likely involved volunteers and nearby living staff (753)." The authors conclude that there also needs to be more comparison between non-ID people and people with ID to understand how each interacts with neighbours.

Therefore, if we are to achieve any measure of success, we must, at an individual level, place a greater emphasis on building the social skills and networks of people with an intellectual disability. At the community perspective we must engage community members to overcome any unfounded myths, fears, and reservations and support them to engage with people with a disability as they would any other member of the

community. Indeed, in opposition to the current practices of *A Fairer Victoria*, one might argue that we must invest in areas where there is greater social cohesion, as it can be argued that these areas have the necessary precursors of existing community networks, infrastructure, engagement and volunteerism available for mobilisation, and that a smaller investment is required to reorient these existing assets for use in supporting people with an intellectual disability.

The following two case studies illustrate some of the work that JCV has undertaken to increase opportunities for people with intellectual disabilities to participate in their local community. The first case study focuses on recreational services and the second on housing options.

### **Case Study 1: Disability Services Funded Recreational Respite and Building Inclusive Communities: Are they Incompatible?**

The Victorian Department of Human Services (DHS) funds a number of organisations across the state to provide recreational respite activities. These are defined in the policy and funding guidelines as "a range of day and overnight supports for people living with a disability and their families and carers. It aims to support and strengthen family relationships and includes:

- Support within the extended family or friendship network
- Camps, holidays or weekends away
- Support in an alternative family environment
- Facility based overnight stays
- Weekend and holiday community based day activities
- Social groups and evening activities.

While regularly revised, the form and intent remains substantively similar to the guidelines issued in 2003. These guidelines do not seek to encourage innovative practices that would connect individuals into their local communities and build more inclusive communities. DHS continues to fund specialist organisations to bring together of people with a disability to provide an activity that could be obtained from many other providers within the community, such as libraries, neighbourhood houses, sporting and recreational groups and clubs. By not seeking to link with these established community services, the provision of recreational opportunities continues to be reliant on family, friends and paid disability support organisations.

In contrast, Jewish Care has embarked on a new path, setting itself the goal of not creating any specialist recreational respite activity by 2014.

Currently, Jewish Care provides 5 recreational respite groups – each of which meets fortnightly and these are streamed according to age and support levels of the participants. Some of these groups trace their beginnings back to the late 1970s. People complete half yearly planning to determine the activities. Over the past three years we have been examining ways of increasing the number of groups available.

In seeking to provide additional respite JCV identified the needs, scope and the demography of the community. An analysis of current respite practice highlighted that respite was currently being provided in one of two ways; either informally via friends and families; or formally via paid disability support workers. Therefore, in seeking to provide additional support in line with the vision of the state plan, increasing the number of disability support workers to continue more of the same was immediately excluded, and the following two options considered:

- Increase social networks of individuals and / or their families; and
- Engage with other recreational providers and support them to include people with a disability.

Establishing a program based around family social networks was not considered viable given the resource intensity required. As a result of this process Jewish Care sought to engage with local recreational providers to build their skills and strengths so that they would be better resourced to support people with an intellectual disability.

### *The basketball team*

Maccabi Victoria is the largest Jewish organisation in Australia with 24 sporting and recreational clubs, over 4,200 active playing members, more than 600 regular volunteers and in total 11,000 members, parents, family and friends. The clubs range from tennis, basketball and swimming through to Active Living walking groups, snooker and lawn bowls. Initially, meetings were set up with the President and the Chief Executive Officer, seeking their support to reach out to the individual clubs to support the inclusion of people with a disability. Following in principle agreements, correspondence formally seeking their assistance was sent to the Maccabi Victoria board. The board agreed to our request and established a sub committee of the board to meet with Jewish Care and develop a more detailed plan.

A working group was established with three representatives from Jewish Care, three from Maccabi and two members of Access, a small Melbourne Jewish advocacy organisation. Over the next 3 months, fortnightly meetings were held

and a formal Memorandum of Understanding was developed and signed by all parties.

With an agreement in place, and a broad understanding of its purpose, Jewish Care staff, in conjunction with Access, engaged with a group of parents who were already renting a gym for 2 hours one night a week and had approximately 10 teenagers with an intellectual disability playing a game of basketball. This group had been established by parents looking to create some opportunities for their children and the group was supported by two siblings and their friends. Meetings were held with the families to explore the possibility of their children playing for Maccabi. The parents were excited by this opportunity and saw it as normalising and encouraging other opportunities for their children.

However, even with broad support, there were a number of issues to overcome, including:

- Transferring responsibility for the team to the basketball club;
- Locating venues and times that were suitable to parents while also matching training times with other groups of teenagers and locating spare time on the courts;
- Encouraging the siblings to undertake coaching training and paying for it, so as to build the skills of the team to prepare them for competition;
- Locating suitable tournaments and competitions;
- Supporting parents to allow their children to compete competitively (so as to provide opportunities to build friendships);
- Moving training venue (and creating transport issues) in locating a venue within a particular DHS region to satisfy their requirements for activities to be provided within the region;
- Funding monthly advisory committee meetings;

But there were also successes:

- Team growing from 10 to 18 people regularly attending training;
- Basketball club sponsoring uniforms for all team members;
- Obtaining sponsorship from local bridge club.

Support through the partnership has now spread to involvement for people with a disability in four clubs (walking group, basketball, lawn bowls and table tennis). There is also interest from the football and soccer clubs. JCV has secured discounted training facilities to begin training next year for the soccer club, but it has taken 18 months to locate grounds that could be made available, due to the

general shortage of sporting facilities and the drought reducing access to grounds. Jewish Care continues to fund transport, attendant carers and venue costs through the respite dollars we receive – but all probably outside the strict interpretations of the funding guidelines!

### *The scouting group*

There are three Jewish scouting groups, and during the past 5 years, one closed due to a lack of volunteers to run the group. While most halls were built through funds raised by churches and other religious groups, in accordance with Scouting Victoria guidelines, titles to defunct groups are returned to Scouting Victoria who then sell the property to fund other activities. A history exists between Jewish Care and the 3rd St Kilda Scouts as the group was established in the 1920s in old train carriages on what is now the car park at one of Jewish Care's aged care facilities. Rather than see a community venue lost, we identified an opportunity to have an additional accessible community venue and began negotiating both with the local trustees of the hall and Scouting Victoria. After twelve months of negotiation we were able to secure the following agreements:

- Jewish Care would fund and project manage the renovation of a 75 year old building to make it accessible;
- Jewish Care would work to recruit volunteers and establish a scouting group including people with disabilities within three years; and
- in return for this investment Jewish Care would have access to the hall for six years to conduct a full range of community support activities at any time, except when a scouting activity is scheduled.

### *Discussion points*

1. How (& where) do disability services staff learn to negotiate formal partnership agreements?
2. What help is expected from DHS partnerships staff? What help can they actually provide? What can they be doing to support these activities?
3. How do we fund partnership development within current funding structures?
4. How do we fund this type of work within the granting of individual support packages?
5. How do we resource disability organisations to support not for profit groups to engage in this space?
6. People are no longer clients of JCV, but members of the scouts or sporting teams. They don't sign consent forms, receiving

information packs as per S. 89 of the Disability Act, so how do we report to government?

7. How would a smaller organisation (or one without a fundraising capacity) generate the funds required to undertake renovations of existing community facilities as part of complex bi- or multi-lateral negotiations?

## **Housing**

There are a number of distinctions between people-centred and place-centred policy approaches in the development of housing for people with a disability. A place-centred approach targets locations and provides assistance mainly in the form of infrastructure and community facilities. People-centred approaches, in contrast, are targeted at individuals with no consideration of their location and focus on issues of education, taxation and financial assistance for individuals to purchase or rent housing wherever they choose. While the Victorian State Disability Plan promotes a person based approach, the Department's own guide to options and assistance available for people with a disability to achieve their housing goals or needs suggests otherwise.

The current policy states that people with a disability should:

*... be able to choose where they live, with whom and in what type of housing—just like most other members of the community. As is the case with others in the community, making such a choice means considering a lot of issues such as, whether you can afford to live in your preferred area, whether you want to share and, importantly, how you find out what options or assistance are available (DHS, 2007).*

Given that most people with an intellectual disability have limited financial resources to a much greater degree than most other members of the community, the housing options available may be limited. For example for Jewish people being connected to your local community means, for the majority, living in the local government areas of Glen Eira, Stonnington or Port Phillip where most members of the Jewish community in Melbourne reside, and where there are a range of community services available.

To illustrate the challenges a Jewish person with an intellectual disability may face: if a person with an intellectual disability receives the pension and rental assistance, their fortnightly income would be \$895.50. The average rent for a one bedroom apartment in Caulfield is \$440.00 per fortnight, leaving the person with \$455.00 per fortnight to live on.

However, a key assumption underlying a person centred policy approach is that "people can and

will move jobs and residential locations to achieve their personal or family objectives” (Stimson et al., 2003, p. 145). For a person with an intellectual disability, a people-centred policy approach, such as that expressed in the State Disability Plan, needs to recognise the diminished income potential of people with an ID and how this can restrict their ability to be connected to and remain within their local community.

Jewish Care believes that people with an ID should be able to remain connected to the communities in which they are born and grow up and have social supports in place. The model developed by Jewish Care Victoria was created through a planned process which involved establishing a vision through engagement with people with an intellectual disability, their families and carers, staff, and community leaders and donors from the Jewish community. This process was undertaken over two years using a community development model. To achieve this affordable housing must be made available in all communities recognising that disadvantage for people with an ID is complex and multifaceted.

To achieve this Jewish Care is placing more emphasis on individualised planning and assistance to enable adults with a disability to remain in their local community. Advocates of people-centred approaches argue that these offer more control for service users because they are free to use their funding packages to purchase services of their choice.

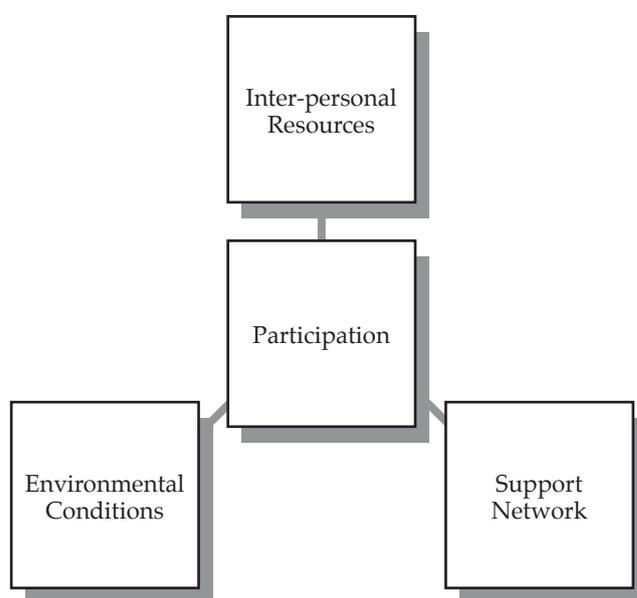
However there are limits to this choice. In Victoria, for example, there is simply not enough private-market affordable housing suitable for the housing needs of people with intellectual disabilities. A study conducted by Berry and Hall (2001) reports that despite the rent-assistance program, low-income households in the general population cannot afford to rent average valued houses of any size in almost any suburb of metropolitan Melbourne, forcing people to search for low-rent dwellings in a time when these rapidly disappear from the market. In other words, individualised funding and rent assistance – both typical people-centred funding schemes – may allow individuals more freedom to choose, but there is very little to choose from in the private housing market that is affordable.

### Case Study 2 – Development of Housing

Jewish Care Victoria has a long and proud history of providing services to members of the Jewish community, including supported accommodation, individual outreach support, transition supports from school, and respite support to families, including recreational and overnight respite.

In developing accommodation for people with an intellectual disability based around community inclusion, we must remember that a community is an ecological system – a ‘living system’. It is a system that sustains life, but one that has a life of its own, and each of us as community members manage, manipulate, react, and adapt to the conditions around us. We are interactive elements of this system. Community participation is perhaps best understood in terms of the compatibility of people’s resources and needs and conditions within their living environment (see Figure 1). Therefore, community participation is a process, rather an event.

Figure 1. A model for community participation

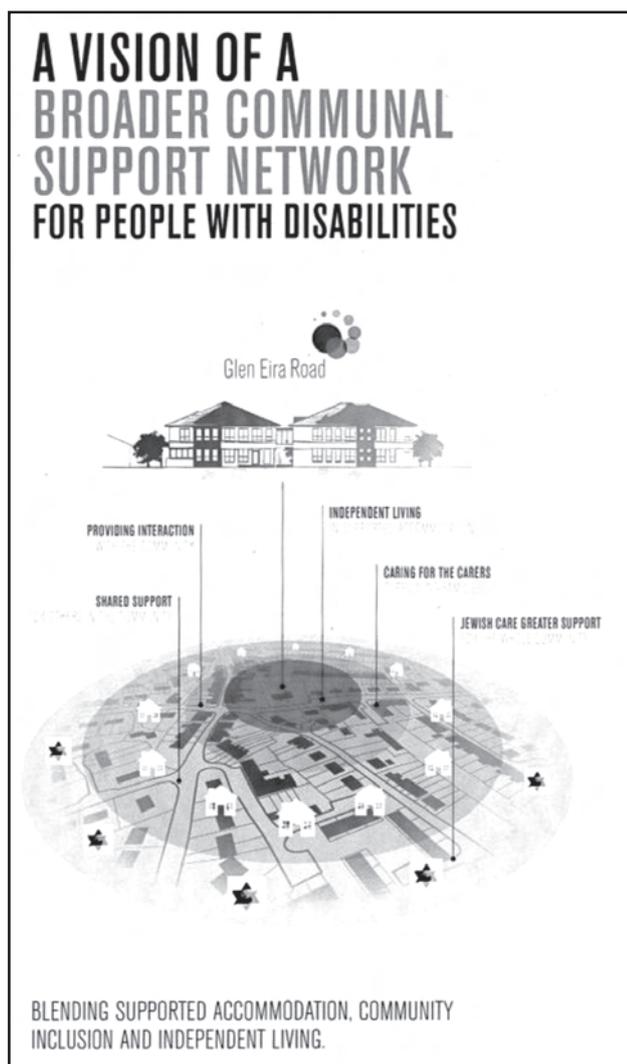


In acknowledging the above premise, the services Jewish Care currently delivers are envisaged as part of a broader communal network which is based on the principle that people with a disability should be encouraged to participate as fully as possible in the Jewish community. This is illustrated in Figure 2. In response to an urgent and growing need for housing for people with an intellectual disability, Jewish Care is creating new housing (Glen Eira Road) that is located in the centre of Melbourne’s Jewish community. The Glen Eira Road development will provide long-term supported-residential accommodation in four houses for adults with disabilities. The will program support people in a safe, stimulating and Jewish environment. Individualised planning will ensure that goals for each resident are established and that a range of range of person centred opportunities for skill development, independence

and participation within the local community is identified and encouraged. This has been largely funded through the Jewish community.

JCV also recognises that while the accommodation will provide a 'community presence', without additional actions it will not necessarily bring about community inclusion. Therefore, as a community service provider, Jewish Care acknowledges it has a key role to play in building structures that facilitate the interaction of people with an intellectual disability in the community as illustrated in Case Study 1 above. This is to be achieved through the creation of new roles for staff, and by intentionally seeking to limit the use of paid staff to meeting essential activities of daily living, such as medical and personal self care tasks, and seeking to develop multiple circles of support, and by inference, increase volunteerism and community participation. While the outcomes are understood, the funding mechanisms for these actions are not yet entirely transparent.

Figure 2: Jewish Care – A community vision for people with a disability



### Discussion Points

1. How do current policies incorporate recognition of the diminished incomes of people with an intellectual disability? Is there a need to do so?
2. Provision of human services has transformed over the past two decades from a welfare model to a consumer model, yet have people with an intellectual disability gained access a full range of housing choices or are they limited?
3. How do we (government, housing associations, disability support providers and philanthropic bodies) fund housing infrastructure for people with an intellectual disability to remain living in inner city communities?
4. Can we meet the additional infrastructure costs?
5. What policy settings are required? (c/f the residential aged care system of bonds being reliant on turnover)
6. Should we develop person based policies that support community development across areas of advantage and disadvantage?
7. Public / Private Partnerships have become a common form of developing essential public infrastructure (roads, water, education, prisons, etc). What consideration should be given to exploring PPPs at an individual level?
8. Are there other creative models of housing that we are afraid to explore?

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# **Shepparton Access: Creating Pathways into the Community. An Evolutionary Journey to Community Inclusion**

Wendy Shanks & Carolynne Young

Established in 1991, Shepparton Access is a small rural community organisation that believes in people and what they can achieve. Our Mission is to create pathways into the community for people with disability. Shepparton Access provides Day Programs, Futures, and Individual Support Packages. We are dedicated to innovative flexible solutions and to promoting participation and inclusion for people with disability. Over the years Shepparton Access has observed people with disability facing many inequalities and barriers to community inclusion. These barriers have become our challenge. The barriers have created opportunities for Shepparton Access to meet the aspirations of people with disability and to address the needs of our local community. Over time our service delivery paradigm has to a certain extent been realised. Or has it? We continue to debate what inclusion is and how we as a service respond to our service users needs. We view this as an evolutionary journey.

## **Our Changing Days Initiative (Dec 2006 – July 2008):**

Shepparton Access was successful in receiving funds through the Department of Human Services, Changing Days Initiative.

*“Changing Days will assist disability day services to realise the vision of the VSDP. It will support the transition to new service delivery approaches that provide individualised planning and support in the community, real choice, and viable pathways to employment and social participation through partnerships with local, generic community services” (Changing Days Initiative, Department of Human Services 2006-2008).*

Prior to beginning the Changing Days journey, we and as we suspect many other disability services thought we were achieving reasonable outcomes. However, after we took the time to reflect upon each person’s activities for each day of the week, we came to the conclusion that we were not achieving the outcomes as we had first thought. Coming to grips with the reality that we weren’t as good as we thought became a fundamental step in the process of Changing Days.

We used our Changing Days experience as an avenue to forge forward with our vision which reflected the vision of the Victorian Government, of being 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 toward society as all other citizens of Victoria” (Victorian State Disability Plan, 2002).

Shepparton Access embraced the vision and has modelled a service response to promote community inclusion.

Focussing on community inclusion presents a fundamentally different way of seeing people with disability and supporting them. Community inclusion has the potential to change the types of activities in which people with a disability are involved, the places they pursue these activities, and the people with whom they share these activities.

Changing Days assisted service users and Shepparton Access to transition to new service delivery approaches, provide individualised planning support, real choice and viable pathways to further education, employment and community activities.

Changing Days required us to be creative and think outside the box in order for Shepparton Access to better meet service user’s aspirations and to address the needs of the local community.

Four positive outcomes for service users included:

- Greater independence
- Greater influence over decisions
- Greater choice
- Greater community inclusion

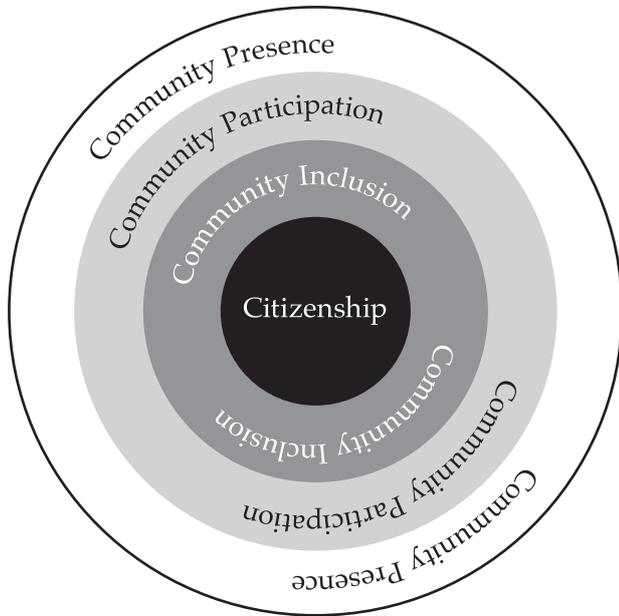
## **So what did Community Inclusion Look Like for us?**

Our challenge was to define what we considered to be community inclusion. It became apparent after conversations with consultants, academics and others within the disability sector; there was a wide variety of definitions, none of which appeared the same.

Shepparton Access came up with our own definitions which centred on meaningful relationships with others in the community. This as a concept had not always sat comfortably with staff members and at times families. Changing Days required that service users take more responsibility. Doubt was cast by families and carer’s as to how safe this new approach was. It was a fear of the unknown.

We were moving away from the “safe” system we had created, which in many ways was designed to protect people from uncertainty, to a philosophy of inclusion which embraces the notion of flexibility, risk-taking, choice, diversity and creativity.

Shepparton Access identified community inclusion within a series of concentric circles where citizenship is the aspiration and vision of all service users.



This implies that from the outer to the inner circle there is increased meaningful interactions with other people in the community, or other citizens.

**Our Definitions:**

From Changing Days, Shepparton Access developed the following definitions:

‘Community Participation’: means individuals or groups being Inclusion’: members of the community, and interacting with the community in activities which are meaningful to each person.

‘Community Participation’: means individuals or groups accessing the community with limited interaction with the community.

‘Community Education’: means courses, both formal and informal, which are funded by the Hume Regional Council of Adult Community and Further Education (and may be provided by Shepparton Access).

‘Community Hub activities’: means individual or group activities that take place within the Mechanics Institute building with other people with disabilities.

**The Evolutionary Journey to Community Inclusion**

As we journeyed through our organisational change process we needed to evaluate what it was that service users wanted, how formal and informal support systems could respond and how Shepparton Access could influence the shape of resources to more effectively support service users. Shepparton Access arranged a consultation session with support workers.

Our move toward community inclusion has been about understanding, what each individual service user’s skills and abilities are and how through the planning process we can work towards building upon these identified strengths. This resulted in support staff identifying a variety of changes to their role, some of which included:

- “identifying enabling and preparing people to do what they choose”.
- “changing from doing a program to providing support in the community”
- “advocating, standing beside or standing behind service users”
- “getting to know and to work with most service users during the week”
- “support staff and service users being recognised and respected in the community”

In saying this, the changed roles were reportedly “more stressful (as well as satisfying) because staff had less control, worked harder and found it more nerve racking (to watch, wait and worry)”. This led to staff turnover during the initial transition and some questioning around position descriptions, roles and responsibilities and the need for review of policies and procedures in line with the new directions.

From the support workers own reflections regarding service delivery, a change in staff roles and position descriptions transpired. This led us away from seeing the support worker’s role as primarily direct support to incorporating advocacy, community capacity building and planning.

Shepparton Access adopted a person centred planning approach and appointed a person within the organisation specifically to carry out this role.

The plans and their reviews have been well received by service users, families, carers, significant others and people in the community who have come to be included in service users circles of support.

With an emphasis on planning, the journey has also been about reframing for individuals the notion of disability and helping individuals redefine their status within the community. Shepparton Access has strived to shift the dependency of the community sectors away from the support worker.

This has been achieved in a manner which has encouraged the service user to take the lead while out in the community, with the support worker fading into the background over time. Initially the response from the community to the service user was "Where is your support worker?"

## Case Studies

To celebrate Changing Days, service users reflected upon their experiences and shared their stories and amazing achievements.

*'We dared to dream and our dreams have come true. We are now a part of our community'*

**Amy:** "I have always wanted to work at a hairdresser's even when I was at school."

Amy transitioned to Shepparton Access from a local secondary college. As part of the process of developing a support plan, Amy had some very clear ideas about what she wanted to achieve, one of which was to work in a hairdressing salon. Over time and as a result of Amy's planning and review meetings, Amy was able to realise this goal.

Amy enrolled in Certificate 1 in Work Education to foster the development of social and personal skills relevant to participation in mainstream employment.

A work placement was established with a local hairdresser, "Freshair". This was within walking distance from Shepparton Access. Amy was supported to cross the busy intersection on her way to work. After 10 weeks of intense support, Amy began accessing Freshair independently. For Amy, and her family, this was an important achievement.

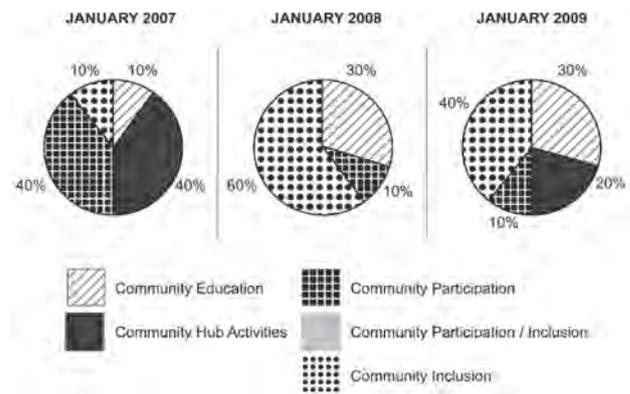
Amy was supported to become skilled at many tasks in the hairdressing salon, including dusting shelves, sweeping the floor, folding towels, cleaning tint bowls and safely preparing tea and coffee for customers.

Through Certificate 1 in Work Education, A vocational plan and job description was developed.

Amy's aspiration to work in the hairdressing salon has been complimented by a variety of other programs such as, money and time, advocacy, literacy and photography. These programs have focused on Amy's physical, social and emotional health and well-being, and her passion for photography. Recently, one of Amy's photos was featured as part of a photographic competition in the local newspaper.

Figure 1 is representative of the program activities Amy has participated in over the past three years and shows the move Amy has made towards connecting and becoming part of a more inclusive community.

Figure 1:



Today, Amy continues to enjoy her work at Freshair and has a critical role on Thursdays at the salon. She is well known to the clientele, many make their appointments, so that they can be treated to their regular cuppa and chat.

**Luke:** "I would like to keep going to work with Barry."

Upon leaving school, Luke was employed by a business service. It was soon identified that Luke was struggling to adjust to the daily work routine of employment. This subsequently led to Luke commencing at Shepparton Access three years ago.

During Luke's Support Plan meeting, Luke clearly expressed his desire to explore employment in the future, and his wish to work in an environment with people who shared his passion for cars.

Luke also indicated his interest in learning to play the drums and joining "Dancing with the Stars".

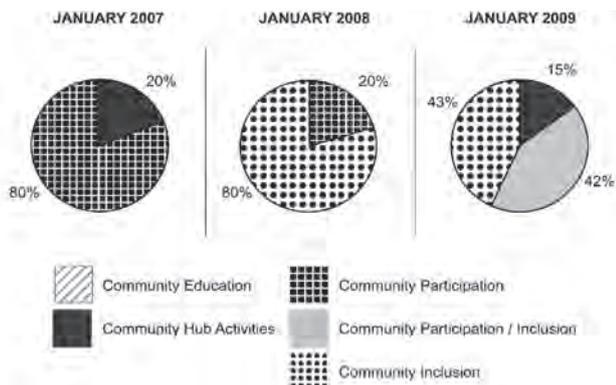
After searching the local community, Luke began lessons playing his newly purchased drum kit, and began dance lessons at the local dance studio.

Luke became a valued member of the McDermott Prestige Panels Workshop team. Luke eagerly attends his new work place to complete his many and varied tasks. He has established many new friendships and enjoys being 'one of the boys'.

Today, Luke continues to work each Monday at McDermotts, and together with Barry and Bill attends the local car club meetings and activities. Luke still enjoys his weekly drum lessons, and plays with a group of musicians at the church hall on Tuesday evenings. Last year at the Shepparton Dance Sport Competition, Luke had the opportunity to partner with Amanda Garner and was runner up in the novice division.

Figure 2 is representative of the program activities Luke has participated in over the past three years and shows the transition he has made towards connecting and becoming part of a more inclusive community.

Figure 2:



**Andy:** "I work with Bob, I am a good worker and Bob is my best mate."

Andy lives in a small rural community with no transport connection to Shepparton. Andy was transported to and from Shepparton Access each morning and afternoon, a one and a half hour round trip twice a day for his parents. After 18 months of travel, Andy and his circle of support embraced the opportunity to explore services in their local community.

Andy had always been a respected student at St Mary's of the Angels Secondary College, and expressed a desire to return to the school and help Bob with his cleaning duties. The principal at St Mary's became part of Andy's circle of support and agreed to Andy joining the school staff for a trial period, with support from staff at Shepparton Access.

Consideration needed to be given to the cost of the initial and possible ongoing support Andy would require to learn and become independent with his allocated tasks. This cost became a barrier to Andy's goal of assisting Bob to clean the school.

Researching a variety of models of support, the natural support model (Dileo, Luecking & Hathway, 1995) became the model of choice for both St Mary's and Shepparton Access. Andy's Individual Support Package (ISP) was utilised to increase Bob's hours of work, which then enabled him to provide the necessary support Andy required to become skilled and accomplished at his various cleaning tasks.

Bob was provided with training to meet Andy's support needs, and the team of Bob and Andy was created.

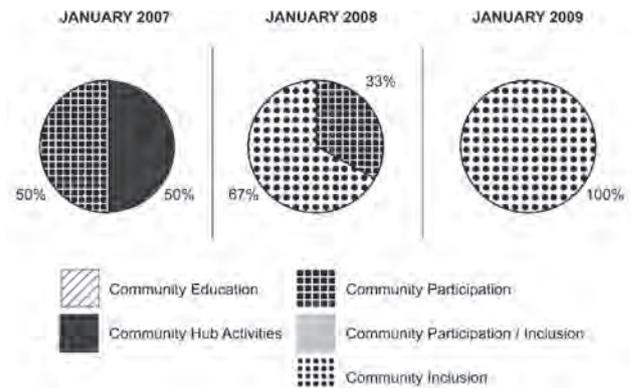
In 2007, FOOTT Waste acknowledged the role that Andy played in the collection of waste within the school and church community, and engineered and constructed a hydraulic hoist to reduce the OH&S risks associated with manual lifting and the emptying of 34 bins each day.

Andy now spends 5 days each week working alongside Bob, and has a significant and valued role within the school community.

During 2009, Andy became adept in taking charge of the pedestrian crossing at the end of the school day.

Figure 3 is representative of the program activities Andy has participated in over the past three years and shows the evolution he has made towards connecting and becoming part of an inclusive community.

Figure 3:



**Joanne:** "One of the things I really enjoy is helping others in the community by doing volunteer work."

Joanne returned to Day Programs in 1999 after many years of illness and has enjoyed learning about the community and becoming involved in the community.

Participation in self advocacy has provided new opportunities for Joanne to speak out and make decisions that impact upon her life.

When preparing for her last Support Plan, Joanne chose to facilitate her own planning process using a person centred approach. She identified her own circle of support, sent out invitations and prepared her preliminary plan. Joanne chaired her Support Plan Meeting and discussed her aspirations and decisions with her family, carers, friends and service providers.

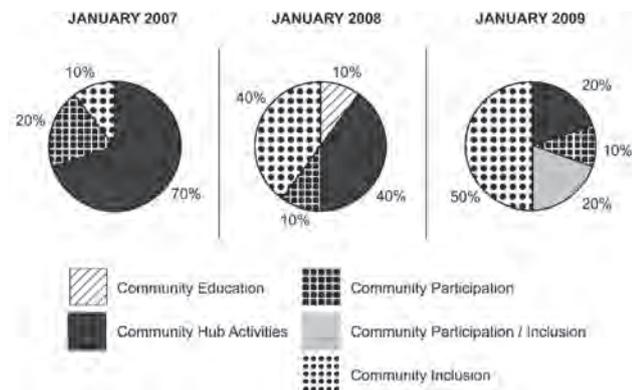
This proved to be quite confrontational for some individuals within Joanne's circle of support. At the conclusion of the Support Plan Meeting Joanne was disappointed by her family and carer's response and their lack of support in relation to her decision to become more independent within the community. It appeared that Joanne's circle of support were more comfortable with Joanne spending the majority of her time in our Community Hub activities.

For Joanne, this became a quandary, as her choices were different from the choices of her family and carers. Over a two year period, Joanne slowly built her confidence and skill level which in turn

became a process of osmosis for family members and carers. As the fear and concerns dissipated, gradual inclusion occurred.

Figure 4 is representative of the program activities Joanne has participated in over the past three years and shows the transition she has made towards connecting and becoming part of an inclusive community.

Figure 4:



With gentle persuasion and careful planning the expectations have shifted and for a number of our service users, enabling them to fade out their level of support and providing them with greater inclusiveness, in order to access community activities independently.

It is impossible to imagine all of the potential problems that can and will arise as we develop inclusive communities. Our trek has required that we ensure sensible but flexible risk policies are in place which do not inhibit our service users' opportunities to form new relationships and embrace new experiences. Shepparton Access has researched various tools to enable us as an organisation to evaluate and plan supports and services as well as marry the philosophy of community inclusion. In order to do this, the emphasis has been to provide appropriate resources and staffing patterns to meet each individuals needs.

Managing risk has required that we are resource intense initially in the planning and setting up phase. The balancing act has been to leave sufficient funds to maintain and monitor individuals programs and activities. Once the program or activity has progressed to the stage that staff supports can be reduced, the wheels have been set in motion once again with the focus shifting toward other individuals in the organisation and their plans. Moving from community hub activities to community participation with the big picture objective, to ultimately achieve community inclusion.

## Where has the Winding Path led us and how would we Describe Community Inclusion now?

Changing Days presented the challenge of looking for ways to rediscover the potential within society, to show the value of inclusion to people outside its walls and to connect with ideas that had broad appeal. It was about acknowledging the importance of trust, reciprocal relationships and understanding, in order to address barriers that presented along the way. Some of which included:

- Families and carer's requiring a guarantee that an equivalent level of service would be provided, as well as a high level of quality service delivery. This is an ongoing need that is as much about human condition and our overall response to change.
- For service users the difficulties associated with inclusion meant "coping with social pressures such as being on their own". Knowing how to cope with insolence from community members was a challenge for both service users and support workers.
- Because of this "safe" system we had created over the years, designed to protect people from uncertainty, this in retrospect possibly guarded service users experiences. This very much became a process about organisational change with staff needing to take a step back, allowing service users to take responsibility for their choices and actions.

Shepparton Access strongly aligns itself with the frameworks that have come from the Victorian State Government. Since 1991 the quest has always been to achieve greater community inclusion and to advance the dignity, worth, human rights and full potential of people with disabilities. We began Changing Days already with insight to the importance of community inclusion.

Shepparton Access provides support to fifty two individuals with disability. Of the fifty two individuals who are supported by Shepparton Access the following table provides an overview of their age range.

Age	18-30	31-50	51+
Percentage	48%	31%	19%

For the purpose of analysing levels of support necessary to achieve community inclusion Shepparton Access have considered this from two angles, funding levels and community inclusion according to our definitions.

Based on the Department of Human Services' funding policy framework the following table is a summary of our service user's overall level of funding within the context of individuals Service Needs Assessment levels (SNA):

Low (SNA 1 & 2)	Moderate (SNA 3 & 4)	High (SNA 4 – 5.5)
20%	52%	28%

From a community inclusion perspective and in accordance with our definitions, we have calculated the following to reflect the support needs in terms of achieving community inclusion:

Low	Moderate	High
8%	33%	59%

Our four case studies are representative of SNA 3 funding level. Traditionally funding levels have been based on segregated settings and the variables associated with community inclusion have not necessarily been taken into consideration. In our view, these funding allocations are not reflective of our service users support needs when aspiring to meet the goal of community inclusion. From our assessment, support needs have increased overall and changed the way we provide support. This shift in classification is primarily due to the acknowledgement that each individual has their own unique support needs in order to take charge of and responsibility for their own lives. Our approach has been based on the values of Self-Determination. As an organisation we have needed to utilise a variety of innovative support models to meet the desires of our service users, community, businesses and services.

The underpinning value of Self Determination has provided Shepparton Access with a steadfast approach to providing people with disability Self-Directed Support.

Since the beginning of Changing Days we have seen a decrease in the low categories for both funding levels and community inclusion. This is largely due to Shepparton Access having created pathways to employment and further education.

From December 2006 to July 2008, some of what we saw as our organisation having accomplished, included:

- Individuals were now included as part of community activities as opposed to carrying out activities in separate rooms within the community. Previously we saw ourselves as a

distribution of satellites across the community but still unequivocally in isolation to the broader community.

- Some of our service users moved from 'participation' having been on the edge, to inclusion where service users were transported to community activities, partaking independently without support workers present.
- Service user's had become regulars at different places and were recognised by community members. Often community members would enquire where an individual was if they were missing from their usual activity within the community.
- Some groups were rostered with no support workers. They go directly to the venue within the community.
- Service users had to rely on one another more as a support network. Shepparton Access observed service user's working in together more and problem solving their way through different activities.
- Many service users had stepped outside their comfort zone and were far more willing to try new things. They had become more accepting or adaptable to change. Slowly shifting away from the "safe" system that had been created to protect them.

Greater community inclusion could only be achieved by developing and rolling out Support Plans. It could also be said that Changing Days was as much about skilling up individuals with a disability as it was about developing knowledge, skills and confidence in the community in order to provide informal support.

In January of 2009, Shepparton Access once again sat down and reflected upon strengths and weaknesses from a service delivery perspective. Again, this led us back to the debate of whether or not our service users were part of an inclusive community. We asked ourselves the question: Has the focus shifted from awareness raising (participation) to action (inclusion)? When evaluating our programs/activities, was our taxonomy a true reflection of what was really going on? We fractioned down the aphorism, community inclusion:

If we look at community as being sustainable we can surmise that it is made up of all kinds of people, who all experience vulnerability and dependence. Often for a person with a disability this is amplified and can be a useful magnification of the human condition in general. For Shepparton Access, the Changing Days Initiative was the right time to reorient ourselves toward a kind of resilience that comes from acknowledgement of

the human condition as involving dependence and vulnerability. This involves a shift in power, towards partnership and reciprocity on all levels. Each and every one of us carries a certain degree of reliance on others around us. For example, on family, and friends for emotional support, on our employers, interest groups, banks, cafés etc. These relationships are usually two way where both parties benefit in some way. This mutual benefit is a cornerstone of society.

We looked at a number of different definitions for inclusion. The most resonating when reading through literature were the following:

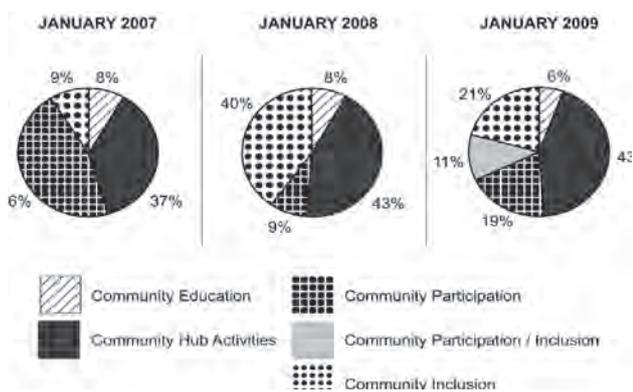
- Quinetta Roberson (2006) who expressed that inclusion requires a paradigm shift in human consciousness, awareness, and interaction and
- Miller and Katz (2002) presents a common definition: "Inclusion is a sense of belonging: feeling respected, valued for who you are; feeling a level of supportive energy and commitment from others so then you can do your best work."
- Miller and Katz talk about inclusion as a shift in organisational culture with all individuals functioning at full capacity, feeling more valued, and included in the organisation's mission.

This posed the question...Do our service users have this experience of dependence and reliance to some extent on the wider community.

Are the individuals we have identified as part of what we think is an inclusive community, functioning at full capacity and feeling more valued as a whole in our wider community?

This led Shepparton Access back to our original definitions of community inclusion and community participation. As we reflected upon our original descriptions, our yard stick changed. We came to the conclusion that we had to a certain extent marginalised our definitions which in affect was limiting our capacity to strive for and achieve greater community inclusion.

Figure 5:



What resulted was the addition of a definition, that being the permutation of community participation/ inclusion. This now allows us to clearly demarcate true inclusion, as well as identify individuals who are on the road to functioning at full capacity within the wider community. We have found this to be helpful in allowing our planners to better identify gaps in service delivery and areas where aspects of the community may require additional supports in order for community inclusion to be attained. You can see from Figure 5, that this has inevitably changed the data we collect and the reflection upon our service in terms of achieving community inclusion. The tables exemplify the rhetorical expression of two steps forward and one step back. This said, they also validate the development Shepparton Access has made towards greater community inclusion for our service users.

## Conclusion

If we are to be true to the definitive of what community inclusion represents, maybe again we have come to the understanding that we are not achieving the outcomes that we first thought. In saying this, we acknowledge what we have accomplished thus far on this journey. We see this as a long and winding road, that leads us to who knows where, who knows when..... By no means has our journey come to an end, we sit comfortably with the fact that this is an evolutionary process and believe our journey is capable of achieving much more.

As an organisation we have begun to contemplate how we might look in 2020. We continue to explore our goals and aspirations and look forward to aligning this with the new 10 year State Plan.

Some of the questions we will continue to ponder include:

1. Will the new State Plan change our direction, thinking and terminology?
2. Will we have the resources to continue to expand our knowledge and expertise to embrace new and innovative models such as SIS and I-CAN to implement continuous improvement?
3. How will we strengthen our partnership with people with disability and their families to continue the transition through the reorientation of disability supports and self directed approaches?
4. What will the future role of the support worker look like; will support workers become part of and sit with generic services?

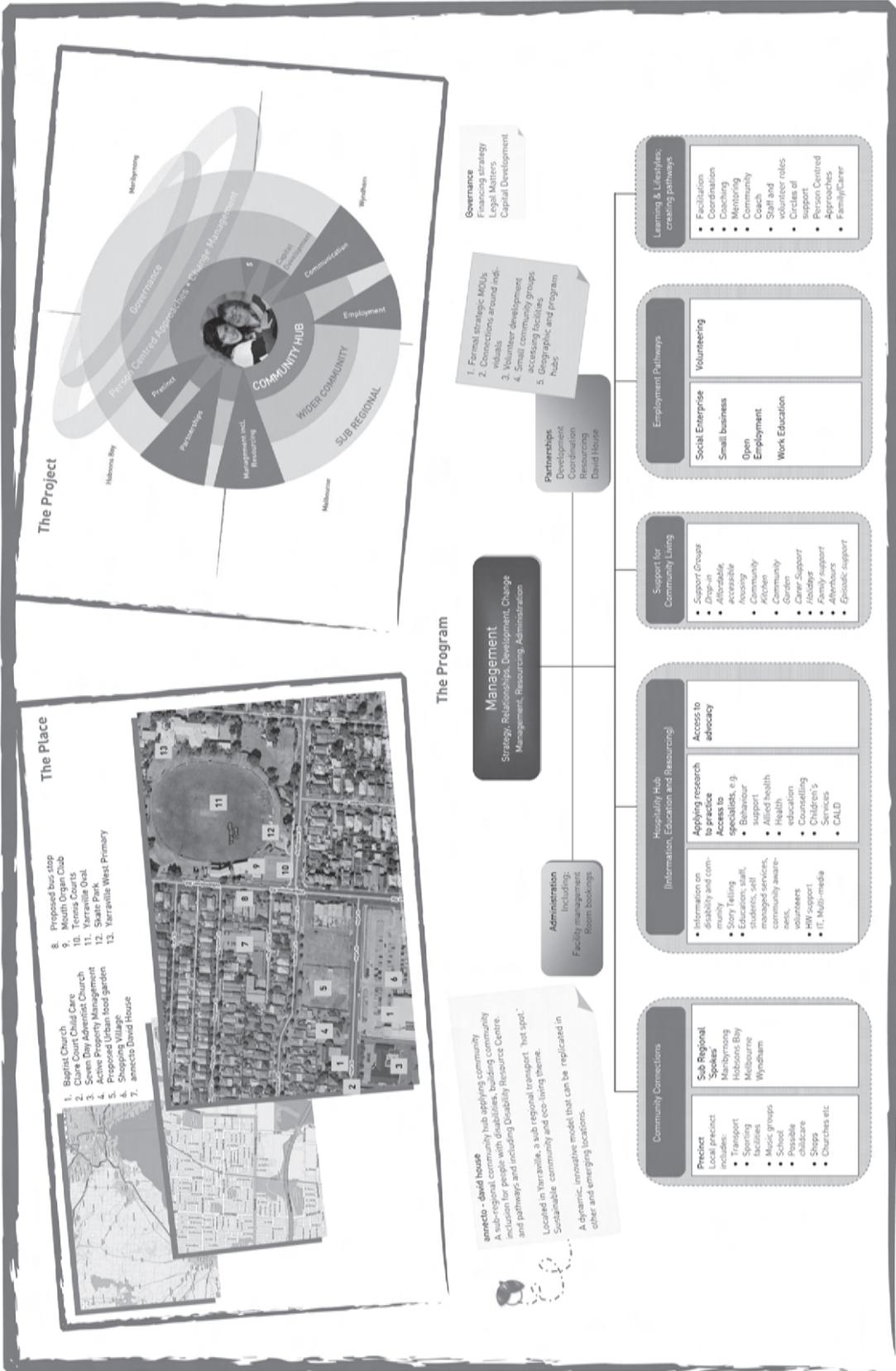
5. Will independent advocacy be accessible within rural communities?
6. Will rural transport costs impact upon our service support?
7. Who will be the future leaders and drivers within services which support people with disability in rural settings?
8. Will Shepparton Access maintain our tradition as a leader and mentor in the sector?
9. Will Shepparton Access be viable in 2020?

## References

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- Miller, F. & Katz, J. (2002). *The Inclusion Breakthrough: Unleashing the Real Power of Diversity*. San Francisco: Berrett-Koehler Publishers
- Roberson, Q. (2006). Disentangling the Meanings of Diversity and Inclusion in Organizations. *Group & Organization Management*, 31(2), 212-236.

# strategies to achieve community participation

the redevelopment of annetto david house

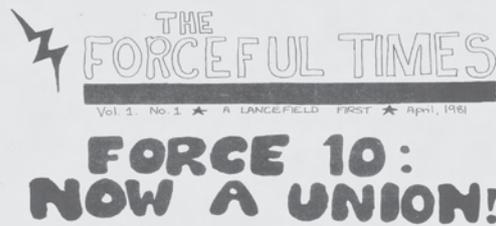


1981 - 2009

SELF ADVOCACY AND INCLUSION –

Self Advocacy History Group –  
Reinforce, Chris Bigby, Paul  
Ramcharan & Patsie Frawley

SELF ADVOCACY AND INCLUSION – SPEAKING UP OVER THE YEARS



**"WE SHOULD STAND UP FOR OUR RIGHTS."**

Weekaway Camp at Sunlock was the place for the most exciting event of 1981. A union, run by mentally handicapped people was formed on Easter Sunday night. It will work to change many of the things handicapped people are unhappy and angry about, from their home to their work.

"It's alright to talk, but what we want is action," is how one person put it. People are tired of waiting and it was felt that intellectually disadvantaged people must work together and form a union. If things are to change.

"We don't want any outside organization, we want our own," was the general feeling of the meeting.

People then talked about what was

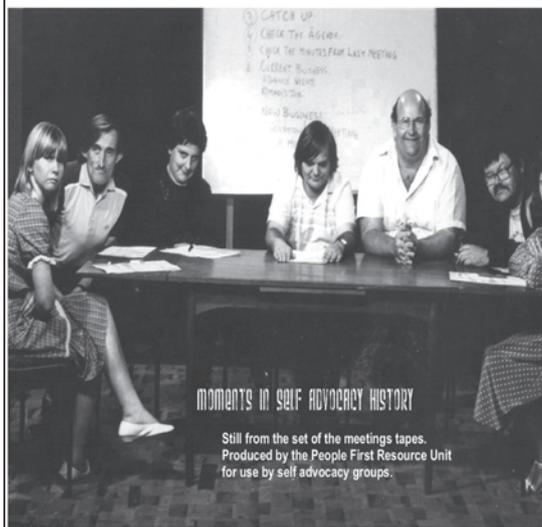
important to them. One woman wanted more small cottages built so that she could move out of the institution she has lived in for 27 years.

After Sunday dinner, a committee of people, from training centres and sheltered workshops, was elected to work on behalf of FORCE 10. The organizers of this conference will assist the committee in the work ahead of them.

**"WE ARE LOOKING AT NOTHING LESS THAN A FIGHT FOR ALL INTELLECTUALLY DISADVANTAGED PEOPLE."**

Getting together and sharing our stories – we used to go on camps and let everyone talk about the things that were important to them – People were **included in deciding what we worked on – making decisions together about what to do and how to do it**

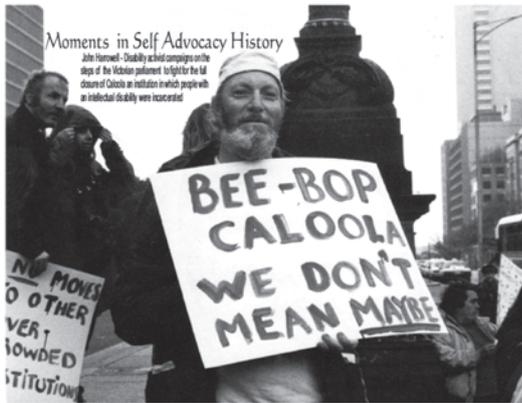
SELF ADVOCACY AND INCLUSION – SPEAKING UP OVER THE YEARS



Getting information in ways you can understand it and working with other people so they get the information too - **Inclusion through knowing how to run meetings and participate in meetings, speak in public, knowing about your rights**

SELF ADVOCACY AND INCLUSION – SPEAKING UP OVER THE YEARS

Self advocates have been involved in **campaigns** about closing institutions like Janefield, Caloola, Mayday Hills in Beechworth and Kew . This year Reinforce is campaigning to close Colanda: **The right to live in the community is a right that self advocacy fights for – inclusion is living in the community**



Moments in Self Advocacy History

John Hurrell - Disability activists campaign on the steps of the Victorian parliament to fight for the full closure of Caloola an institution in which people with an intellectual disability were incarcerated

SELF ADVOCACY AND INCLUSION – SPEAKING UP OVER THE YEARS



Moments in Self Advocacy History

Radical action led to self advocates squatting in a house in Drummond St and demanding it be used to house people with a disability.

Self advocacy has used lots of different ways of being heard – early on self advocates joined together and did things like squatting in houses to get community housing, demonstrating on parliament steps, talking to politicians. **Inclusion is being able to speak out like other people in the community - being political**

SELF ADVOCACY AND INCLUSION – SPEAKING UP OVER THE YEARS

DES MCINTOSH - 5<sup>TH</sup> Stand Asia Pacific Mental Retardation conference Melbourne 1981



Being included by speaking to government, academics, service providers and other self advocates at conferences, meetings and forums: **Inclusion is having a voice and being heard – Self advocacy has given people a voice**

## Attendees

Alma	Adams	Unaffiliated
Arthur	Rogers	DHS
Carolynne	Peterson	annecto
Carolynne	Young	Shepparton Access
Cath	McNamara	VCASP
Catherine	McAlpine	Down Syndrome Victoria
Christine	Bigby	School of Social Work and Social Policy, LaTrobe University
Chris	Fyffe	Grimwood
Chris	Noller	St John of God ACCORD
Christine	Owen	DHS
Claude	Staub	St John of God ACCORD
Daniel	Leighton	Jewish Care
Deb	Thurecht	Melbourne City Mission
Deb	Rouget	PLA
Diane	Craig	School of Social Work and Social Policy, LaTrobe University
Enaksha	Garde	Scope
Erin	Wilson	Deakin University
Estelle	Fyffe	annecto
Evelina		Swedish student on placement DSC
Gabrielle	Urban	Jewish Care
Gill	Pierce	Carers Victoria
Goran		Swedish student on placement DSC
Helen	Bryant	National Disability Services
Hilary	Johnson	School of Human Communication Sciences, LaTrobe University
Ian	Mclean	Golden City Support Services
Janet	Owenst	Deakin University
Jen	Deurwaarder	Melbourne City Mission
Jenni	Hendy	SCOPE
Jennifer	Boulton	Yooralla
Jennifer	Clegg	Nottingham University
John	Chesterman	Office of the Public Advocate
Kathryn	Lamb	DHS
Leanne	Dowse	SSIS, UNSW
Lee Ann	Basser	Law Program, LaTrobe University
Liz	Bishop	St John of God ACCORD
Lorna	Hallahan	Flinders University
Lynne	Coulson Barr	Disability Services Commission
Margaret	Nicol	St John of God ACCORD
Marie	Braudigom	annecto
Mark	Feigan	Politics Program La Trobe University
Michael	Bink	Scope
Mirella	Danelutti	DHS

Moira	Buchholtz	Office of Senior Practitioner
Natalie	Thomas	Office of Disability
Patise	Frawley	School of Social Work and Social Policy, LaTrobe University
Paul	Ramcharan	RMIT
Pauline	Johnston	La Trobe Lifeskills
Peter	Newsome	St John of God ACCORD
Phillipa	Angley	NDS
Pina	Telgenkamp	St John of God ACCORD
Ralph	Hampson	Jewish Care
Sally	Robinson	Griffith University
Sanjib	Roy	Yooralla
Sarah	Fordyce	NDS
Shanker	Pragnaratne	Scope
Silvana	Gugliandandolo	St John of God ACCORD
Sue	Balandin	Molde University
Teresa	Iacono	Monash University
Tim	Clement	School of Social Work and Social Policy, LaTrobe University
Tom	Worsnop	Melbourne City Mission
Wendy	McGrellis	SCOPE
Wendy	Shanks	Shepparton Access
Yvette	Proud	NSW Council for Intellectual Disability

