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# Inclusion: making it happen

*Key elements for disability organisations  
to facilitate inclusion*

**scope**

FOR PEOPLE WITH A DISABILITY

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## Acronyms

AAA	Access for All Abilities
ASD	Accommodation Services Directorate
CALD	Culturally and linguistically diverse (background/community)
CBD	Central business district
CI&D	Community Inclusion and Development Unit
CPRD	Convention on the Rights of Persons with Disabilities (United Nations, 2008)
CRC	Communication Resource Centre
DADAA	Disability in the Arts, Disadvantage in the Arts Western Australia
DHS	Department of Human Services
DSC	Disability Services Commission
LAC	Local Area Coordination
PIN	Planned Individualised Networks
PCP	Person centred planning
TAFE	Technical and Further Education
YMCA	Young Men's Christian Association

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### Purpose

The project looks at the role of disability organisations in working together with people with a disability, families and communities to foster inclusion and investigates *how disability organisations can enhance their function in facilitating inclusion*.

Specifically, the project aims to:

1. Provide clear **definitions** and examples of what is meant by terms associated with this work such as 'community', 'participation', and 'inclusion';
2. Identify the key factors, **enablers and barriers** (that occurred at an individual, family, community and organisational level) to connecting individualised and person centred work with inclusion;
3. Identify the **changes** or **outcomes** (that occurred at an individual, family, community and organisational level) as a result of a selected sample of this work; and
4. Identify the **key organisational tasks** or ingredients needed to enhance this work.

The focus of the study is not on *why* foster the work of inclusion, but rather on *how* this can happen, *how* it currently works, *where* the evidence is found of how it works, and *how* it is incorporated into identified practices.

### Method

The research involved a range of methods including reviewing existing literature largely from the fields of disability and community development, as well as grey or organisational literature within disability organisations who participated as part of the project; and analysing evidence from interviews conducted with inclusion workers. Interviews were conducted with key informants currently involved in inclusion work from within a variety of service types (e.g. day services, residential services, community development activity, specialist services work). Two broad sets of interviewees were identified:

1. A range of practitioners within Scope, across a range of service types, who were generally seen to have successful experiences in relation to the work of community inclusion. Scope was seen to have a history of inclusion work including a dedicated 'Community Inclusion' section, as well as two work areas actively utilising two conceptual inclusion frameworks as practice guides;

2. A range of practitioners and program managers in Western Australia. Western Australia was selected due to its extended experience with the Local Area Co-ordination inclusion model, a model quite different from that in use in Victoria.

## **Analysis**

Section 2 presents a number of key ideas from the literature that seek to define 'community', 'participation' and 'inclusion'. For the purposes of this study, inclusion work is defined in the following way:

*Inclusion work involves 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.*

This research proposes three Orientations as a helpful way to understand the 'what' of inclusion practice.

*Orientation 1: Individual person-centred work leads to inclusion.*

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

*Orientation 2: Opportunities are created in community.*

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

*Orientation 3: Broad level community change.*

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

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.

The study presents some examples of how different agencies have structured their inclusion work. The research team has attempted to capture commonalities in organisational approach and have identified three main groupings:

- *Single focus work:* An agency organises inclusion work around individual people with a disability and their families, OR around a single field of activity / interest (eg recreation);
- *Broad regional work:* An agency organises the work around a geographic region, or a set of broader systemic community development or capacity building projects;

- *Service redesign*: where agencies have re-constructed their entire organisation in order to provide more individualised support to people with a disability or focus on inclusion in different ways.

In terms of personnel requirements, inclusion work involves a broad range of job roles and practitioners need to be generalists across these. All inclusion work is underpinned by a set of practice principles that ensure the work matches its purpose and is ethical. The literature of community development is helpful in delineating the skills and strategies associated with inclusion work.

## Findings

Thirteen (13) case studies of successful inclusion practice are presented from interview data. Case studies are organised according to the Orientations to inclusion work discussed in section two. The majority of interviewees provided case studies relating to Orientation One, hence the higher number of these examples provided. There is a significantly lesser emphasis on supporting the community with social change and inclusive practice (Orientations two and three). This is a point for further reflection and discussion.

All interviewees were asked to identify the factors that affected the outcomes of their practice example or work generally. In each section, factors are identified in relation to the individual (i.e. the person with a disability); the staff and organisation; and the community. Additionally, interviewees identified outcomes for each of these groups. Finally, data is presented that reflects interviewees' identification of key factors to influence the success of inclusion work.

### Enablers for inclusion work identified at the level of each stakeholder group

Individual and family	Staff and Organisation	Community
<ul style="list-style-type: none"> <li>• Trust</li> <li>• Expressed choice, interest</li> <li>• Determination &amp; commitment</li> <li>• Resources</li> <li>• Role &amp; relationship with family, agency &amp; inclusion worker</li> </ul>	<ul style="list-style-type: none"> <li>• Flexibility</li> <li>• Reconceptualising organisation's role</li> <li>• Relationships</li> <li>• Organisational support &amp; skill sharing</li> <li>• People with a disability in control</li> <li>• Staff</li> <li>• Resources</li> <li>• Promoting good practice</li> <li>• Time and patience</li> <li>• Joint focus</li> </ul>	<ul style="list-style-type: none"> <li>• Attitude, commitment and personalities</li> <li>• Disability specific communities</li> <li>• Flexibility</li> <li>• Legislation and public awareness</li> <li>• Partnership</li> <li>• Leadership</li> </ul>



### Challenges for or barriers to inclusion work identified at the level of each stakeholder group

Individual and family	Staff and Organisation	Community
<ul style="list-style-type: none"><li>• Fear and lack of confidence</li><li>• Communication</li><li>• Age, health &amp; disability</li><li>• Informal and formal support</li><li>• Access and infrastructure</li><li>• Safety</li><li>• Finances</li><li>• Personality</li></ul>	<ul style="list-style-type: none"><li>• Staff</li><li>• Resources and time</li><li>• Organising the work</li></ul>	<ul style="list-style-type: none"><li>• Attitude and lack of awareness</li><li>• System and organisational issues</li><li>• Resources</li></ul>

### Outcomes for inclusion work identified at the level of each stakeholder group

Individual and family	Staff and Organisation	Community
<ul style="list-style-type: none"><li>• Increased networks, relationships, &amp; friendship</li><li>• Increased independence, confidence &amp; trust</li><li>• Skill development</li><li>• Access to further opportunities</li><li>• Increased well being, safety &amp; mental health</li><li>• Greater number of interactions, lifestyle changes</li></ul>	<ul style="list-style-type: none"><li>• Implementation of a flexible, developmental approach</li><li>• Outcomes reinforce organisational re-orientation</li><li>• Staff skill development</li><li>• Replication of strategies</li><li>• Resource adjustment</li></ul>	<ul style="list-style-type: none"><li>• Improved attitude</li><li>• Valued partnerships &amp; relationships</li><li>• Skills transferred</li><li>• Increased knowledge</li><li>• Support provided to disability organisations</li></ul>

## **Conclusions**

Section 4 summarises current issues relating to inclusion work, occurring to varying extents in disability agencies. This is followed by a discussion of the key areas for, and ingredients of, change towards comprehensive and embedded inclusion work.

### Current issues with practice

- Inclusion as community tourism;
- A de-valuing of communities of peers with disabilities;
- Inclusion work is ad hoc and not systematically supported in organisations;
- Lack of focus on resources and targeted work to overcome barriers;
- The silo effect that prevents coordinated work across different disability services and supports.

### What needs to change – new understandings and approaches

- Inclusion is both personal and social change;
- People are part of multiple communities – all are important;
- The work is both large scale and skilled;
- Inclusion is all staff's responsibility and needs to be organisationally embedded;
- Inclusion work requires flexibility;
- Inclusion relies on collaboration, partnerships and co-ordination;
- Strategic planning is needed to manage the breadth of inclusion work.

### **Implications**

A systemic, consistent approach to inclusion work is urgently required. Inclusion work must be explicitly planned, resourced and staffed.

#### 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 requires identified investment that is long term and based on identified areas of need;
- Clarify the practice of inclusion work;
- Actively develop cross-sector collaboration in inclusion work.

#### For organisations

- Inclusion work is core business for disability agencies and must be explicitly present in organisational mission, strategies, staffing and resourcing;
- Resource all staff to undertake inclusion work;
- Develop organisational systems and processes that are designed to be responsive to individual contexts;
- Explicitly require and resource the connection of person centred planning and inclusion work;
- Identify explicit leadership and collaborative roles for people with disabilities and their families.

#### For Practitioners

- Reflection on practice is critical to successful inclusion work;
- Be continually aware of power differences when working with people with a disability, their families and communities;
- Identify and address structural barriers collaboratively;
- Allow sufficient time to facilitate inclusion work;
- Adjust your strategies and approaches based on changing contexts.



## Section one: What is this inquiry about?

---

### Introduction

What is inclusion?

How do we enhance greater connections between people with a disability, their family and community?

How do disability organisations enable inclusion to occur?

What works? What are the challenges?

How can we build on what's working well?

This project was undertaken by Scope and commissioned by the Community Building Unit of the Victorian Department of Human Services. Scope is a disability service organisation with a mission "to support people with a disability to achieve their potential in welcoming and inclusive communities" (Scope 2008). This mission is achieved through the provision of a range of services to people with a disability, their families and communities across the state of Victoria.

This project is interested in inclusive communities and a greater connection between people with a disability, their families and communities. The project looks particularly at the role of disability organisations in working alongside people with a disability, families and communities to foster inclusion and investigates **how disability organisations can enhance their function in facilitating inclusion**. It explores changes that are required for disability organisations to support inclusion in more meaningful, effective and sustainable ways.

Specifically, the project aims to:

1. Provide clear **definitions** and examples of what is meant by terms associated with this work such as 'community', 'participation', and 'inclusion';
2. Identify the key factors, **enablers and barriers** (that occurred at an individual, family, community and organisational level) to connecting individualised and person centred work with inclusion;
3. Identify the **changes** or **outcomes** (that occurred at an individual, family, community and organisational level) as a result of a selected sample of this work; and
4. Identify the **key organisational tasks** or ingredients needed to enhance this work.

These findings, we hope, will generate a greater commitment and guide 'inclusion workers', disability organisations and government bodies to further support meaningful and sustainable inclusive practice.

The researchers have refrained from using academic language in the hope that the information, findings and change actions will be as accessible and relevant as possible to practitioners and organisations.

## **Context**

The project sits within a particular historical context. In brief, this is one where there is an increasing policy focus on people with disabilities as equal citizens in Victoria who are able to pursue individual lifestyles of their choice within welcoming, accessible and inclusive communities (State Government of Victoria 2002, p. 5). For disability services, this has meant an increasing focus on individualised service delivery along with an emphasis on desegregation and participation in community places and activities. The set of practices broadly associated with person centred approaches has been identified as key to this work. The Victorian Government has recently legislated the use of person centred plans as a core ingredient of ongoing service delivery (Disability Act, 2006).

Victorian disability organisations and agencies are currently adapting to this policy context and changing the way people with a disability are supported. Some of the changes include a significant transition:

- from people being only physically located in a community, to being active participants and community members;
- from block funding of organisations, to consumer-focused and individualised funding;
- from charitable, paternal values of care, to professional, standards-based, rights-focussed services with quality improvement accountability systems in place;
- from community ignorance and limited information and exposure to disability, to greater awareness, understanding and experience with encountering people with disabilities;
- from people with a disability being in positions of significant dependence, to empowerment of individual consumers with rights and choices; and
- changing roles of staff from 'carers', to inclusion workers.

(Adapted from O'Brien & Inglis 2002).

Changes also include a focus on person centred planning and self direction around how a person would like to be supported.

In short, in this context, there is a twin emphasis on implementing individualised, person centred approaches to service delivery and support, along with work to build inclusive communities and link individuals to chosen opportunities within these.

This change process most often requires a re-orientation of organisational practice. It requires careful planning, consultation with people with a disability and their families, discussion

amongst government and service providers, along with major system changes that incorporate all aspects of organisational processes and methods of working with people.

Within Australia, organisations have gone about this in a variety of ways. Some have embraced change across all facets of the organisation often requiring a dismantling and re-building process. Others have changed part of their organisation, simultaneously running the 'new' alongside the 'what they know'. Other new organisations have developed in response to the new context.

This project occurred at a time when Scope was undergoing a restructure in an attempt to more effectively connect people with a disability to their community. The project was therefore immediately relevant to Scope, with the anticipation that findings and ideas generated by the project would effectively support Scope as well as the disability sector during this time of change.

Given the transitional context, this report is timely in that it provides a range of creative practices and frameworks existing in two states of Australia (Victoria and Western Australia). It identifies key ingredients of good practice in order to prompt practitioner and organisational reflection on their current practice and to refine future practice.

## **Research framing**

With these issues providing the backdrop to the research project, the research team developed the project aims as detailed above.

The focus of the study is not on *why* foster the work of inclusion, but rather on *how* this can happen, *how* does it work, *where* is the evidence of how it works, and *how* do we incorporate identified practices? Rather than create an idealistic 'never been tried' new theory, the research team decided that a useful tool to assist Scope and the sector with their thinking in terms of service change would involve capturing the practical and workable 'how', by documenting various examples where such practice already occurs.

To do this, the researchers needed to define what practices were in view for this study. This led the researchers to adopt a broad definition of inclusive practice. The definitions have been further refined into three 'Orientations' to practice that will be discussed in section 2.

Additionally, researchers needed to define the notion of 'inclusion worker' and the range of roles this encompassed. Within government and non-government disability organisations, a range of directions and models are seen to create or enhance inclusive processes at the individual, family and/or community/systems/policy level. Organisations resource these models with differently skilled people that may include direct support workers, person centred planners, community development facilitators, local area coordinators, leisure workers, support

workers, community connectors and therapists. Whilst we understand that the aforementioned workers contribute to inclusion in various ways, for the purposes of this project, we will refer to them all as 'inclusion workers' or practitioners. This study aims to be relevant to all of them.

## **Research method**

The research involved a range of methods including reviewing existing literature largely from the fields of disability and community development, as well as grey or organisational literature within disability organisations who participated as part of the project; and analysing evidence from interviews conducted with inclusion workers. These methods are summarised below.

## **Use of literature**

A literature review was conducted in the initial stages of the project that sought to contribute to definitions of 'inclusion', 'participation' and 'community' and identify practices to foster these. This review included literature from the fields of community development, disability studies, participatory research, and development studies. Given the breadth of this literature and the complexity of ideas within it, researchers decided not to include the literature review within this report but to summarise only a few key ideas towards offering a clear definition of these terms for use in this study. This selection was also influenced and supplemented by organisational literature within Scope and other participating agencies that documented ideas about inclusion and/or key practice approaches and principles. In particular, organisational and published literature was utilised to document several practice methods for inclusion work, presented in section 2. In presenting both definitions and models of work, the intent has not been to collate and summarise all literature but to select a limited set of key ideas as starting points to thinking and action.

The practice models presented will not be critiqued or graded, nor will a 'one size fits all' framework be identified. Wilson (2005) states that "frameworks are mental models designed to hold together key ideas and practices in a way that explicates the inter-relationship of these ideas" (p. 134). They act as a guide for choosing actions. Wilson (2005, p. 134) cautions:

[Frameworks] represent ways to work and are not the work itself. It is important that the frameworks be adapted to fit localised contexts and not be universalised (Gore 1993). As they stand they do not offer 'a model of practice for all places and times' (Lane 1999, p. 135).

As people are different and unique, communities are also different, unique and fluid. There is no effective formula that fits all people and all communities (Kenny 1999). Across the disability and community sector, creative and flexible processes are occurring that fit unique people and communities in unique circumstances, producing meaningful outcomes. These processes and outcomes may be completely irrelevant for another person, group, or community.

In presenting key ideas from the literature researchers considered how to support relevant and meaningful practices without over prescribing these. It was agreed researchers would identify key elements that could underpin and guide the practice embodied in a small number of models and frameworks. As identified above, it is intended that these function as guides to practice or 'stepping off' points that require constant adaptation to context.

## Interviews

Interviews were conducted with key informants currently involved in community inclusion activity from within a variety of service types (e.g. day services, residential services, community development activity, specialist services work). Two broad sets of interviewees were identified:

1. A range of practitioners within Scope, across a range of service types, who were generally seen to have successful experiences in relation to the work of community inclusion. Scope was seen to have a history of inclusion work including a dedicated 'Community Inclusion' section, as well as two work areas actively utilising two conceptual inclusion frameworks as practice guides;
2. A range of practitioners and program managers in Western Australia. Western Australia was selected due to its extended experience with the Local Area Co-ordination inclusion model, a model quite different from that in use in Victoria.

Data collection occurred between March and October 2007. Interviews were held with eight staff of Scope. These represented staff from a range of sections within the organisation including: person centred planning; day services; community inclusion and development; and specialist services (therapy and psychology), as well as staff in urban and rural locations. In addition, nine interviews were undertaken in Perth, Western Australia, with some of these including multiple participants. These represented staff at both Chief Executive Officer level and at practitioner level, and in government and non government agencies. Unfortunately, all interviewees were based in the Perth metropolitan area though some held management responsibility for service delivery to rural areas.

Table 1: Sample characteristics

Number of interviews from various settings	Victoria	Perth
Day service or alternative to employment settings	2	1
Specialist services / therapy settings	3	1
Community development or inclusion settings	1	2
Person centred planning settings	2	0
Managers of non government disability services	0	2
Government representatives	0	3



Two interview schedules were developed: one for use with practitioners and one for use with managers of services or government representatives. In one instance, the interview with government representatives used the practitioner schedule in order to report on a specific activity. All interviewees had access to the interview questions prior to the interview.

Practitioners were asked to:

- Tell a story about their work that spoke to one of the three Orientations. The story was guided by prompting around the background, aim and process of the work;
- Identify the Orientation the story represented;
- Explain the key factors of success – i.e. what it took for the goals to be achieved, at the level of individual, staff / organisation, and community;
- Identify the hurdles to the work, at the level of individual, staff / organisation, and community;
- Identify the outcomes, changes and/or benefits that occurred for the individual, staff / organisation, and community;
- Identify ways to increase the outcomes from this work; and
- Name the three things the host organisation could do to enable good inclusion work to occur.

Managers and government representatives were asked to:

- Identify which of the Orientations did most of the work of the organisation fit with;
- Identify the goals of this kind of work in the organisation;
- Explain the key factors of success;
- Identify the hurdles to the work; and
- Identify ways to increase the outcomes from this work.

The data from interviews was transcribed and personal identifiers (such as names of individuals, workers, organisations and localities) were replaced with pseudonyms, except where organisations wished to be identified. Interviews were analysed for key themes against each interview question, and quantified by determining which themes were most frequently identified across the interview cohort.

Researchers used all data (from literature and interviews) to answer the research questions presented earlier. Though researchers generally worked in a way that drew conclusions from across the entire data set, this report has tended to present findings from the literature, and those from interviews in two separate sections (literature in section 2, and interviews in section 3).

## **Starting assumptions**

This project was conducted by a research team situated within Scope, an existing disability service organisation. The research team took this to be a strength of the project and this context heavily influenced the assumptions and knowledge brought to it, including those listed below.

### **Ideological positioning:**

- Every person has capacities, abilities, gifts and ideas, and living a good life depends on whether those capacities can be used, abilities expressed, gifts given and ideas shared (Kenyan 2007);
- Everyone can communicate;
- People with a disability benefit from being involved in their community, just as the community benefits from their involvement with the person (adapted from Niemann, Greenstein & David 2004);
- We do not make the assumption that the disability sector can or should meet the whole life wants and needs of all people with a disability (Britten 2001).

### **Understanding of issues:**

- Inclusion, community and participation mean different things to different people. Therefore supporting people with a disability to be included requires listening to what is important and meaningful to them if inclusive practice has any chance of success and sustainability;
- Service delivery, whilst beginning to take up notions of person centred practice and individualised approaches, is still in various stages of infancy regarding the task of facilitating community participation and inclusion for people with a disability;
- Community education, community capacity building and inclusion activities are not always linked to actual clients receiving services elsewhere in the organisation;
- There is growing evidence to suggest that staff do not share a common understanding of the meaning of participation or community inclusion for people with a disability;
- There is a significant risk that the reorientation of services towards increased participation and inclusion will focus on, and be largely satisfied with, community presence (i.e. access to ordinary places, (O'Brien, J. 1987) as opposed to participation in and contribution to the community. In some instances, this is apparent in the activity of re-scheduling or re-venueing activities offered by services to make use of community facilities, without any further interaction or connection of people with a disability to the community of people also utilising these venues, or with little or no reference to the aspirations or preferences of people with a disability;
- There are significant resource and expertise deficits in the disability and community sectors that affect the work of inclusion;

- The new focus on bringing inclusion practices into the heart of the service system, whilst generating positive outcomes initially, may run the risk of re-cementing the service system, albeit around a new set of practices. In some cases, a focus on re-organising the service system towards inclusive practices, fails to consider the ongoing need for the service or options to it;
- A focus on inclusion does not necessitate a focus on individuals at the expense of recognising people with disabilities' preferences for group opportunities, where they express these preferences.

## **Limitations**

This study is small in scale (including a limited interview sample) and as such does not gather evidence of all models of practice.

The study is also limited to the perspective of staff in disability organisations and government. It lacks the scope and timeframe to directly engage with the views and experiences of people with a disability. This is a significant limitation, and the research team recommends a second stage to validate or develop new findings from people with a disability as to how disability organisations work along-side them to facilitate inclusion. It would be equally useful to engage directly with the community sector to ascertain their views about the inclusion process.

## Section two: What is inclusion and how is it facilitated?

---

This section seeks to describe inclusion work: what is meant by key terms; why do the work; what the work consists of; and some of the 'how's' of doing it.

Any research needs to engage with what is already known about a topic. This topic is a conceptually complex one. Within the context of disability services, the research question asks us to engage with notions of inclusion, community, and participation. Additionally, the research seeks to explore the factors affecting this work, and the available models or frameworks to guide this work.

This large task has been limited by three factors:

1. The lack of published material about how disability organisations facilitate inclusion;
2. A large number of documents defining inclusion, social inclusion, community, and participation that translate to vastly diverse practices;
3. Evidence of a lack of understanding of such terms. Clement, Bigby and Johnson (2008) identify that staff in a number of community residential units lack a shared and clear understanding of these terms and are "often left to work out their own versions of [such] concepts ... which may have little resemblance to the intentions of official versions" (p. 65). Further, staff have a "narrow understanding of the goals of community inclusion" and "the abundance of terms that are available to discuss the end goals of building inclusive communities seems to confuse rather than clarify" (p.103). This conclusion resonates with the experience of the research team for this project, who engaged in discussions about understandings of inclusion in a range of forums inside the host organisation prior to and during the conduct of the research.

For these reasons, the research team decided to:

- Define our understandings of concepts associated with community, participation, and inclusion. We are proposing these definitions as a way to re-focus the myriad of definitions and understandings. It was felt that there was already a large and accessible literature on the person centred aspects of this work so this area was omitted from this discussion;
- Summarise recent literature including grey literature (i.e. organisational documents) regarding models for structuring and supporting inclusion work;
- Present practice frameworks in use by organisations where interviewees worked, where these were documented.

## **Understanding inclusion**

The focus in this section is to provide accessible explanations of key ideas related to inclusion work rather than fully capturing the vast literature in this field.

### **Community**

There are many ways of defining 'community'. Various attempts to define it have generated dozens of meanings (Bell & Newby 1971; Dempsey 2002). As a concept, it is used to describe:

- a personal or inter-personal experience (i.e. feeling a sense of community or belonging);
- a group of people or "communities of attachment" Crow and Maclean (cited in Dempsey 2002, p. 142) who share interests (e.g. sailing), identity (e.g. women, Italians), or culture (hip hop, Indigenous) etc.;
- a particular geographical area or location.

Discussions of community most frequently frame it as a positive thing, though clearly experience of and in community (like any relationship) usually includes both positives and negatives.

Most significantly for this study, current Victorian policy statements in the disability sector imply a notion of 'community' as being comprised of 'mainstream' agencies (i.e. those not specifically set up to cater to people with a disability) and people without disabilities. Such a definition focuses attention on work to 'introduce' people with a disability to 'community' (see State Government of Victoria 2002). This is contrasted with a definition of 'community' that recognises that people with a disability are part of many communities including some whose members may be largely or exclusively people with a disability and that such communities are equally valid. The research team adheres to the notion that individuals are usually part of many communities simultaneously, and engage and withdraw from these at different times in their lives.

Each person's understanding of 'community' differs and we will be drawing upon the data to contribute further to the notion of community in section four.

### **Presence and participation**

Is presence the same as participation?

Are disability organisations facilitating both?

For the purposes of this study, we have distinguished between the concepts of presence and participation, as does much of the literature.

Smull and Sanderson (2001) discuss the continuum of inclusion utilising the notion of an individual “being present” in an event or community, “having presence”, and “actively participating” (Smull & Sanderson 2001, p. 139). Such a schema echoes the distinction between physical integration as physical location of people with a disability in communities, (particularly via non institutionalised settings), and social integration which involves both the quality of personal relationships as well as a sense of connectedness to communities of choice (Cummins & Lau 2003).

O’Brien (1987) describes community presence as “the sharing of the ordinary places that define community life” (p.179). Without focused effort, people with complex disabilities will be separated from everyday settings by segregated facilities, “special” activities, and different schedules. Valued activities will increase the number and variety of ordinary places that a person knows and can access.

According to O’Brien (1987), “community participation is the experience of being part of a growing network of personal relationships that includes close friends” (p.179). However, O’Brien also includes a focus on respect, competence and choice, alongside presence and participation, as key ingredients required for a life of inclusion. Presence and participation are two of five elements required for a full and valued life. Refer to diagram 1 below.

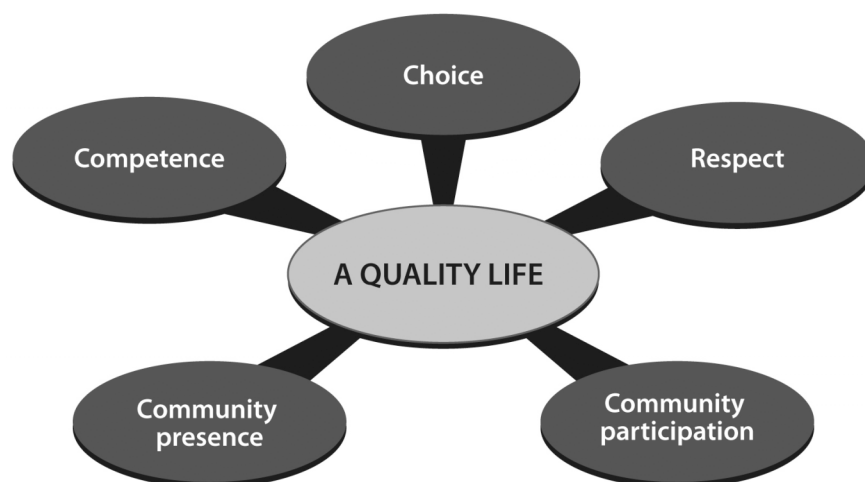


Diagram 1: O'Brien's elements of a quality life (adapted from O'Brien 1987, p. 179)

Britten describes participation as

*How people become immersed in the culture of a community, how they identify themselves in relation to that community... It is about what people give to a community and what they receive in return. Participation goes both ways (2001).*

Britten reports that meaningful participation consists of the following elements:

- Emotional
- Social
- Intellectual, and
- Physical.

See diagram 2.

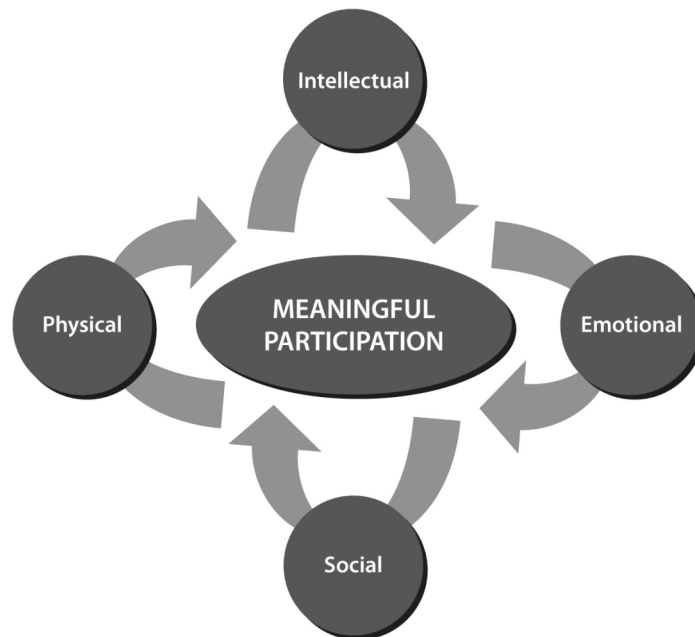


Diagram 2: Britten's elements of participation (adapted from Britten 2001)

So, in an education setting, whilst a child may be present in the class room and may be able to participate on a physical, emotional and intellectual level, she may be teased in the play ground, may not have any friends and as a result does not want to return to school because she is restricted from participating socially.

Britten's theory encourages inclusion workers to consider all elements of participation (2001). However, it is ultimately up to the individual as to how they participate and what form of participation is meaningful to them. The literature on person centred approaches within disability services suggests that, at all times, determining the meanings of presence and participation will be highly personalised, contextualised and therefore widely divergent across the population.

Whilst the individual decides what level and type of participation is pertinent, it is also imperative that inclusion workers consider the internal and external factors that enable or hinder the occurrence of participation. Even as the individual is internally influenced by an array of factors, there is a range of external factors that also require attention so that participation is enabled. The International Classification of Functioning, Disability and Health (ICF) considers a range of elements that inclusion workers can work with to systematically remove barriers and further enable participation to occur. These include:

- Products and technology
- Natural environment and human-made changes to environment
- Support and relationships
- Attitudes
- Services, systems and policies (World Health Organisation 2001).

This discussion suggests that presence and participation are different ideas. Additionally, participation may take many forms and involve different internal and external elements. It is the individual who drives preferences about the extent and nature of both presence and participation in different contexts. Each individual will make different choices at different times about areas of life they wish to engage in and whether they wish to be present or participate. It is the external factors that require significant investment to ensure that opportunities to participate are available. In short, this framing emphasises distinctions between physical presence and a range of wider social and participative outcomes which are highly individual in nature.

## **Inclusion**

The literature on inclusion is both broad and extensive, and encompasses a number of key framings. 'Inclusion' can be understood as a concept in its own right, embracing a range of understandings, or partnered with other concepts, such as 'social inclusion' or 'community inclusion' to foreground a particular set of concepts and values. Considering the extent of available literature, we did not see it as a useful exercise to critique it. Rather, we wish to define what inclusion means to the researchers, bringing it together with notions of community, presence and participation and, hence, how this understanding impacts on how we might go about doing inclusion work.

There are current debates within State and Commonwealth governments as to what 'social inclusion' means and how it will be achieved. In general, these debates draw on an understanding of social inclusion as a broad concept, encompassing ideas about social engagement with people and activities; service access; economic inclusion; and political engagement (Saunders 2007). Notions of *inclusion* often draw on understandings of *exclusion* and the need to address these barriers to inclusion. These barriers are understood in a range of ways. The identification of factors that perpetuate exclusion is akin to the social model of disability that emphasises the way external factors function to create disability. In this analysis, disabling barriers may be physical (e.g. physically inaccessible places and spaces), attitudinal, behavioural and structural (including how policies are made and resources allocated). Inclusion work is sometimes described as creating *enabling* rather than *disabling* environments, with a focus on overcoming a wide range of barriers (for example, Swain et al (Eds) 2004).

This set of concepts has resonance with ideas about freedom proposed by Sen (1999). Sen poses the concept of development in terms of the 'freedom to' a number of broad life factors and 'protection of' these essential freedoms. He states that in order for an individual, as well as a society, to develop individuals must have a set of freedoms available for them to enjoy. These include access to education, health care, employment, food and shelter, but also non-tangible freedoms such as a choice to participate in a religious, political, cultural or linguistic



group. Applying such concepts to definitions of inclusion suggests that all human beings would like to participate in various priorities of their choosing that they consider will support their personal development. These freedoms must be both *available* and *protected* so that the person is not deprived or excluded. Freedoms must not just apply to specified or elite groups but to all members of a society.

If we look at inclusion in terms of a rights based framework, then accessing freedoms, pursuing priorities and participating in communities of choice are considered civil, political and social rights as a citizen. Responsibility is a notion that is frequently paired with that of rights. The Disability Services Commission (DSC) of Western Australia discusses responsibility in their understanding of inclusion as “a sense of belonging, sharing responsibility, contributing and being seen to be of value regardless of one’s circumstance” (KPMG Australia 2007, p. 2).

This broad approach to ‘inclusion’ is echoed in Victorian State Government disability policy that proposes that an ‘inclusive community... [is] where everyone has the same opportunities to participate in the life of the community’- socially, economically, culturally, politically and spiritually (State Government of Victoria 2002, p. 7). However, despite this policy, the notion of inclusion within the disability sector appears to have had generally a more narrow interpretation. Within parts of the sector, there seems to be a strong link between inclusion and the notion of ‘presence’ discussed above. Such an understanding of inclusion focuses on ‘outings’ or participation in community ‘activities’ (sometimes referred to as community ‘tourism’). In practice, this kind of ‘inclusion’ is sometimes further reduced to an individual accessing the local community or neighbourhood house, i.e. focusing on a narrowing of an individual’s life to their interest in one particular life area only.

The research team proposes an approach to defining inclusion work for people with a disability that focuses on the priorities of an individual's life in terms of the whole of who they are and how they live their life. This broad whole of life approach emphasises the importance of what an individual wants to achieve, do and be in life. Individuals will choose the communities in which they wish to belong, contribute and be valued, and the extent of their presence and participation in these communities. Their involvement is enabled by overcoming the barriers that currently function to exclude or devalue them. Inclusion is a broad concept and will mean different things to each person.

As facilitators of the inclusion process, *inclusion work involves 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.*

## Why do inclusion work?

Inclusion work seeks to bring about a world where there is equal justice, freedoms, protection and opportunities for all citizens to pursue their priorities and practice their beliefs. Essentially inclusion work operates on the belief that people with a disability are as entitled to this kind of justice and freedom as those without disability.

Cocks explains that inclusion workers need to understand, believe in and be driven by *why* they are doing the work. He defines the most important feature of an effective inclusion worker as having a set of values that enables them to “stand up for and believe in what they are doing”. He also maintains that the organisation that promotes inclusion work must have a “strong, explicit commitment to positive values about the people who use the service” (1992, pp. 46 - 8).

## What is inclusion work?

*Inclusion work involves 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.*

Reflecting upon our definition of inclusion, and for the purposes of this report, we consider inclusion work to encompass any individual, practitioner or organisation that uses 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. In this section, we aim to describe the ‘what’ of the work. In particular we discuss different ways to focus the work, the breadth of the work, and the different ways agencies have organised or structured the work.

## Orientations to the work

Disability organisations have employed various modalities and approaches towards inclusion work. Some focus on individuals, some on opportunities in community, some on larger systemic changes, and most on combinations of these. These different ways to focus the work were identified by researchers and are called ‘Orientations’ in this report. This research proposes three Orientations as 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 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.

#### **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 and opportunities as well as limited life experiences, 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.

#### **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 include people with a disability as actors. This work is generally ground-breaking and foundation-laying work with organisations and communities.

#### **Breadth of the work**

The three Orientations are very different from each other yet all have a place in working to create inclusion from different directions within community. 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 relies on 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.

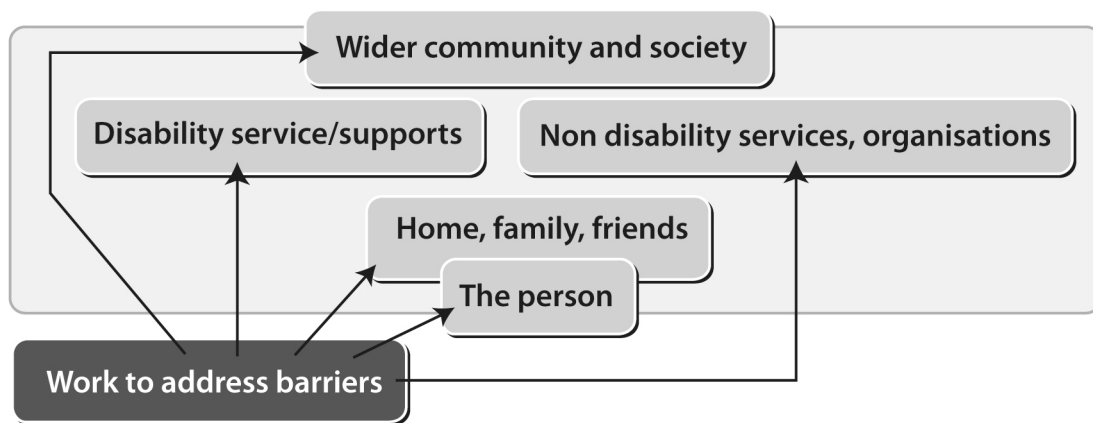


Diagram 3: Work to address barriers across range of dimensions and environments

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:

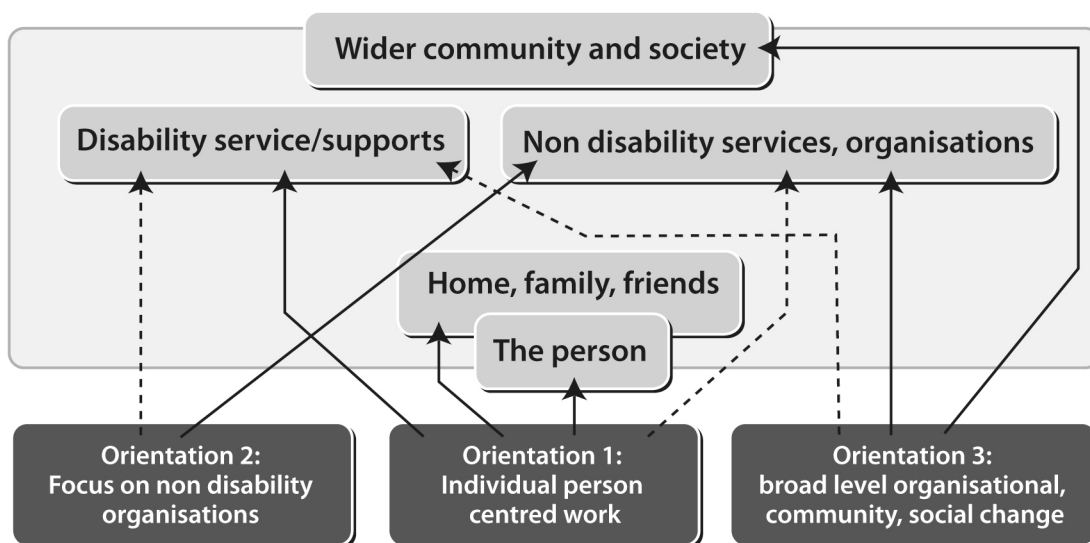
- personal and home barriers;
- barriers in disability services (e.g. residential or day services);
- barriers in non disability organisations (e.g. shops, neighbourhood house etc).

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.



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

Diagram 4: The focus of the three Orientations of inclusion 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. Of course, some inclusion workers operate across the entire spectrum, but the research presented later in this report suggests that most workers and organisations focus their work in one or two of the three Orientations only.

Considering freedoms or enablers are required across a number of different dimensions to facilitate inclusion, systematic placement of inclusion workers across the three Orientations would enable a more strategic approach to inclusive practice. This would result in more comprehensive benefits and freedoms – further supporting people with a disability to pursue their priorities.

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 all three Orientations. 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 facilitate the linking of change actions and build upon established successes to achieve more sustainable outcomes.

## **Organising inclusion work within agencies**

The previous discussion identifies that inclusion work is a broad scale activity that requires the combined focus of Orientations 1, 2 and 3. The work ranges from a focus on the personal to broad social forces and structures. This section identifies ways that agencies have framed and organised their inclusion work, and is based on current examples in Victoria and Western Australia.

Agencies have organised inclusion work in various ways. In general, these ways align with the three Orientations discussed above, or include a focus on two Orientations together. Within each Orientation though, organisations have structured their work in different ways. The research team has attempted to capture commonalities in organisational approach and have identified three main groupings:

- *Single focus work*: An agency organises inclusion work around individual people with a disability and their families, OR around a single field of activity / interest (e.g. recreation);
- *Broad regional work*: An agency organises the work around a geographic region, or a set of broader systemic community development or capacity building projects;

- *Service redesign*: where agencies have re-constructed their entire organisation in order to provide more individualised support to people with a disability or focus on inclusion in different ways.

Examples of each of these organisational approaches can be found within the three Orientations. The examples below draw largely on published 'grey' literature but do not capture the full set of activities in Victoria or Western Australia. We have omitted the work of person centred planners and specialist (allied health) services from this list given that these approaches are common across many disability services. In some cases, there is a degree of overlap across the Orientations, but examples have been categorised according to what appears to be the dominant mode of organising their work.

## **Orientation 1: Individual person-centred work leads to inclusion**

### Single focus work

Within Orientation 1, many agencies organise their work around specific individuals. These agencies actively use, or broadly align with, person centred approaches.

#### *Recreation and Sport Network Inc:*

This organisation works individually with people to discover what their recreational or sporting interests are and links them to activities within the community. For example, if a person likes to make model trains, the facilitator will link him or her to a model train club. The facilitator will provide initial support and follow up to both the club and the individual to ensure the interaction is working for all and the individual is as included as he or she can be (Recreation and Sport Network Inc. 2006).

#### *My Place:*

Supports people with a disability to live in their own homes and organise their own supports whilst aiming to support the person to be an included and valued member of their local community (My Place n.d.). My Place received additional funding to provide a group of ten individuals with 'community connectors', i.e. people who would get to know each individual and support him/her to connect with people or activities that build on the individual's interests. These roles are in addition to the support workers already working with the individual. The community connector also works with the local community and government to build relationships with people who organise or are part of the activities individuals are interested in.

#### *Planned Individual Networks (PIN)*

This organisation is run by families who have adult or younger children with a disability. Their aim is to develop the capacity of a broader number of families to plan for the future through person centred planning, advocacy and workshops. By doing

this, they would set up a 'good life', through planning and developing an enduring network around a person that would be life long. These networks aim to endure past the event when primary carers or family members pass away. They promote family leadership, safety and security through relationships and self sufficiency, believing that everyone can communicate and contribute (Planned Individual Networks Inc. 2008).

*The Lost Generation Project:*

Aims to utilise arts and culture as a medium to support people who are living in the service system to connect with their local community. It was recognised that people with a disability living in group homes were extremely isolated, with only distant, if any, connections with their family. A joint partnership between West Australian Disability Services Commission's Accommodation Services Directorate (DSC ASD) and DADAA Inc, and other institutions (such as TAFEs and universities) aims to open up a range of opportunities for skill development, participation in the arts and the development of relationships around identified individuals (Government of Western Australia n.d.).

*Fremantle Connections:*

Through an effective relationship, a group of inclusion workers and the local government formed a new agency called "Fremantle Connections" that supported isolated people in the local area. Through talking to other local inclusion workers, a number of isolated people with a disability were identified as vulnerable to experiencing poor mental health. Fremantle Connections invite local people to support isolated individuals. People with similar interests are invited to be part of an individual's life and, slowly, they break down barriers that prevent the individual from participating. Local people utilise their own connections within the community to facilitate further connections. Fremantle Connections also supports local clubs' capacity to include the individual using strategies that will enable the club to include anyone with a disability. People are supported until no longer required (City of Fremantle n.d.).

Broad regional work

Within Orientation 1, agencies also organise their inclusion work around individuals on a large scale case-management / development basis. This is often done on the basis of region or locality as in the example below.

*Local Area Coordination (LAC):*

LAC's are regional inclusion workers that support a range of people with disabilities and their families within a specific locality. Each LAC worker is allocated a case load of individuals/families within their region that they work with over a long term period (for example, an individual may be registered with and receive support from their LAC from childhood to 60 years old). LAC's focus is to develop relationships with individuals and

families to identify what is important to them in order to lead a 'good life', factors that include present and future aspirations. LAC's will then share a range of links and information to facilitate individual/families' aspirations. LAC's work alongside individuals and families on various locally driven community projects that support inclusion to happen. LAC's support person centred processes and ideally stay in the position long term so that relationships are strengthened with individuals and families as well as the local community (Government of Western Australia 2004, pp. 2-5). This approach clearly overlaps with Single Focus – Individual examples discussed above but is categorised here because it is organised on the basis of geographic region.

### Service re-design

Orientation 1 work has led to a need to re-design or re-structure the entire organisation in some cases. Inclusion Melbourne offers a documented case study of this approach.

#### *Inclusion Melbourne:*

A 58 year old organisation reformed its day centre services for people with intellectual disabilities, closed the centres and provided individual services as an alternative. The re-structure involved "both cultural change based on person-centred values and ethical frameworks, and the development and implementation of strategies focused on technical and operational issues" (Craig & Cocks 2009, p 41). Inclusion Melbourne has highlighted a fundamental gap in the funding available to support people with high support needs and the ability to support quality outcomes for this group.

## **Orientation 2: Opportunities are created in community**

### Single focus work

Whilst Orientation 2 work requires a focus on the creation of opportunities in community, not necessarily explicitly linked to identified individuals, many organisational approaches tend to specialise in a particular area of interest or community sector, such as arts or recreation. This specialist approach has led us to categorise these organisational models as single focus.

#### *Access for All Abilities (AAA):*

Works with the sport and recreation sector, and aims to build a "culture of inclusiveness and participation as well as access to sustainable, quality sport and recreation activities and facilities" (Sport and Recreation Victoria 2008, p. 2).

#### *ReCharge:*

Aims to provide a respite service to families caring for an adult family member with a disability whilst building the community's capacity to host and co-manage respite events. Respite takes place within various community organisations and the various activities are held at different locations. Individuals and families identify which



opportunity will be of interest to them. Examples of ReCharge respite include water aerobics, cooking classes and art (Scope n.d (a)., pp. 2-4).

### Broad regional work

Other organisations adopt an Orientation 2 approach but organise their work by locality or region, ensuring all regions are covered.

#### *Metro, Rural and Deaf Access:*

Metro and Rural Access Workers are placed in a specific local government area and aim to work alongside local government to develop more inclusive communities (Department of Human Services n.d.-a, p. 1). In a similar fashion, Deaf Access workers work along-side of rural community organisations and services to develop strategies and provide practical advice to include deaf and hard of hearing people (Department of Human Services n.d. b, p. 1).

#### *Victorian Statewide Speech Therapy Initiative:*

There are eleven Regional Communication Services located across Victoria. The services support individuals to communicate effectively and participate in their own communities (Scope 2005, p. 1). Services use a community capacity building approach to work with family, friends, shops, community services and people with complex communication needs to build inclusion focusing on inclusive communication strategies.

#### *Leisure Action:*

Works with people with a disability, local government, community recreation and sporting providers, and other specialist services to enhance participation in recreation, sport and leisure activities (Scope 2006).

### **Orientation 3: Broad level community change**

Whilst it could be argued that some of the examples above in both Orientations 1 and 2 also include an Orientation 3 focus (in addressing community structures and attitudes), it is a lesser function of their role and their work to address barriers might usually not extend beyond the local context (i.e. not extend into larger scale policies and structures).

However, in focusing on broader scale social change, some organisations have found it necessary to re-design or re-invent themselves entirely as part of inclusion work. This work to re-shape community and change structures and attitudes, also links to Orientation 2 work by creating new opportunities for people with a disability in specific settings.

## Service redesign

### *Nulsen Haven:*

This agency has redefined and reconstructed its organisation to ensure its relevance to people with a disability, community and government. It has now positioned itself as a community organisation rather than a disability organisation. For example, Nulsen Haven won a tender to operate a 'mainstream' 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. Other community services delivered by the organisation include: running an independent administration service; 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). Nulsen Haven have also developed a partnership with a local private hospital over the past 14 years so that people with a disability with significant health issues are known to the hospital and receive immediate assistance (personal communication Trewern, G. 2007).

## **How do inclusion workers do the work?**

The previous sections discussed the key intents and understandings of inclusion work. Inclusion work encompasses a wide range of work including a focus on supporting individuals to achieve their goals, creating opportunities throughout communities, and on larger systemic changes. This breadth of work suggests that the *how* of doing it is likely to be diverse and complex, and involve a wide range of roles and skills. Because of the commitment to the purpose or the *why* of the work, how workers do the work is necessarily underpinned by core principles of practice. Without these, workers can undertake identified tasks but in a manner that undermines rather than fosters the valuing of people with a disability as active citizens and agents. This is pertinent given people with disabilities' history of oppression. Conscientious action is required in order to not repeat behaviour that further oppresses rather than empowers people with a disability.

This section aims to identify some of the elements of *how* to do the work. Since the work has many similarities with community development, we draw on this literature. Within this field, Ife (2002) advocates against 'cook books' that describe the *how to* of community work. Firstly, he indicates that community work is not linear, it is fluid and the parameters of the work require constant re-adjusting to suit the fluidity of people and their community. Secondly, each community is unique, so different approaches are required to suit different communities. Thirdly, each community worker is unique, so each will have different working styles, personalities and bring various qualities to the job. Finally, Ife describes the fact that skills related to community work are intermeshed with personal values and knowledge. So whilst it

is useful to draw on different materials and ideas for reflection and practice development, there is no single right method to do the work (2002).

Keeping this caution in mind, below we present:

- Key elements of inclusion work;
- Community work roles;
- Principles.

All of these help answer, in brief, the *how* of the work.

### **Key elements of inclusion work**

As with community development, it is possible to think about the work of inclusion according to key segments or elements of the work activity, i.e. what things do / should inclusion workers mostly do?

During the research project, we encountered two documented models, operating within a disability service (Scope), for thinking about the key elements of the work. While further research is needed to determine the relative merits of each, these models provide two interpretations of these key elements of the work. There is a high degree of conceptual overlap between them.

#### Community Inclusion and Development Unit

This model describes six 'key action areas' (Scope n.d (b)). These are:

##### *Building support*

This action is based around a person centred approach to identify individual aspirations. This becomes the focal point for analysing and exploring opportunities and challenges at a local level. A first step is to create awareness and support within targeted organisations / communities. This includes developing shared agendas and a readiness for the change process.

##### *Building relationships*

It is necessary to build relationships around the work both internally and externally to the host organisation. Relationships support the development of a shared vision, identification of mutual benefits and responsibilities, and commitment to shared action.

##### *Building resources*

This action focuses on developing physical, human and financial resources, including funding acquisition, equipment, networks, specialist support, information, training and advocacy.

### *Building opportunities*

This action focuses on enhancing processes, systems and structures within organisations / communities. It includes work to develop enabling policies and practice, services, monitoring and evaluating participation, and developing support structures and communication systems. The focus here is on building the capacity of organisations/communities to sustain an inclusive culture into the future.

### *Building leadership*

The focus of this work is building leadership potential in communities. Leadership encompasses energy, vision, problem solving capacity, and involves being a catalyst for change.

### *Building empowerment*

This action supports the potential and existing assets of people with a disability, staff and organisations. It involves developing skills, knowledge and resources towards being pro-active and assuming control of inclusion work.

## Speech Therapy Initiative Community Capacity Building Model

This model identifies a set of key strategies to 'increase the capacity of local communities to support the inclusion and participation of people with complex communication needs' (Scope 2004, p. 1). Reflection is central to the model when considering each strategy.

Key strategies include:

### *Community Mapping*

Understanding the context and determining existing resources, networks and community agencies within the geographic area where workers are based is critical to the work. This process is useful to identify opportunities, and gaps within the community.

### *Planning*

The planning process provides for clear objectives and a plan of action to be undertaken.

### *Working in partnership*

The development of a shared vision and goals support sustainable projects with long term outcomes. Clearly identified partnerships can guide the project with partners having defined responsibilities to the work.

### *Educating and developing people – skills, knowledge and attitudes*

Building awareness and skills of community members will support them to be more mindful and inclusive of people with complex communication needs.

### *Enhancing the policy, practice and systems of organisations and communities*

Enhancing organisations and community agencies to adapt their policy, practice and systems to be inclusive of people with complex communication needs is just as important as building individual people's knowledge and skills. It allows for systems to be more accessible to people with a disability.

### *Building resources*

Resources encapsulate a range of assets that will complement community and organisational awareness along with their capacity to include people with a disability. Resources include human and physical resources such as intellectual knowledge, skilled staff/leaders, additional supports, infrastructure, equipment or funds.

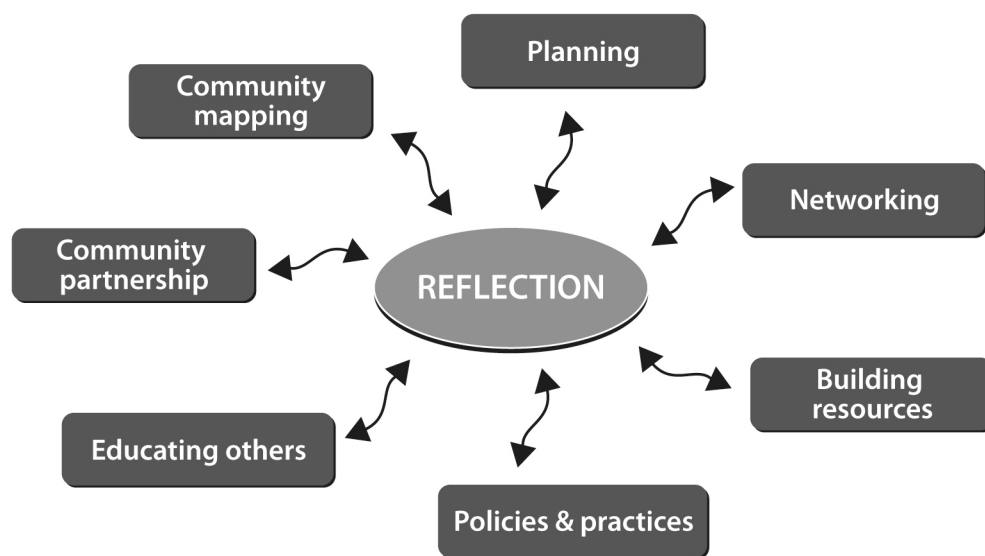


Diagram 5: Speech Therapy Initiative Community Capacity Building Framework (adapted from Scope 2004).

This framework has been widely used within the Victorian Statewide Speech Therapy Initiative. As a result it is accompanied by a documented set of competencies, related to each strategy, which enable workers to self assess their level of skills and their need for skills development in some areas.

### **Community work roles**

The tasks and activities of inclusion workers are broad and diverse. 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.

As seen in diagram six, each of these four clusters then 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. "The community worker, by the very nature of the task, must be a generalist" (Ife 2002, p. 230).

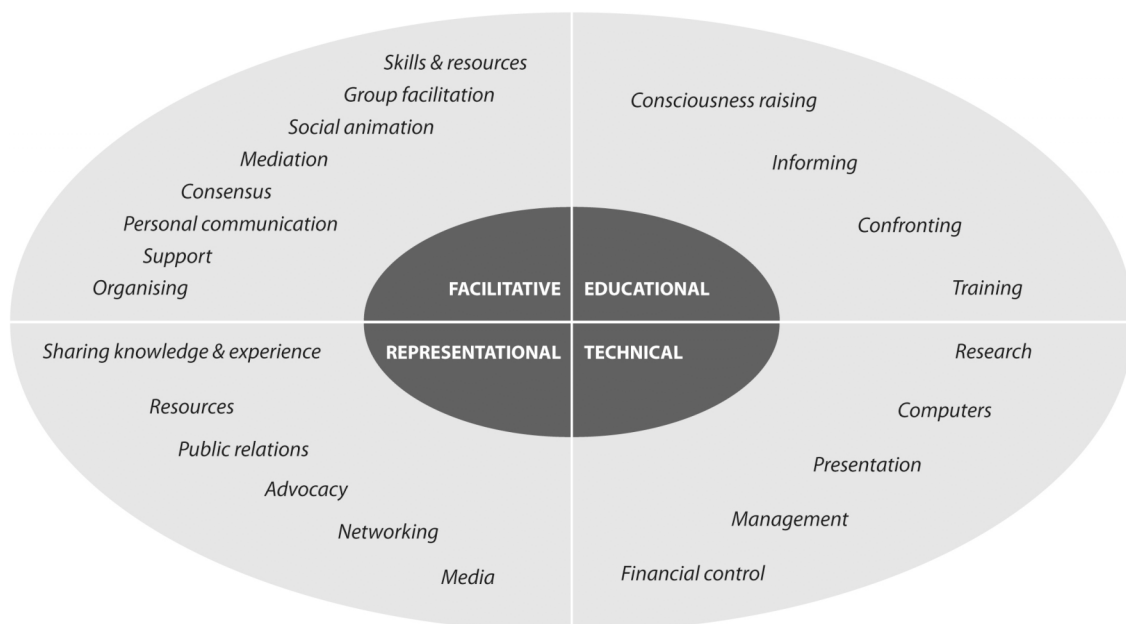


Diagram 6: Community work roles (adapted from Ife 2002, p. 257)

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. Ife emphasises the importance of not limiting roles to the examples seen in the diagram above. This is important when applying these ideas to inclusion work as there are additional ways to interpret these roles in this arena. For example, the role of personal communication (within the facilitative cluster) involves additional elements in inclusion work, where workers require specific communication skills in order to effectively communicate with people with a range of communication modes.

Though Ife (2002) cautions to not overly focus on roles when defining community work, having an understanding of this breadth of roles within the work helps explain its complexity as well as identify potential areas for professional development for those undertaking the work. It is also useful for identifying and matching suitable workers during recruitment processes.

## Principles

Underpinning the diverse roles and contexts in which inclusion workers carry out their work, there are a number of key principles identified to support good practice. As discussed previously, practice principles underpin the work and relate to its purpose and goals. They bear a close relationship to the ethics of the work.

The principles discussed below are drawn from community development literature. Whilst the principles relate to more complex theories, they are summarised here and references provided for further reading.

Ife (2002) discusses twenty-six core principles of community development work. He proposes these principles as a checklist and helpful guide for practitioners when reflecting on their work. Whilst Ife describes twenty-six principles, we will only briefly define the five major categories in which they sit (diagram 7).



Diagram 7: Principles of community development (adapted from Ife 2002)

### 1. Ecological principles

"Every event or phenomenon must be seen as part of a whole" (Ife 2002, p. 41) therefore understanding the bigger picture is a vital element to the work, as is working to foster diversity, sustainability, organic and balanced development.

## 2. Social justice principles

The importance of addressing structural disadvantage and oppression; identifying and deconstructing discourses of power; empowerment; supporting communities to define their own needs; and a commitment to human rights are all aspects of social justice principles.

## 3. Valuing the local

The essential focus here is the value of grass roots/ bottom up/ local community development. This category requires valuing and working with local knowledge, culture, resources, skills and processes. This privileges the views of those most affected by an issue.

## 4. Process principles

Process principles outline not only the importance of process, but also the significance of developing a joint vision, involving others throughout the process, ensuring that the pace of development is inclusive of all parties, and that the methods used are non-violent or coercive. This means that the timing of the work has to suit the community and the worker needs to adjust and work within these requirements.

## 5. Global and local principles

Globalisation and its impacts are evident even on the smallest communities. Understanding the impacts of globalisation on local communities is vital for community development workers when understanding and working with the community. Also, being aware of and addressing power levels of all those involved, including the worker, is critical throughout the work and a vital enabler for empowerment.

Working in ways consistent with these community development principles, disability organisations have developed principles for working with people with disabilities, their families and communities. Disability Services Commission's Local Area Coordinators work by a set of values that guide the work (2004). Three of the ten principles are presented below.

1. As citizens, people with disabilities have the same rights and responsibilities as all other people to participate in and contribute to the life of the community;
2. People with disabilities and their families are in the best position to determine their own needs and goals, and to plan for the future;
3. Families, friends and personal networks are the foundations of a rich and valued life in the community (Government of Western Australia 2004, p. 3).



## **Conclusion**

This section has discussed a definition of inclusion and associated ideas, and identified aspects of the work.

Inclusion work involves 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.

This work has a broad focus, described here in terms of three Orientations to the work. These Orientations focus on individuals; on the creation of opportunities in community; or on larger systemic changes. Of course, some of the work involves combinations of these. This section has identified that for inclusion work to be successful, there needs to be sufficient attention paid to all of these Orientations, to ensure that barriers to inclusion are addressed at the individual, family, service provider, community and government level.

Agencies in Victoria and Western Australia have gone about structuring and organising inclusion work in different ways. In general, agencies align their work with an Orientation and organise their work either around a single focus; a geographic region or set of more systemic issues; or through comprehensive service redesign. This section provides a range of examples of agencies that have organised their inclusion work in these different ways.

Inclusion work is comprised of key elements or clusters of work activity. Scope has organised these practice elements into two practice models (with a high degree of consistency between them) that frame and guide the work. The work involves a broad range of job roles such as facilitative, educational, technical and representational (Ife 2002, p. 257) and practitioners need to be generalists across these. All inclusion work is underpinned by a set of practice principles that ensure the work matches its purpose and is ethical.

Together, this information generates a picture of inclusion work as tremendously broad and varied. The analysis presented here suggests that this breadth is vital to ensuring that barriers across all levels of society and in all environments are adequately addressed. However, given the breadth of the work, the range of ways it is organised, and the range of roles and skills it entails, it is not surprising that there is a reported lack of clarity about what it is or how to do it (Clements, Bigby & Johnson 2008).

The next section, section 3, aims to address this further by providing concrete examples, from interviewees, of inclusion practice. In addition, section 3 reports the key enablers and barriers to the work. This data adds specific information and examples to enable organisations to better support the work.

## **Section three: What do practitioners say about their practice?**

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As discussed in section one, interviews were held with a range of practitioners, service managers and government representatives in Victoria and Perth, Western Australia. These interviews provided a wealth of information about the nature of inclusion work.

### **Defining by example: case studies of practice**

The stories that interviewees told of practice, especially given the different Orientations of practice (as described in section 2), provide some useful understandings of the work of inclusion. Most of the case studies are summarised below. In presenting these, the aim has been to capture the nature and process of the work as a way of helping to define and understand this work. As a result, factors affecting their success have been excluded here and will be discussed later in section 3.

Case studies are organised according to the Orientations to inclusion work discussed in section 2. In general, these are distinguished by different levels of engagement with individual people with a disability and their aspirations, and a different rationale for selecting the community inclusion actions. The first Orientation leads directly out of identified person centred plans and preferences and undertakes community inclusion activity in order to directly implement these. The second Orientation draws on a general understanding of the preferences of people with a disability, but is more opportunistic and community oriented in working to develop opportunities for inclusion, often developing these based on a mapping of community possibilities and networks. The third Orientation focuses energy on structural and attitudinal barriers preventing inclusion and works to overcome these, often quite divorced from specific individuals with a disability.

The majority of interviewees provided case studies relating to the first Orientation, hence the higher number of these examples provided below. Taken together across orientations, the case studies presented here provide a picture of varied work contexts and approaches but are not intended to represent the whole range of inclusion work in any Orientation, as they are limited to examples provided by a small pool of interviewees. Pseudonyms have been used in all stories.

### **Orientation One: Person centred work leads to inclusion**

#### Example 1: Pursuit of a hobby

Binh attended a day activity centre, and expressed his wish to make friends and participate in photography. An inclusion worker spent time getting to know Binh's interests, exploring community opportunities, and matching leisure interests with skills.

With Binh's permission, the inclusion worker contacted the local photography club, to introduce Binh and identify whether the club would include him in their activities. The club agreed that Binh could join their club. Binh and the inclusion worker decided to learn more about photography prior to attending the club. With the inclusion worker's support, Binh attended a one day course at TAFE on digital photography where he was able to learn basics. The TAFE staff were very supportive and flexible by allowing the inclusion worker to attend with Binh. The inclusion worker and Binh spent some time experimenting with photography before each monthly camera club meeting. Binh then attended monthly club meetings with the inclusion worker's support. Binh has developed relationships with a couple of club members in particular. These members will intentionally sit with Binh and take additional time to clarify concepts to him that are being presented.

The inclusion worker reported that photography has given Binh something to do in his spare time when he is at home or out by the river. It has also given Binh something to talk about when he meets people.

#### Example 2: Independent travel and employment

Camira attended a day program and it was clear that she didn't like being in the building. She had previously tried but didn't enjoy participating in supported employment (i.e. services funded by the government to employ people with a disability).

Camira identified that she wished for an adventure and wanted to explore her community including rural communities. She expressed this desire to staff with whom she had a good relationship and her wishes were formally documented via the person centred planning process. Camira purchased an electric wheelchair which enabled greater independence and movement for the first time in her life. Those involved in Camira's life supported her with her decision to embark on an adventure. Camira would start each day by dropping into the day service and planning her day over a cup of tea with a staff member she trusted. She would then embark on various adventures that revolved around exploring her community and catching trains to rural locations. Support was rearranged so it would be provided in the form of a train ticket, for example. For a period of time, Camira went to a rural town by train on a weekly basis.

A person centred review held last year reaffirmed Camira's desire for employment. With support from the day service co-ordinator and a psychologist, Camira sought out employment with the 'Big Issue'. She worked for the 'Big Issue' for 15 months. Upon her second winter, the enjoyment of selling the magazine was reduced during winter months when she felt cold and others were too cold or busy to buy magazines, bringing in little revenue. Recently, Camira attended training and is now exploring other employment options that may include leading tours of the CBD for those who are new to using electric wheelchairs or scooters.

Camira's adventure has given her the freedom to explore her state by train. She has developed self-confidence and taken more personal responsibility as a result of greater autonomy. Camira has developed relationships with people in her local community as well as in rural areas. She is now well known in her local area and this has increased her sense of safety.

Family members were hesitant initially about Camira going anywhere on her own for safety reasons but they have since accepted her choices after seeing the difference it has made to Camira's life and personal happiness.

### Example 3: Going to school

Abbie was a five year old girl about to start school. Her family chose a non-government school for her to attend. The inclusion worker mentioned that Abbie's family were anxious about her safety whilst in the school environment particularly considering her complex communication requirements. The inclusion worker reported that parents' concerns over their children's safety is a common experience when children have either complex communication, use alternative communication methods or are at an age where they are still learning and developing their communication style. In addition to this, supporting children with high support requirements within an inclusive setting requires some joint planning, exchange of information and dialogue to ensure the experience provides positive and safe outcomes for the child, parents, teacher, class mates and school.

The disability service ran a kindergarten readiness program that Abbie and her parents were included in. In conjunction with this they also ran Parent and Child Activity Sessions that included eight sessions after the morning play group and afternoon information sharing between prospective parents and teachers and parents who have children already attending school. Teachers who have recently taught children with disabilities in their class spoke to the parents about their experiences including children with a disability in the class room and school.

Once Abbie's enrolment was accepted, Abbie's future teachers were invited to a teachers' workshop that covered topics such as learning about cerebral palsy, manual handling, teacher/parent stories and problem solving. The disability service supported the family to develop a personal profile for Abbie along with photos and descriptions of what is important to her and how to care for, support and communicate with Abbie. This profile was given to the teachers who were able to problem solve things in the second semester before Abbie was due to attend. For example, the profile included communication strategies that the teachers could use or ideas of how to safely lift a child that is wriggling. This preparation gave teachers confidence to include Abbie in school.

Once at school, Abbie's peers provided daily support and looked out for her well-being. For example, if Abbie started to look unwell, students would alert the teachers immediately. An inclusion worker at the disability service and the teacher spoke regularly throughout the year.

This established agreement enabled any additional support, information or resources to be shared with the teacher as required thereby maintaining a positive experience. Attending a local school provided Abbie with an opportunity to learn to communicate with a variety of different people. At the end of the year, the inclusion worker asked Abbie's teachers to be involved in the teachers' workshop again but this time, their role was as mentors to future teachers and families. Their experience provided invaluable information and reassurance to new parents and teachers.

#### Example 4: Building friends around independent living

Joe, a 32 year old male, spent the second half of his life in an institution. According to the inclusion worker, there came a point when the institution decided Joe could live on his own. It was reported that the institution set Joe up with limited support in a flat and then reduced all support, never seeing him again. According to the inclusion worker, the institution viewed their role in 'de-institutionalisation' as physically placing individuals in their own accommodation without thought about how they were going to manage in a community without any established connections or support. Joe went from having twenty-four hour support, to a one hour visit every fortnight by a support person from a community based disability organisation 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 no longer had contact with them. Joe struggled to communicate with people he wasn't familiar with and he didn't know what he wanted. Within a year and a half of living in isolation, 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. The inclusion worker's connections with the local community enabled her to introduce him to other people his age with similar interests. 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. Through the inclusion worker, Joe met a few men his age and identified the person he felt most comfortable with to spend time with. Joe and his new contact were a similar age and they started going out together. Joe developed trust as they went to the pub regularly, ate meals together and played pool. His new friend introduced Joe to other contacts that shared similar interests and gradually, his support network increased. Joe became a member of a football club and through another contact, was picked up each week to go and watch the game.

With the support of the inclusion worker to organise the enrolment and necessary support, Joe attended a modified DJ course through a University. On completion of the course he 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 now DJ's once a week for a local community radio station and has become well known in his area.

Through a solid and long term relationship with the inclusion worker, Joe was able to learn to trust again and share his dreams. She reported that she has seen Joe develop in confidence and is able to articulate his thoughts more clearly. Joe is proud to report that he has achieved his dreams. He no longer accesses the mental health system. Joe is now actively involved in his community and he proudly reported to the inclusion worker that he had fifty local friends attend his recent birthday party. According to the inclusion worker, Joe considers himself a mentor to other people with a disability, always encouraging others to achieve their dreams. This process occurred over a five year period.

#### Example 5: A dream come true - Living alone

An inclusion worker discussed the story of Jack and in particular, the level of support and collaboration required to facilitate Jack's dream to live alone.

The inclusion worker described Jack as someone who didn't fit into the disability service system and who was labelled within the disability system as 'challenging', 'high support' and 'at risk of entering the justice system'. The inclusion worker reported that Jack had been shifted frequently across various supported accommodation facilities and a long term solution had not been found. Jack was reportedly unhappy with this transient lifestyle and wished to have a place he could call his own. The organisation facilitating his support requested that a different organisation work with Jack and provide the required support.

A different disability organisation agreed to support Jack and facilitate a person centred plan. The inclusion worker met and provided support to Jack through this organisation. The first step was for the inclusion worker to get to know Jack and listen to what is important to him. Through this process, Jack and the inclusion worker developed a relationship based on trust and honesty. The inclusion worker reported that Jack had never had a key staff member involved in his life over a long period of time. The consistent support, its long term nature, and the inclusion worker's genuine desire to support Jack to accomplish his dreams, enabled Jack to develop trust in this process.

There presented a gap between Jack doing what he wanted and being healthy and safe. Jack's particular interests placed safety risks on himself and others. Through a person centred planning process, Jack invited his family, friends, his psychologist and staff to become involved in his plan. Through this involvement, all of Jack's family and friends became aware of his wish to live alone and do what he wanted. It was discussed together, how Jack could achieve his goal but at the same time remain safe. A number of strategies were discussed and agreed upon. Gradually, Jack's family accepted and supported Jack's dream. Staff that could not foresee how this dream could be made possible left their position.

The inclusion worker admits it was a challenging time for Jack and the inclusion worker when staff resigned. Jack needed the support of staff if his goal was to be realised. The disability service then intentionally recruited staff to match Jack's personality and interests as well as support him to achieve his goal. The inclusion worker reported that the recruitment of staff to

match an individual's personality and interests was a new concept for the organisation. This commitment worked and Jack was surrounded by people that genuinely supported him in his day to day life within his own home and local community. The inclusion worker reported that the new staff were from the local community, some with experience in community development. None of the staff had worked for disability organisations before. This was considered to be an asset in this situation. Safety was still a paramount concern and staff adhered to the planned strategies.

Supporting Jack to pursue his interests and at the same time balance safety and risk was a daily task that was facilitated by the inclusion worker. Central to this facilitation was a joint agreement with Jack. A high level of coordination between Jack, his family, support staff, day program staff and a range of key community members was essential. Working together in flexible ways along with regular communication between all Jack's supporters further enabled Jack to accomplish his dream.

Jack has developed a good relationship with staff in the library, an employment service, a team from the fire brigade, police and railway staff. The inclusion worker supported these services to better understand Jack and people really watch out for him now "in a good way."

This dream was previously considered impossible by the original organisation working with him and his previous support staff. The inclusion worker needed to systematically remove barriers and advocate for Jack's rights within the disability service system, between disability agencies, amongst mainstream agencies, key community members and volunteer groups to support Jack's dream to become a reality. This task is ongoing and requires a large commitment not just from Jack, but all involved in his life. The inclusion worker reports that as a result, Jack has taken on the additional responsibility of managing his day to day affairs well, he has matured, he is happy, settled and busy. Jack holds a more positive outlook on life – particularly in terms of what can be achieved.

#### Example 6: Regaining communication

A stroke self-help group requested an inclusion worker visit to discuss different forms of communication. The inclusion worker visited and showed examples of communication aids available. One lady, Lois, identified a need for a communication device.

Lois had a stroke 5 years ago and as a result had difficulty with speech, word finding, memory and could no longer write or spell. Lois reported that since the stroke, a lot of her friends and family had withdrawn their support. Lois requested a communication aid to assist her with her shopping. The worker went with her during her daily routine to figure out how and where she could benefit from a communication aid. A book was developed with small photos of shopping items that Lois liked and used. The book was developed to assist her memory whereby Lois can make her own photo list, then mark them off as she puts them in the trolley. Lois and the worker took a lot of time and energy to develop the comprehensive catalogue.

Inclusion workers realised this tool could help others and they contacted the regional self-help group and told them they were welcome to use the resources. There have since been a number of people who have requested this support. People now have a local contact within their region if they require individualised support.

#### Example 7: The big step to Kindergarten

Saeed, a four year old boy was due to start kindergarten. Saeed's family were new to the country, they had no supports and Atiya (Saeed's mother) had never left Saeed in the care of others. Atiya reported that Saeed had a negative experience at three year old kindergarten and he refused to leave the house on kindergarten days. Atiya indicated that if things didn't work out well at four year old kindergarten straight away, she planned to withdraw Saeed.

Atiya agreed to work with the inclusion worker who offered support to facilitate Saeed's transition to kindergarten. This involved working alongside Atiya, the kindergarten teacher and assistants. The inclusion worker was able to support Atiya to articulate her concerns about Saeed attending kindergarten as well as the particular requirements Saeed needs in order to understand what is happening around him.

Saeed was initially fearful and uncomfortable to be in a new environment when he first attended kindergarten, even with his mother's constant attendance. Saeed did a range of things that made him feel safer. For example, he strapped himself in a pusher and stayed in the pusher for the entire time over the first fortnight. The inclusion worker reported that ordinarily, most teachers would not tolerate this or allow parents to stay in the setting. However, the teacher was understanding and flexible. She was able to adapt things to suit Saeed and she gained trust with Atiya. It was crucial that Saeed's mother was allowed to stay until she felt comfortable. Atiya was then able to leave Saeed in the care of the teachers and feel confident that he would be okay. The teacher gradually withdrew the pusher over time as Saeed's sense of security increased.

The inclusion worker's ongoing support meant that Atiya could speak regularly about her fears or concerns. Over time, Atiya became more confident as to what was available to her and how things work. She became more social with other mothers and the inclusion worker hopes this will lead to her developing relationships and feeling more a part of her community. According to the inclusion worker, Saeed is now much more aware of other children, putting him in good stead for the next transition to school.

#### Example 8: Making new friends

Fern lived alone but reported that she felt isolated and scared to go out on her own. The role of the inclusion worker in this instance was to get to know Fern. Fern asked to receive some additional support to increase her networks in her community. The inclusion worker aimed to connect Fern with others, based on her areas of interest.



Getting to know Fern, the inclusion worker learnt of her keen interest in art. She supported Fern with her conversation skills and also to articulate her thoughts in a journal. The inclusion worker facilitated Fern's involvement in a local art group, and through this, she has tried different mediums and further honed her artistic interests. The inclusion worker initially supported Fern in the art group and facilitated conversations between Fern and the other members. Gradually, the inclusion worker reduced her support as Fern and the group members became more comfortable with each other. Fern became more confident and initiated and maintained conversations on her own. Fern continued to develop relationships over time at the art group. Phone numbers have been exchanged and transport shared.

Being involved in the art group led Fern to develop interests in particular mediums, generating new ideas for future projects. Subsequently, this interest opened up further opportunities for Fern to be involved in various community art projects.

The inclusion worker reports that Fern now goes out more and runs into people from art class at the local shops. Friendships and connections have also been made with local community members. Fern enjoys many more informal conversations with local people in her neighbourhood. Fern has developed a reciprocal relationship with a couple of local people that visit her at home. Fern reportedly takes more pride in her appearance. She feels more confident going out on her own and now does her own shopping without formal support.

#### Example 9: Staying home and staying together

Isaac is a 5 year old boy who lives with his parents. Isaac has severe multiple disabilities and a condition that is life threatening. His physical disabilities and complex communication along with his medical condition have enormous impacts on him and his family. Isaac is regularly admitted to hospital for long periods of time, and each time this occurs, the family need to adjust their lives to support Isaac in hospital. The family have accessed several rounds of financial support to fund needed items such as equipment and childcare so as to enable the family to spend more time together.

The family income earner was self-employed and when an injury occurred, this income ceased. Medical expenses also placed additional financial strain on the family. Isaac's family were consequently faced with eviction from their rental property. The family identified that their immediate need was to stay stable, and remain in their property.

Isaac's family were supported with flexible support funds to pay the household rent for a specified period of time. This support prevented the family from imminent homelessness and allowed additional time to undertake a planned change of residence and access respite during the move. Inclusion was described by the practitioner in this particular instance as staying in their home, staying in their community of choice, staying together and having the resources to continue caring for their son. The inclusion worker recognised the ongoing stress the family is faced with and acknowledged that accessing resources to avoid homelessness was one method

to reduce the urgent nature of their difficulties and meanwhile, continue in their capacity to care for Isaac.

## **Orientation Two: Opportunities are created in the community**

### Example 10: Sailing

In 2001, a group of people with a disability tried sailing through a recreation promotion program run in the local rural area. After this experience, at least 10 people indicated in their personal support plans that they would like to continue to sail.

A local provider received funding to purchase sailing equipment which included four boats specifically designed for people with a physical disability, a rescue craft, pontoon and trailer. However, the steering committee ran out of resources to enable people with a disability to sail, so a disability organisation took over management and operation of the program. The organisation formed a partnership with the YMCA whereby people with a disability run the 'sailability' program from the YMCA premises to train school children, in return for free access to the YMCA pool and subsidised gym memberships. This reciprocal relationship involves day program staff supporting people with a disability to train children. The interest in sailing involved the re-skilling of staff in rescue craft and first aid. Some staff have been required to obtain national power boat licences and all staff have learnt how to modify equipment and set up safety procedures.

The outcomes of this story are still being realised over a seven year period. Sailing was hampered by the drought and there was no water in the lake for nearly four years. Now that water from the local mines has been reused and pumped into the lake, sailing will commence again. People with a disability have accessed opportunities to increase their skills through specialist training in sailing, putting boats and pontoons together, teaching others, tying knots and using flags. One member of the sailing club has volunteered his time to train up one individual with a disability to a level where he now competes at state and national championships. The accessible boats have also been used by another club member whose son has a disability. They use the boat regularly and sailing has become a shared interest between father and son, something that was previously not available to them due to the lack of equipment.

### Example 11: Introducing people with a disability to the community

This project focused on a large number of people who have been moved from institutions into community houses, usually far removed from the community in which individuals grew up. These individuals were observed to be "parallel citizens" meaning, people that live and are present in the community but are not engaged with the community. Via a partnership between the State government and a drama and arts organisation, the project connected with local governments to see what is offered within the community and to focus on the common interests of the community with the aim of assisting the participants to connect to their communities through arts and culture. The project started by running workshops with staff,

local area managers and residential managers with a community development focus to look at possibilities around what can be done to assist individuals to connect with their community. The project progressed to include a series of stages:

1. Arts workers come in to group residences and offer an opportunity to participate in a variety of art mediums;
2. Arts workers facilitate a 'whole of community activity' where interests of individuals connect with interests of community;
3. Story telling: individuals write down what they would like to tell in their story and a film is developed about them. University media students produce the films in conjunction with the individual. This opportunity is offered through a specifically designed unit that the students reportedly learn a lot from.

During the project, house staff are taught how to connect with local government and access their local community. A range of other activities have developed from the project including a dance project (linking with University sports science students), and training at TAFE in arts and horticulture.

#### Example 12: Fishing

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 Three: Broad level community change**

#### Example 13: Changing from a disability to a community organisation

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: running an independent administration service; 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).

#### Example 14: Building relationships and skills in mainstream health services

A disability agency supports a large number people with a disability that also have complex health requirements. The organisation encourages all individuals to pay for private health insurance. The organisation has developed a reciprocal relationship with a private hospital. As a result, an agreement has been reached whereby individuals who are likely to require hospital care are introduced to the hospital beforehand. In the event that the individual attends the hospital when unwell, the hospital will be able to access the individual's health history including details about how the individual communicates and what support is required to ensure the care is immediate, appropriate and effective. The disability organisation has worked to build the capacity of the hospital to effectively care for people with a disability. The hospital is also helping the disability service with governance and the CEO of this hospital is on the service's board.

## Discussion of case studies

Whilst the case studies have been organised into the three Orientations to practice discussed in section 2, it is clear that there is some slippage between these Orientations. That is, one piece of work may commence from a specific Orientation (e.g. as a result of person centred planning or getting to know a specific individual) but may lead to work that crosses into another Orientation (e.g. the development of increased opportunities in the community).

The breadth of work across Orientations and the range of case studies provided evidences a broad understanding of what constitutes the work of community inclusion. These examples sometimes challenge notions of community inclusion. Here, ensuring that a child is able to be included in everyday family life, or that a family is able to maintain their everyday functioning in their world, are considered to be practices of community inclusion. Stories range from a focus on community access (or community presence as defined by O'Brien, 1987) to building relationships and participation in community groups, services and activities. Given these variations, the Orientations appear to be useful in highlighting the different foci of the work.

The interview data also provides an opportunity to identify which of the Orientations practitioners used. Each interviewee was asked to identify the Orientation of either their example of practice, or the dominant Orientation of the work of their agency. Sixteen (16) of the seventeen (17) interviewees identified that their work sat with Orientation One. This indicated that nearly all of the interviewees report they are actively listening to people with a disability and responding directly by undertaking community inclusion or capacity building work. By contrast, only four (4) of the seventeen (17) interviewees identified that their work sat with Orientation Two. It is interesting to note that these four organisations (two Victorian and two Western Australia) support people with multiple disabilities, the majority of whom have lived in accommodation services and many have previously lived in institutions for various amounts of time. Similarly, five (5) of the seventeen (17) interviewees identified that their work sat with Orientation Three. Each of the five services that identified Orientation Three as integral to their work also identified their work to sit within Orientation One. Overall, seven (7) respondents identified that their work sat with more than one Orientation. In addition, one organisation chose to identify that their capacity building work sat in an alternative Orientation.<sup>1</sup>

This data suggests that the majority of inclusion work is being done to directly support people with a disability to connect to their community – Orientation One. There is a significantly lesser emphasis on supporting the community with social change and inclusive practice (Orientations two and three). This is a point for further reflection and discussion.

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<sup>1</sup> A family run organisation utilised families and carers to then support and replicate a model that would benefit a larger number of families and carers.

All interviewees were asked to identify the factors that affected the outcomes of their practice example or work generally. The researchers have collated these by theme and below present those that are most frequently discussed. In each section, factors are identified in relation to the individual (i.e. the person with a disability); the staff and organisation; and the community. Quotes from interviewees are provided to illustrate points.

## **Enablers**

All interviewees were asked to identify factors that enabled and supported the inclusion process.

### **For the individual and family**

#### Trust

The key enabler at the level of individual and/ or family was that of trust, identified by five interviewees. Interviewees discussed organisations' or community services' need to first gain the trust of the individuals and their family in order for them to continue working together. This occurred particularly in contexts where the individual had limited ability to communicate their present wishes or needs. Additionally, interviewees reported that people with a disability need to develop trust in the inclusion worker in order to feel comfortable disclosing their aspirations and interests. Trust in the staff, organisation or community was also necessary in order to feel confident that these members would follow through on the work required to achieve the person's goal.

*'Parents need to entrust their child to the school's care. This is a significant factor for parents whose children can not easily articulate what happened to them during the day – good or bad'.*

The fact that trust was the most frequently reported enabler for people with a disability perhaps reflected their previous negative experiences with either a high turnover of inclusion workers or program changes where trust may have been lost along the way. This is supported by the identification of bravery and inner strength (by three interviewees) as an enabling factor, indicating that interaction with a facilitator and the community can be scary and requires confidence for a person with a disability (according to the practitioner or service provider interviewed).

#### Expressed choice, interest

Three interviewees highlighted that a key enabler to inclusion was people with a disability and families expressing their choice or interest areas. They stated that where individuals and families were able to express their preferences, this provided a good direction for practitioners to facilitate opportunities that are relevant and meaningful.

*'Participants chose whether they would like to share their story with their community'.*

#### Determination and commitment

Three interviewees identified determination and perseverance of the individual and family as key enablers to inclusion work. One interviewee described the "shift" for the individual to "allow people to come into his life". The fact that "determination and perseverance" is mentioned also indicates that a certain level of confidence and effort is required from people with a disability. The following quotes from interviewees typify this attitude.

*'X's mother is highly articulate, is able to identify what she needs in order to manage and has good inner strength.'*

*'J has been brave as, even though he has tried a lot of things and been in a lot of trouble, he is resilient and still gets up in the morning and tries new things.'*

Other interviewees identified the importance of the individual's ability to make a commitment to a plan of action and to self monitor his or her own behaviour and its impact on others.

#### Resources

A further three services each identified resources or funding as significant enablers for the individual and/or family. Three interviewees identified a range of concrete resources that acted as enablers for the individual. These included access to person centred planning, identification of compatible support staff (i.e. those who will support the individual's goals and activities and let the individual assume responsibility for their actions), specific skills training, and physical resources (e.g. physical access to venues or equipment such as art supplies). Specialist or generalist resources to support access are also mentioned.

*'An electric wheelchair gave C the freedom and independence to explore her environment.'*

#### Role and relationship with family, agency and inclusion worker

Two interviewees identified that family played a significant role in supporting the work, as well as being articulate about the individual's needs. Additionally, interviewees commented on the benefit of the individual having had a previous positive experience with the agency, and of the importance of a positive relationship with the inclusion worker.

#### **For the staff and organisation**

*'In summary, a combination of framework that sits behind the work, skilled people with the right values, consistent supervision and a well funded program brings about good sustainable and viable work.'*

### Flexibility

The key enabler at the level of staff and organisation was that of flexibility, identified by twelve interviewees. Flexibility was required in the way the organisation facilitated support, identified working hours and used resources.

*'Allow creativity and support wacky ideas'.*

*'The program allows for us to provide immediate support to families rather than waiting the normal period.'*

### Reconceptualising organisations' role

Organisational environments that foster a 'focus on citizenship rather than disability' and where change is embedded across the whole organisation were identified as key enablers by twelve interviewees. An organisational commitment to change along with the provision of necessary support during this process was identified as a key enabler by three organisational managers.

*'A commitment to change at the micro and macro level [is required]. A whole of directorate approach. It is a total direction for the organisation and modelling behaviour has been critical in supporting change. Management teams are involved, in making the directions and involving house staff'.*

### Relationships

Building good relationships (with people with a disability and community members) was identified as a key factor by ten interviewees. This was often discussed in terms of staff requiring significant time to do this work and the work being understood as long term.

*'It's ultimately about relationships – which gets things happening, develops opportunities and supports sustainability'.*

Interviewees discussed the link between relationship building and the skills of staff in learning different methods that people use to communicate. One interviewee commented 'through the development of an effective relationship, I got to know [the person] very well, and understood his language. I would then use particular language that [the person] identified with'.

### Organisational support and skill sharing

Support to individuals, staff, community, collegial support, and management support were all seen as fundamental enablers for inclusion. Organisational support also includes concrete practices, priorities and directions that impact on the work. Across the ten interviewees identifying the importance of support, nine discussed mentoring of staff and families. One interviewee described this as 'informal training' that supported staff to develop a 'reasonable



and supportive relationship [with the individual] that also demands mutual respect, required in any other relationship between adults'. For another, mentoring involved modelling good practice and 'checking in on staff'.

*'Acknowledge where people are at, and their contribution. Work together, grow ideas together'.*

*'Being able to debrief and brainstorm ideas with colleagues to think of good options for particular families. It is currently an informal process but we would like to make it more formal, to recognise its value'.*

Ten interviewees identified training and skill development (within the organisation and the wider community) as enablers. Interviewees identified a range of training to further enable inclusion work. This included training in person centred approaches, activity related skills, behaviour management, community facilitation, leadership, community capacity building, community inclusion, and disability awareness training (for community agencies). Two interviewees identified that this training was linked and accredited to formal qualifications pertaining to inclusion work. Resources also include technology that aided workers in the development of their skills.

*'We have constant professional development where we are exposed to new concepts. We are able to access constant refreshers and we are all trained in person centred planning'.*

*'The planning, relationship building and problem solving that occurred prior to her enrolment [in kindergarten] challenged preconceived ideas and gave people confidence to support A in the way she needed. It definitely led to A's successful inclusion in class'.*

*'We provided Disability Awareness Training (run by people with a disability) to fishing club members and the Department of Fisheries staff. 24 people attended and this made a big difference'.*

#### People with a disability in control

Ten interviewees reported that people with a disability were able to drive the work as a result of inclusion workers building good relationships with the individual and knowing the person well. Person centred planning and person centred approaches were identified by four interviewees as effective strategies. People with a disability (and their families) directing the work proved to be an effective and sustainable enabler according to two interviewees.

#### Staff

Skilled staff were highlighted by eight interviewees as a critical enabler to facilitate inclusion. Staff that were able to embrace flexibility and genuinely support inclusion were often 'newer

staff that have not been in the system' whilst conversely, another interviewee identified the importance of 'skilled and mature staff'. A further six interviewees discussed the shift in role from carer to connector as a crucial element. The following quotes provide examples of responses to the issue of staff and their qualities.

*'The key to a good organisation is good staff'.*

*'A good facilitator must be in-tune to group protocols and aware of subtleties in a group. Skilled staff are required to support connecting and conversations. They must be aware of their own and others' body language and conversations. It requires a great deal of confidence as well as an ability to re-direct conversations to involve the individual with the disability'.*

*'An inclusion worker needs to gauge when the individual needs support and when he doesn't'.*

*'Empathy, the ability to listen and knowledge of resources available to families are key features our team members need to have.'*

*'This is what we do, we care for people's well being and safety, but also their inclusion into the community. Both are equally important'.*

Six interviewees stressed the importance of recruitment practices based on values and personality rather than qualifications.

### Resources

Seven interviewees identified the need for additional resources. In several examples, this involved the funding of extra staff, including supporting the identified aspirations and activities of the individual and to create 'community connector' or co-ordinator positions. In addition, interviewees identified the support of psychology, therapy and planning staff along with administration staff as enabling factors.

Two interviewees also commented on the importance of having available funds to provide immediate support, described by one as 'small, targeted, strategic amounts of money'.

*'The \$4000 from the trust fund was able to cover all the adaptive fishing equipment, a barbeque, costs for 'come and try fishing days' and four inclusion workers to mentor support staff at the local fishing club.'*

One interviewee discussed the need to relocate the agency to ensure it was more centrally located within a community and closer to individuals' interests. Another interviewee identified

the ability to purchase additional aids and equipment as a significant enabler, as was the ability to develop customised information sharing resources (e.g. resource packs, videos etc).

*'The resources we develop are well thought out and they add sources of information for teachers. We use power point and video as well as video conferencing for rural therapists and teachers to ensure they have access to the same skill development'.*

#### Promoting good practice

A further seven interviewees identified sharing of experiences. For example, story telling was noted as an effective enabler to promote inclusive practice.

*'If a family is able to get up and share their story, this is worth five years of inclusion work.'*

Constant reflection and reflective practices were identified by four interviewees. Reflection leads to change, which if done well, leads to individual, organisational and communal growth. The approach to the work was viewed by the same four interviewees as developmental or 'unfolding' rather than time limited and fixed. This requires an adaption to communities', as well as individual, interests as they evolve, as well as a commitment to support the inclusion process as required.

*'We want to build a culture of reflective practice as inherent. It's a culture, not an hour on Friday afternoon, it's about how we work all the time'.*

*'Constant reflective practice to ask ourselves "are we doing things right, or doing the right thing?"'*

*'We did not want to 'dump and run'. Support is needed step by step to support the club slowly through relationship building.'*

*'Understand the ebb and flow of community: communities constantly change. How do we grow and develop ideas with that so it's community capacity building, not community stagnation?'*

Three interviewees identified the importance of celebrating and sharing good work, inside and outside the organisation.

#### Time and patience

It was recognised by three interviewees that a significant amount of time, persistence and determination is required to facilitate inclusion work. They mentioned that the nature of the work is long term. This is due to the fact that it takes time to get to know people, their family and community. Trust doesn't occur instantly and the work is of a developmental nature.

*'It's a battle, but we have wins, and the more wins that occur, the more the momentum will build that supports change'.*

*'It's not all easy and it takes time, be ready for the ups and downs'.*

*'The seven year project has been tiring, but it is hoped the hard work will pay off'.*

#### Joint focus

Two interviewees identified the 'joint focus of person centred planning and local community development projects' as a key success factor. One interviewee discussed the importance of an organisational language.

*This is not 'his or her work', but 'our work', it's everyone's job.'*

#### **For the community**

##### Attitude, commitment and personalities

The key enablers at the level of community were a positive attitude and culture along with a sense of welcoming, identified by five interviewees. Interviewees discussed this in terms of a commitment to interact or include the individual, and seek the resources to support this.

A further three interviewees identified a willingness to communicate, problem solve and work on issues as a key enabler at the community level. People's personality traits, such as 'willingness', 'good connector', 'good rapport', were seen to support the connection to community.

##### Disability specific communities

Two interviewees talked about disability specific communities as providing a good source of support to their members and shared resources. They recommended that disability organisations recognise and promote, rather than dismiss, the value that such communities offer to people with a disability and their families.

*'There is a Stroke Community existing and they are quite successful in sharing resources with their members and providing support.'*

##### Flexibility

Flexibility was highlighted by two interviewees as an enabler within the community and an asset to inclusion.

*'Most kindergartens would tell mothers to leave straight away but this would not have worked in this situation. It is crucial that S's mother was allowed to*

*stay until she felt comfortable. Some teachers get stuck and don't know how to adapt their routine to include a child with special needs, but these teachers really adapted things to suit S.'*

#### Legislation and public awareness

One interviewee commented on the observed 'level of readiness' existing within the community that, she believes, had been brought about by legislation and public awareness campaigns.

#### Partnership

Partnerships were identified as a significant enabler unlocking funds, facilities, specialist skills, as well as volunteering and mentoring support.

Though mentioned specifically only by one interviewee, most implied the importance of a re-conceptualisation of the role of disability services and community.

*'It's about a seamless service system where we [disability services] are just a factor in the way the family are supported via an increasing array of informal support.'*

#### Leadership

Leadership played a role in promoting a change in attitude and enabling inclusion to occur, as illustrated in the quote below.

*'We have found that if the principal is supportive, the teachers are more likely to be supportive. X's teachers were open and willing to start the process early. The principal enabled the staff to attend training and seek additional resources'.*

Table 2 provides a summary of most commonly reported **enablers** at the level of each stakeholder:

Individual and family	Staff and Organisation	Community
Trust	Flexibility	Attitude, commitment and personalities
Expressed choice, interest	Reconceptualising organisations' role	Disability specific communities
Determination & commitment	Relationships	Flexibility
Resources	Organisational support & skill sharing	Legislation and public awareness
Role & relationship with family, agency & inclusion worker	People with a disability in control	Partnership
	Staff	Leadership
	Resources	
	Promoting good practice	
	Time and patience	
	Joint focus	

Table 2: Enablers for individuals/families, organisation and community

## Challenges

All interviewees were asked to identify the hurdles they encountered during the inclusion process. Again, factors are identified in relation to the individual (i.e. the person with a disability), the staff and organisation, and the community.

### For the individual and family

#### Fear and lack of confidence

The key hurdles or barriers at the level of individual and family were reported by five interviewees to be fear and lack of confidence. Interestingly, trust was identified as the biggest enabler and fear and lack of confidence as the largest hurdle. Stories provided confirmed that it takes a considerable amount of confidence to meet new people, try new things, and overcome initial fears.

*'X initially lacked the ability to articulate his thoughts and dreams. When he felt safe that he was being listened to, he improved the way he communicated his wishes'.*

In one case, the interviewee commented on the poor personal appearance of the individual that was linked to their nervousness and fear in relation to pursuing their goal of employment.

### Communication

Difficulty in communicating aspirations and needs was also identified as a barrier in five cases. In some cases, complex communication needs were exacerbated by a past history of unsatisfactory communication attempts (others did not understand messages the individual was communicating) that had resulted in the individual adopting difficult or overly compliant behaviours. These behaviours improved once the person experienced effective communication (being listened to and able to safely communicate their wishes). Another interviewee discussed the fact that many individuals who acquire a disability were not given alternative options to speech at a time when they are ready. This prevented them from developing an effective communication system and hence participating in every day life. One interviewee discussed that families from culturally and linguistically diverse backgrounds were further isolated from inclusion work.

### Age, health and disability

Five interviewees discussed the significant impact of health (physical and mental) on a person's ability to commit to and engage with their own plans for inclusion. In some instances, this meant that planned events and activities could not always be attended. A family led organisation reported that the health of individuals impacted on carers' ability to contribute to the organisation, which made deadlines difficult to meet or predict.

*'J's mental health impacted on his confidence and his ability to commit to things'*

A further four interviewees identified age as a barrier. This included a wide range of age groups, where each was seen to have particular issues associated with it, for example: being too young to have developed effective communication; maturity and identity challenges experienced by young people; and middle aged identity issues.

*'The biggest hurdle for S was for him to BE in kindergarten and STAY there. He needed to learn to experience a different environment.'*

Three interviewees identified multiple and complex needs, or needs that fluctuate, as barriers. Fluctuating needs impact on individuals' and families' abilities to plan, maintain a routine, or attend commitments.

*'I's needs vary so quickly that it strains the family's coping strategies and they never know what next month will hold.'*

Additionally, interviewees reported they experienced challenges when supporting families that were aging.

### Informal and formal support

Isolation and lack of informal supports presented as a major hurdle for some individuals and families according to four interviewees, especially for people that had previously lived in an institution or for families that had moved from interstate.

*'I went through hell over the last 2 years as no one tried to really understand him and what was important to him. Things really escalated as a result and the support he received was quite reactive.'*

One interviewee discussed the fact that individuals' interests were limited by their support staff's (defined in this instance as staff that support individuals living in supported accommodation) negative attitude. Such attitudes impacted on individuals' ability to attend activities of interest and also impacted on other individuals in that the support given was inappropriate and did not facilitate communication with community members. This is also mentioned as a challenge for the 'staff/organisation' stakeholder group below.

*'So many individuals said they wanted to attend the workshop but only seven attended. I followed this up with each person and their staff stopped the opportunity because it was too far, transport was a problem and they basically made up excuses as to why it was too hard to support the opportunity.'*

### Access and infrastructure

In some cases, individuals with complex needs experienced significant barriers due to the lack of physical access to community venues, identified by three interviewees. This included lack of appropriate personal care facilities at venues (such as an accessible toilet, hoist, or change table).

*'R needs fully accessible facilities, hoist and change table in the work place or near by for her personal care needs for employment to become a reality.'*

Lack of appropriate equipment was identified as a barrier by three interviewees. In one case, the individual's wheelchair was sustaining damage from increased use in the community and was not suited to long distances and mixed terrain.

*'C's wheelchair has sustained damage and will need replacement. It is hoped that C can be involved in designing a four wheel drive wheelchair that can better sustain and complement C's lifestyle.'*

Another interviewee reported that the individual she worked with required several pieces of equipment but was only able to access one piece via the government funded aids and equipment scheme. This lack of equipment led to further barriers as, given that equipment was needed at all venues (e.g. home and school), this led to stress on the family and



increased the need for better transport arrangements to enable them to transport equipment between sites on a daily basis.

One interviewee also commented on a lack of transport infrastructure as a barrier.

### Safety

Two interviewees discussed safety as a paramount barrier to inclusion. Safety concerns included families feeling their family member with a disability may be vulnerable whilst out on their own, particularly at night. In one situation, family disagreements over the 'safe' level of support required prevented the person from participating in an activity of their choosing. Two other interviewees discussed safety predicaments parents face when placing young children with limited communication in school settings and the fear that their child will not be able to report to them any good or bad events that happened during their day. Another interviewee talked of safety concerns to others due to an individual's particular behaviour.

### Finances

Two interviewees identified the lack of finances as a barrier to the individual and family. Personal finances were unable to cover the fees charged by the community agency, and the funding provided via government was not enough to support the person in the way they wished (nor were these funds adequately indexed).

*'Resource restrictions mean people have to go out in groups. People get lumped together and may have to go swimming because that's what other people want to do. Funding is not enough for people that have high support needs'.*

One interviewee discussed the lack of the individual's control over her own money as a barrier. Whilst increased control was thought to be important it was also identified that the individual would need to increase her own financial management skills in order to have effective control over her financial affairs.

### Personality

Two interviewees discussed personality or behaviour traits as a hurdle. These included individuals lacking insight, being inwardly focused, dominating in groups or behaving aggressively.

## **For the staff and organisation**

### Staff

A lack of skilled support and inclusion staff - those with the right values, behaviours and attitudes - was identified by seven interviewees. In two instances, success was dependent on a particular residential staff member's attitude and where this supportive staff member was absent, negative responses from other staff became insurmountable barriers. In another

instance, good staff left the project when the inclusion work stalled due to other factors. Two interviewees referred to lack of consistency of staff as a barrier, even over shorter time periods, as staff need time and space to build relationships with individuals.

*'R wishes to learn how to cook, but staff will not support her to do this, so she is not able to learn how to cook at home. R has to wait until a staff member is on that she can ask for particular support.'*

*'On top of the weekly catch ups, J would pop into the office every second day with a new thought or idea. I couldn't always support him or commit time to listen to him due to other commitments.'*

*'The initial support staff were a major hurdle in preventing J from fulfilling what was important to him. The new staff were all locals, very flexible and not so focused on personal care and a clean house. They had not worked in the field and they were so supportive of J and his interests.'*

*'Success is sometimes dependent on particular house staff members' attitudes. If the particular house staff member has a negative attitude, they can hinder C's freedom and choices.'*

A further four interviewees identified the function of the historical paradigm as a barrier to changing staff roles from carers to 'facilitators'. It was identified that the facilitator role involves significant role shifts within it as staff are required to undertake a range of functions including support/carer role, trainer to people with a disabilities (around specific skills related to community activities), and as a trainee themselves (in learning new skills related to community activities).

*'The historical paradigm started and finished with caring for people with a disability. Care is necessary for some people but it's about extending this role to a facilitator role.'*

*'We don't care for people within four walls, we support people to be part of their community. The concept that "it's not my job" needs to be challenged. The reasons for this are varied and include values and confidence levels.'*

*'If people are good facilitators, connections with the community will be so much more successful. We need new language that is more demonstrative of what the role now incorporates. Changing the name from carer or support worker to 'community facilitator' supports people to think about what the role entails.'*

*'Some agencies consider the work to be so specialist that they miss "we are all people" and the only reason we are doing something well for that person is that we have got to know that person. That experience can be transferred to community groups.'*

*'Staff will take people out in the community, but will do everything for them, rather than give people the opportunity to learn how to interact, order their own coffee, manage their own money and have conversations with people.'*

*'Staff either reluctantly supported the individual's interest or they didn't support it at all. The staff struggled to support individuals and presented negative attitudes i.e. "John won't be able to fish", "John can't hold the equipment so he won't be able to do it" or "It just won't work". It was the fishing club members that engaged with the individuals better! They supported people to actively fish and try different adaptive equipment. The club members helped support staff to engage in active facilitation support.'*

*'Support staff seem to be good with direct care support but there is a clear gap when facilitating participation.'*

Another interviewee noted that positive change in staff had occurred only in some instances, with others "still concerned about risks" and maintaining negative attitudes towards the individual's choices.

*'Some staff have become more accepting. Other staff are still concerned about risks and they need to 'let go' accepting that the responsibilities lie with C.'*

*'Take a risk! Balance it with risk management. Be careful not to get trapped in bureaucracy balancing risk management and occupational health and safety guidelines.'*

One interviewee reported that supporting people with a disability in relation to sexuality was not currently well facilitated by staff.

*'Sexuality is challenging to traditional support workers' roles but it needs to be discussed and supported in a way that is relevant to the individual.'*

Three interviewees discussed the challenge of recruiting and retaining the right staff and a high staff turnover was mentioned as an ongoing difficulty within the sector. Another interviewee discussed the difficulty in retaining staff when they were only able to offer lower wages as compared to government wages.

*'Recruiting, training and retaining skilled staff is a constant challenge. Our pay scale cannot compete with government wages'.*

One interviewee also commented on the difficulty of building 'adaptability' with staff. More training was identified as required to support staff attitude, behaviour and actions so that they moved away from the concept of 'community tourist' (an expression that describes a person who *visits* the community but is not a valued member and does not interact or meaningfully participate in any way i.e.: presence versus participation).

Inclusion workers with significant expertise most often worked set hours. Two interviewees recognised this as a barrier as inclusion workers needed to be available to individuals, families and communities over more flexible hours (e.g. after hours, after school, weekends).

#### Resources and time

A considerable hurdle or barrier for staff and organisations as identified by seven interviewees was insufficient time and lack of availability. Interviewees also noted that staff have to be able to maintain a commitment across lengthy time spans, as the work takes a significant amount of time to develop and implement (for example, five years in one case, and seven years in another).

Six interviewees reported the lack of resources as a barrier. This included problems with finding the time and resources needed in order to seek funding. The lack of funding led to an over-reliance on over-stretched volunteers and carers to do the leg work of supporting individuals and service organisations. The need to find additional funding and resources for individuals and their activities has, however, led to an over-emphasis on this aspect at the expense of supporting relationship building. This was considered to be a significant risk, as reported by one interviewee, of combining inclusion support roles with funding case management activities. The reason given for this concern is that case management activities are often time limited and oriented to short term support.

#### Organising the work

Connected with resources and time, several interviewees identified a high workload as a barrier to effective inclusion work. In one instance, this revolved around a high number of individuals the worker was supporting. In this case, she was not able to adequately follow through all the queries and ideas generated by individuals. In another situation, it was felt that the worker needed to continue to support individuals due to the lack of other identified staff to pursue the inclusion work, despite this being beyond the organisation's expectation of her job role. Two interviewees identified a gap between the planning and connecting roles.

*'The short term nature of planning is very difficult. I am supposed to pull out, but there is no one to support the 'connecting' to happen'.*

*'Unless other people around X can understand and assist her to achieve her vision, the plan doesn't go anywhere. I go beyond my role to support the connecting to occur'.*

Organisational bureaucracy operated as a barrier to partnerships in one situation as the disability agency was unable to quickly progress authorisation of the partnership agreement with a community agency. In another, the rigidity of structures within disability agencies was seen to be incompatible with more fluid processes and structures in other community agencies. In yet another, the structures of the disability system (i.e. divisions around age and client category) were seen to be significant barriers at times of transition from one category of the system to another. At these times, an individual's funding changed along with support staff, which placed person centred and inclusion work at risk.

In particular, two interviewees commented on the difficulties of re-aligning the finance and administration systems of the disability agency to the more flexible and individualised requirements of inclusion. Where disability agencies fund the wide range of expenses identified as necessary to an individual, this can generate a large increase in invoicing and payments. This administration load was largely unexpected.

One major provider discussed the problems of supporting and maintaining connections between a large workforce of inclusion workers. In this example, the organisation acknowledged the struggle to maintain values and coherence across this large structure.

*'Often inclusion work is done in fragmented ways, but we need to ensure there is a consistent flavour across governments, Aboriginal communities, CALD families and elderly carers. With no structure, you will have local flavour and no consistency. With structure, we have consistency with local flavour.'*

Another dilemma identified by two interviewees and managers in the disability sector is the difficulty of translating the nature of the work and in measuring its outcomes. This acts as a barrier to funders, government, community and families who may lack appreciation and understanding of the work.

*'This area is soft, it's not tangible, you can't count it. How do you translate the richness of community building and long term work into worth?'*

*'We need to determine how to identify and measure short term and long term outcomes. Finding a family friendly way to measure outcomes is important'.*

Given the complexities of connections and influences in an individual's life, an organisational dilemma is raised when trying to capture and define the outcome of the inclusion worker's involvement.

*'It's hard to measure the inclusion worker's good work separately from other good things happening around a person and their community and in a way, that's not a problem. That's the nature of how things work'.*

In all cases there was a clear recognition that the change required as part of inclusion work is difficult. Two interviewees advised on 'complete change' across the organisation ('bite the whole bullet') rather than a piecemeal or single level approach. This also encompassed involving families, staff and unions in understanding 'why we are doing what we are doing'.

*'If the organisation goes forward in a new direction, they need to take the whole thing on, at every level. Otherwise if they don't embrace complete change, problems will arise four or five years down the track'.*

## **For the community**

### Attitude and lack of awareness

A lack of awareness about disability was reported as the most significant barrier at the level of community by seven interviewees. Two interviewees reported community members feeling nervous or uncomfortable during their initial interactions with people with a disability. In one example, the person with a disability was frequently offered donations by people she met, as they automatically mistakenly perceived this to be why she was out and about in the community. The interviewee felt that such attitudes and assumptions would slowly shift as more people with a disability were seen to be present and participating in community. Schools can play a significant role in fostering awareness and attitude change.

*'Acceptance of A amongst school children was not instant, but something that developed over time'.*

*'Teachers reported of initial fear and biases but described the benefits and how their attitude has changed.'*

A further four interviewees identified negative or mixed attitudes to disability and inclusion. One interviewee found that generic agencies won't get involved with a person with a disability as they consider that disability-specific agencies should provide 'whole of life' support. Other agencies consider only traditional or medical approaches to supporting people with a disability meaning that individuals miss out on appropriate information and resources that would have assisted them to be more independent.

*'There is a culture with some speech therapists and hospitals that see alternative forms of communication to speech as a failure, it is second rate. We have worked hard to change this shift in attitude and now run a network to get different forms of communication respected.'*

#### System and organisational issues

Two interviewees identified problems with a lack of consistency within the organisation. A further two interviewees also identified problems with disability organisations and staff working in silos, rather than together. This functioned as a barrier or hurdle for the community when interacting with a person with a disability.

Whilst interviewees identified bureaucratic and system problems within disability organisations, they also identified these within community settings. In two examples, the bureaucratic requirements associated with using community facilities (i.e. constant application forms, notification periods etc) or accessing other funding sources were seen to be barriers that considerably increased the workload of staff doing inclusion work. Community organisations are reportedly not well set up for working with people with a disability. This includes issues in understanding and organising compliance with occupational health and safety legislation, physical access to venues, and the way they structure the workload of mainstream staff (with insufficient time allocated to the individual needs of people with a disability as participants). It was felt that as community settings (e.g. schools) experience increased participation of people with a disability, (i.e. more than one student at a time), they need to develop better ways to co-ordinate the support provided via the range of disability agencies they have contact with.

*'Coordination is required for schools as each have a number of children with disabilities in their school and with each child, comes the supports of various agencies such as the Cerebral Palsy, Muscular Dystrophy and Deaf Associations. This is resource intensive for teachers and can create tension to manage the services. Directional wrapping is required to support the community. The school is the key here.'*

#### Resources

A lack of resources such as funding was described as hindering the inclusion work in community by three interviewees. An example of this included the lack of funds for a teacher's aid so that a child could be adequately supported to participate in his local school. Another discussed a family's socio-economic difficulties (such as renting and additional medical fees) that added a further strain on their coping mechanisms and ability to care for their child.

Summary of most commonly reported **challenges**:

Individual and family	Staff and Organisation	Community
Fear and lack of confidence	Staff	Attitude and lack of awareness
Communication	Resources and time	
Age, health & disability	Organising the work	System and organisational issues
Informal and formal support		Resources
Access and infrastructure		
Safety		
Finances		
Personality		

Table 3: Challenges identified for the individual/family, organisation and community.

## Outcomes

*'The richness of our lives is the fabric of relationships'.*

Whilst the focus of this research was not to provide evidence for 'why' do inclusion work, the researchers felt it important to identify the changes or outcomes that occur as a result of this work. Rather than focus only on outcomes for individuals (i.e. people with a disability), all interviewees were asked to identify changes and benefits at each of the levels of individual and family; staff and organisation; and community. Respondents here were not asked to evidence their views, nor was it expected that they had collected evidence to support their conclusions. These responses represent the viewpoints of interviewees only and this must be kept in mind when reading the information. More accurate data would be collected from people with a disability, families and communities themselves and this is recommended for future research.

### For the individual and family

There were large amounts of data in this section and this question seemed relatively easy for people to discuss. Many concrete examples of change were provided. It was clear that the interviewees enjoyed answering this question and reflecting on changes in the life of someone they know well.

#### Increased networks, relationships and friendship

The most commonly reported change or outcome of practice as reported by nine interviewees 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 40<sup>th</sup> birthday party and he had plenty of friends'.*

*'Photography has assisted B to develop relationships. Photography gives B something to do when he is bored, he will play with the functions at home, or go to the river or beach to take photos. Photography also gives him something to talk about with people'.*

#### Increased independence, confidence and trust

Increased personal skills such as assertiveness, confidence and trust were mentioned by eight interviewees.

*'Individuals with a disability learnt about fish and how to catch fish, interact with club members, go on fishing trips and have fun! People indicated that fishing builds their confidence and independence.'*

*'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'.*

*'S's mother learnt to trust others and leave S in kindergarten. She is less anxious and more confident as to what is available to her and how things work. She feels comfortable to request support i.e. she knows she can ask the inclusion worker to explain a letter she doesn't understand.'*

Five interviewees reported on changes in levels of control and initiative. This led to an increase in independence of the person with a disability according to the interviewees. Examples included an individual organising her own transport to events, visiting the local shops without support and taking increased personal responsibility for life and household.

*'F now organises her own transport which is a first for her.'*

#### Skill development

Seven interviewees also reported an increase in skill development, including communication skills (with a range of people) and specific skills related to a desired activity (e.g. art, disc jockey [DJ], photography).

*'J has become a DJ, something people never believed he could accomplish, according to J'.*

*'Now that T uses alternative forms of communication, her family have become quite involved in supporting her with this, and give her photos to add to her book. T's butcher is well aware of how to use the book when T is placing an order!'*

*'A's communication skills have improved as she is required to communicate with a variety of people at school. This would not be as available if she was in a segregated setting'.*

*'Her art skills have really developed and this has opened up the door to other activities. She has tried different art mediums and further honed in on her interests. She has also been invited to be part of the Shire's art project'.*

*'It was B's first experience fishing since becoming deaf and blind. He used to fish regularly prior to obtaining his disability. The fly fisher member along with B devised alternative methods to fish that relied on touch rather than visual cues'.*

#### Access to further opportunities

In three cases, interviewees commented on an increase in political or civic activism with individuals adopting advocacy roles. One interviewee reported that a person's experiences around inclusion have led to the person becoming a mentor to other people with a disability. Similarly, another activity led to increased volunteering opportunities for people with a disability.

*'J sees himself as a mentor to others with a disability. He believes he is a good advocate, due to what he has been through.'*

Additionally, three interviewees noted that individuals received material gains such as free recreation club memberships (as a consequence of volunteering) and provision of free personal care in exchange for involvement in other activities. Others received payment for artwork created.

*'Opportunities to explore and develop artistic talents has led to income generation for some individuals.'*

#### Increased well-being, safety and mental health

There were reports of decreased stress, anxiety and improved mental health and well being along with a sense of security. For three individuals this appeared to strongly affect their behaviour and increased a positive approach to the world.

*'L is a lot less anxious over what is occurring around time frames and what is happening. This is all resolved with a photo calendar. Now that she can communicate, she is able to plan her week and her day.'*

*'For children with life threatening conditions or significant medical issues, these issues will never go away but we can maintain and support the family with their coping mechanisms and networks.'*

Two interviewees discussed a reduction in 'safety concerns' related to increased independent interactions in community. In one case, the person was better known with a wider informal network which led to increased visibility, interaction, and overall safety.

*'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.'*

*'F can independently and successfully shop and make her own decisions. As a result, she is more relaxed and feels safer and more secure with her life.'*

One interviewee identified that community members were now able to actively support the individual in a range of ways (e.g. helping with mobility, monitoring health and wellbeing, supporting participation), replacing the need for paid support during some of the inclusion activity.

#### Greater number of interactions, lifestyle changes

Seven interviewees 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.'*

### **For the staff and organisation**

#### Implementation of a flexible, developmental approach

The most frequently reported changes or outcomes for staff and organisations were identified by six interviewees to be that of an increasingly flexible approach (by staff and organisational systems such as finance). This was sometimes characterised as staff 'letting go'. This was often linked with staff adopting a developmental or 'unfolding' approach where staff were able

to work flexibly to suit emerging needs and interests. Additionally, many interviewees noted the benefits of a more flexible model of work.

#### Outcomes reinforce organisational re-orientation

Six interviewees reported various positive outcomes as a result of working in flexible or creative ways. In particular, inclusion practice supported the organisation to further extend or redefine the parameters of their work. In one case, an outcome was noted as being the organisation's changed role in the community with the disability residence joining the Safety House program, and offering this service to its community members.

*'We are continuously learning that there are no limits to ways that families will and can be supported. We now inform families and the broader sector of the possibilities.'*

There appeared to be greater organisational growth and knowledge of the importance of working together with community.

#### Staff skill development

Four interviewees identified an increase in staff patience, positive learning experiences and skill development of staff. Additionally, staff were inspired and motivated as a result of witnessing positive outcomes and increasing their confidence in their facilitation role. Both staff and organisations received positive accolades in relation to the work in the form of positive media coverage or personal "thank you" letters from individuals.

*'It has been a joy, very exciting and meaningful for those involved to watch F develop her confidence and do more things for herself. This has shown us what is possible'.*

#### Replication of strategies

One interviewee identified that changed attitudes and increased skills had led to staff becoming trainers and mentors to other staff and families about the possibilities, including strategies to support inclusion in a specific setting. This flow-on effect or ability to replicate strategies was also mentioned by other interviewees.

*'Some staff initially reported that particular individuals would never be able to fish, but were challenged and surprised that in fact, they could. Staff reported that seeing people in a different environment and doing different things changed their perspective of the individual. They saw the person differently'.*

#### Resource adjustments

Four interviewees noted resource or structural changes in the organisation. Examples of change included altered staff position descriptions and work hours, the development of

appropriate finance and budgeting tools, changes in the service venue, and the implementation of related research in the organisation.

#### Comments:

In one case only did the interviewee note that there had been no changes or benefits for staff or the organisation in this instance, though similar work has led to changes elsewhere in the organisation.

### **For the community**

#### Improved attitude

The most frequently reported changes or outcomes at the community level were reported by seven interviewees to be attitude and value shift. The shift was apparently a result of interactions with people with a disability, or more formal disability awareness strategies. Two interviewees linked these changes to community members seeing the level of achievement made by people with a disability. In two cases, this change was seen in terms of an initial increase in 'comfort' and acceptance of people with a disability in public, as a first phase of attitude change.

*'A is a valued member of the school. She is greeted by the school children each morning. The children will assist A with pushing her wheelchair into class, assisting with the classroom routine, raising the alarm to the teacher if A does not look well and generally assisting her with mobility'.*

*'Community attitude and behaviour has been challenged individually by J through his connections with people and his weekly radio appearance. He challenges perceptions of disability by showing what he can achieve'.*

One interviewee identified a change of ownership and initiative within partnerships with partners now driving the activity, rather than the disability organisation. This appeared to be reinforced by the feedback of community participants who valued the inclusive activity highly in preference to other activities that lacked a focus on the inclusion of people with a disability.

#### Valued partnerships and relationships

Four interviewees reported changes in terms of positive partnerships, particularly relationships between disability organisations and community groups. In some cases, initial partnerships have received public recognition and awards that in turn have generated more extended or rigorous partnership activity. Another interviewee commented on the value to community organisations of a reciprocal relationship with disability agencies and groups of people with a disability, where the links generated volunteer labour, shared equipment and expertise, and an ability to support the individual as a member of the group.

### Skills transferred

In addition, four interviewees reported a transfer of skills and sharing of knowledge, with community members teaching others how to adequately support the individual. Two services also indicated the interaction has provided positive opportunities for other people with a disability. In one instance, the interviewee reported a community group had 'completely modified all their equipment and they have a welcoming attitude.'

*'A's teachers have trained and shared their stories and tips with new teachers in the information sessions this year. The training benefited the centre, future teachers and other families. We received the best feedback about the teachers, out of all the training. Success builds on itself.'*

### Increased knowledge

A common theme was picked up from the majority of interviews about various community groups that learnt how to include, communicate, support, teach and work alongside people with a disability. One interviewee commented on specific skills developed by a local retailer who 'learnt how to make a milkshake to [person's] requirements, and undertake the transaction in a way that suits [the person]'.

*'Club members learnt how to speak directly to the person with a disability, rather than a support person. They also learnt to speak to and treat adults with a disability as adults, not children.'*

### Support provided to disability organisations

One unexpected outcome included the fact that the community members were so proactive that they encouraged the support staff (from disability organisations) with their roles to ensure they adequately support people with a disability. In this situation, the support staff were negative about the individual's capacities, or chose not to facilitate communication. It was the community members who said "no, we think B can do it" or to the individual "can I check your bag to see if you have a communication aid?".

*'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.'*

### Comments:

In one case the interviewee reported no change for the community. Over all, there was far less data recorded about changes for the community. It is not clear whether this is because there are fewer benefits for the community or because it is not considered as an outcome area explicitly to be noted by practitioners.

A summary of the most commonly reported **outcomes** is provided in Table 4:

Individual and family	Staff and Organisation	Community
Increased networks, relationships, & friendship	Implementation of a flexible, developmental approach	Improved attitude
Increased independence, confidence & trust	Outcomes reinforce organisational re-orientation	Valued partnerships & relationships
Skill development	Staff skill development	Skills transferred
Access to further opportunities	Replication of strategies	Increased knowledge
Increased well being, safety & mental health	Resource adjustment	Support provided to disability organisations
Greater number of interactions, lifestyle changes		

Table 4: Outcomes identified for the individual/family, organisation and community.

### **Factors that increase positive outcomes**

Interviewees were asked to identify key factors that influence the success of fostering individuals' and communities' capacity to connect with each other in a positive and meaningful way. Firstly, interviewees were asked about factors that would increase positive outcomes, and secondly, interviewees were asked to name three recommendations their organisation could undertake to enable good connecting work to occur. This data has been combined as the researchers found a high degree of replication.

There are two broad themes that group the data and reflect core ingredients for successful inclusion work:

1. Investment in additional resources for inclusion work;
2. Improvement of organisational practices.

These themes are encouraged, and often evidenced, by experienced practitioners as key factors to increase inclusion outcomes and are seen as the way forward for organisational re-development.

## **Invest in additional resources for inclusion work**

### Allocate additional funds

The most frequently reported area (by eight interviewees) was that of increased resources for the purposes of inclusion work. In one case, a significant injection of funds would enable the employment of a targeted worker to focus on the project, thus freeing up existing staff and speeding up the process.

### Allocate additional time

In two cases, interviewees stated that more time allocated to working with the individual would have improved outcomes. This included increased availability on a daily basis, as well as increased time spent in developing the initial relationship with the individual (e.g. an additional 2 months). In two other examples, the provision of a longer time frame (2 years) would allow the work to generate results. A call for greater recognition in the time required to build relationships with individuals, families and communities was repeated amongst interviewees.

*'A manageable workload is needed to ensure we can do effective relationship building, person centred planning and community development projects, as otherwise, we just end up 'band-aiding'.*

## **Improve organisational practice**

### Invest in change

Investing in and valuing inclusion work were mentioned as critical enablers to further enhance the work. To do this, nine practitioners recognised their organisations needed to change current practice and potentially reconstruct the organisation and re-align supports.

*'If our work is important, the system must support it. We must be resourced to enable staff and families to have confidence and a sense of value and respect.'*

Overall, there was a major focus on change - investment in and alignment of practice and policy. Improved structures and processes were identified as required to enhance this re-orientation process and enable, rather than hinder, good outcomes. Additionally, supporting and involving stakeholders with change processes was reported as critical. An example would be re-writing position descriptions and roles and then supporting staff with their change in role. Change was recognised as needing to be deliberate, planned and supported across the organisation so that the change was embraced rather than partially accepted or rejected. A range of methods for undertaking change were suggested by interviewees:

*'Support change through a variety of mediums such as service improvement forums, investing in international specialists, find and share local examples of good practice, support people to develop intrinsic motivations that are*



*driven by beliefs and values and support the development of more generalist services. Set standards and expectations that support the lives of people with a disability to be as great as they can be. Recognise and provide encouragement to agencies and facilitators for the good work that is happening.'*

*'Change has involved dismantling the organisation and a clear strategic plan with 3 enablers incorporated:*

- 1. Environmental scan –to set the scene;*
- 2. Engagement with key groups and;*
- 3. Staff involvement in the process.*

*Everything we do now we relate back to the strategic plan.'*

### Improve coordination

Greater coordination between staff (including house and day program staff), families, and service providers through improved and integrated systems, was reported as a major theme by eight interviewees.

*'Work better together between services, connect day and house staff. Planning assists the bringing together of two services to share responsibilities and decide who is doing what to support an individual'.*

*'More timely responses and quicken up decision making processes. Better processes for information. If the processes are unclear, everything slows down. This community project was not regarded with a sense of urgency (by the organisation).'*

*'Share skills: teachers have so many skills and we have specialist skills so working together will create the best environment for children. Remove the "us" and "them".'*

### Value inclusion work

Part of this re-orientation process includes organisations valuing the inclusion worker role, as identified by six interviewees. Skilled staff were mentioned as holding a pivotal role in inclusion work. Valuing particular roles was recommended, particularly the role of person centred planners, local area coordinators and early intervention workers. In addition to this, interviewees requested that inclusion workers' responsibilities of building increased supports around individuals and relationship development be validated by their organisation. Celebrating success was identified as a method that interviewees encouraged to re-affirm the staff's valued role, as well as to promote good practice. Organisations that recruited creative staff with the right values and with a community development background were all features that interviewees considered would enhance the inclusion process.

*'Value staff that work outside the square, try different models and take a risk!'*

*'People have to want to do it! Why are staff really working here? Explore the values and support staff to have confidence in what they do.'*

Investing in skill development for staff was also raised as a significant factor. Sharing the responsibilities amongst staff in the organisation was recommended to promote the concept that inclusion is 'everyone's job'.

#### Improve communication mechanisms

Increasing communication internally amongst organisations but also with people with a disability was identified by six interviewees. Interviewees reported that a commitment to increased and formalised communication processes will allow for more streamlined work to occur along with greater opportunities for the empowerment of people with a disability and their families.

#### Invest in people with a disability and their families

Aside from the focus on building relationships with people with a disability as a vital enabler for success, a determined effort to develop informal networks, and to expand meaningful opportunities for people with a disability in their home and in their community, was requested by three interviewees. This included supporting people who lived with their family, friends, or alone as well as people who lived in supported accommodation.

One interviewee emphasised the importance of involving people with a disability in all the organisation's decision making processes. A further interviewee discussed the need for organisations to increase their accountability to people with a disability. This includes taking complaints seriously.

*'Nothing about us without us. In all the meetings that I attend, I encourage individuals to present, report on progress and do the talking. As managers, we still have a tendency in meetings and seminars to get up and tell the stories. We need to take the extra step and encourage people with a disability to tell their story and be involved.'*

A call for greater funding to support people with complex and multiple disabilities to pursue their priorities remained a current gap across the sector according to interviewees. Another identified shortfall that required attention was a greater investment in the promotion and support of leadership opportunities for people with a disability.

### Build on learning and good practice

A significant factor is the transference of good models and practice. Five interviewees identified the need to build on what has been learnt, share stories, spread opportunities across and within organisations in order to encompass a larger population, and to transfer successful models so more people benefit. For some, this involved maximising and building on the potential of established initiatives.

*'Using knowledge from previous experience of how supports can make a difference. I.e. if asked if we would fund a family's rent again, we would say 'definitely!' The money took pressure off the family for 2 months and without assistance, this stress may have potentially led to the family falling apart.'*

*'Increase the outcomes of this opportunity with [special interest] clubs in other places. Use the local club to mentor other clubs, rather than the disability organisation.'*

One interviewee recommended that the organisation document the ongoing acquisition of intellectual knowledge to ensure this intellectual knowledge was retained and built on rather than lost with a changeover of staff. Linked to these ideas of learning and good practice were recommendations to increase reflective and evaluative processes throughout the work.

### Promote flexibility

The repeated theme of the value of, and request for, greater flexibility was reiterated here by five interviewees. Flexibility was mentioned across a range of organisational processes including as an asset to be valued in skilled staff and as a critical element in new models of work. It also involved freeing up structures and processes so that relationships and partnerships can be enhanced in creative and meaningful ways rather than hampered.

### Invest in relationships and partnerships

Four interviewees mentioned that their organisations needed to value and invest in the development of relationships and partnerships (with people with a disability and the community sector) as an enabling factor for inclusion. Whilst it is understood the process takes time and cannot be hurried, the benefits and outcomes of these relationships to both people with a disability and their community need to be understood and supported by organisations.

*'It needs to be acknowledged that building relationships is resource intensive, and trust is a key element to ensuring successful outcomes for people with a disability.'*

One interviewee reported the disability sector's need to move towards gaining corporate sponsorship for inclusion work. She mentioned that engaging with the business sector would instil greater community responsibility to enhance inclusion in practical ways.

#### Invest in person centred approaches

Four interviewees called for a serious investment in person centred approaches to be implemented and embraced by all sectors of disability organisations. This would impact upon structures, processes, work priorities, job roles and the nature of work undertaken, according to interviewees. This investment would increase outcomes for people with a disability, their family and community.

*'Re-write job descriptions so people understand it's not just about direct care, it's about connecting and enabling'.*

*'The organisation needs to value person centred planning and the role of the planner. The organisation brought me in to do something new but I became a problem because I did do something new. The organisation is still trying to figure out how to support person centred approaches'.*

*'Work holistically with entire house [i.e. residential service]. Put staff through person centred training, support the house over 18 months and this makes a noticeable difference for people living in the house'.*

#### Invest in research

Two interviewees requested further research to capture the intangible nature and outcomes of the work. They mentioned that such research findings would be a useful tool in supporting donors to understand the work. It would also further determine success factors to build on and strive for to ensure inclusion work is of a sustainable nature.

#### Build capacity for the future

Taking into account the changing contexts amongst communities, families, and individuals with a disability, future planning was highlighted as crucial to providing effective long term and sustainable facilitation and support. Examples included planned support networks for individuals so that they are supported in their community at a time when their family is no longer able to provide the same level of support (refer to Planned Individualised Networks earlier in section 3). Another example included consideration of people with complex and multiple disabilities as they age, and planning for future high support accommodation options rather than be placed in a nursing home.

There was also an interest in workforce planning and development given there is a noticeable increase in support staff coming from culturally and linguistically diverse (CALD) backgrounds. One agency reported that dialogue has commenced with the government to consider how to support staff to undertake their work with consideration to their CALD background.

### Work with the community

Getting to know the community in which practitioners work, understanding the context and mapping community resources, were regarded by two interviewees as equally important as developing a relationship with individuals with a disability. In both cases (both in Western Australia), inclusion workers combined their knowledge of local people with a disability as well as that of their local community. This use of combined knowledge and connections enabled the facilitation of meaningful links between the two parties based on shared interest.

Different strategies for working with the community sector were found to be effective and reinforced in organisational practice. For example, several interviewees reported the benefit of locating local 'champions' as a resource to utilise and support the work. Organisations defined a *champion* as 'a person who has passion for an outcome they wish to achieve in the hope they can bring people along with them'. These champions were described as 'natural leaders' in their community.

*'Identify champions in the community who are keen to support and include people with a disability. These champions have excellent connections and they will use their connections to support individuals, and the links are invaluable'.*

Two interviewees reported the need for ongoing community awareness to 'see the person' rather than the disability.

*'Support the concept that families and children are seen as families and children rather than the concept of a 'disabled family', a concept that sits with some government and education sectors'.*

*'Being seen as a person with all these amazing achievements in life, rather than being seen as a person with a disability. T is still the same person since she had the stroke but she is being labelled. This has been most difficult with friends.*

Two interviewees also noted that organisations need to recognise, value and invest in disability communities, not just for the information and resources they share, but for the strength of relationships that such communities can offer to people.

Table 5 provides a summary of the **factors that would increase positive outcomes:**

Broad themes
<p><b>Invest additional resources</b></p> <ul style="list-style-type: none"> <li>Allocate additional funds</li> <li>Allocate additional time</li> </ul> <p><b>Improve organisational practice</b></p> <ul style="list-style-type: none"> <li>Invest in change</li> <li>Improve coordination</li> <li>Value inclusion work</li> <li>Improve communication mechanisms</li> <li>Invest in people with a disability and their families</li> <li>Build on learning and good practice</li> <li>Promote flexibility</li> <li>Invest in relationships and partnerships</li> <li>Invest in person centred approaches</li> <li>Invest in research</li> <li>Building capacity for the future</li> <li>Work with the community</li> </ul>

Table 5: Factors to increase positive outcomes.



## Section four: Where to from here?

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### Why bother with inclusion?

People with a disability repeatedly report that inclusion is integral to a life well lived. The UN Convention on the Rights of Persons with Disability (CRPD) (United Nations, 2008) tells us that people with a disability are entitled to the same freedoms and protection as their peers. Inclusion work strives to work alongside people with a disability, families and communities to remove existing barriers and open up opportunities so that people with a disability and their families are able to enjoy the same freedoms and life opportunities as their peers. Inclusion work is not an optional extra, it is a must do. If disability services are not facilitating and delivering inclusion, they are not delivering core business.

Inclusion doesn't *just happen* and is more than government rhetoric or disability sector discourse. Merely talking about inclusion, or adding 'inclusion' to a job description is not enough. To date, there has been very little investment beyond 'talk' that supports change across government, society, and service systems to undertake significant inclusion work. We need to turn talk into action. In a world where people with a disability and their families have been systematically excluded, active investment is required to challenge and remove layers of embedded oppressive thought, behaviour, policies and structures to enable freedoms to be accessed and enjoyed.

Within Victoria, there are currently no clear guidelines or recommendations as to what inclusion actually is and how the government, disability sector or practitioners should go about facilitating it. Therefore, organisations and practitioners are left to devise their own definitions and approaches to inclusion work. As a result, the pace of change is slow, there are few resources committed to the difficult work of sustainable structural and attitudinal change, and many people with a disability continue to have only superficial experiences of participation. As a result, many people with a disability and their families remain distrustful of, and sceptical about, the inclusion work of disability providers and governments. Without clear strategy, structure, methodology or accountability for inclusion work, people with a disability and their families may or may not have their dreams or priorities realized in contexts and communities in which they wish to participate. This haphazard approach results in many people with a disability and their families missing out on their right to be included and supported. With a lack of support and direction, many communities don't act on their responsibility to include people with a disability (and their families) and consequently miss out on the benefits of inclusion and diversity. There appears to be a lack of accountability on all fronts.

From a service point of view, inclusion workers vary drastically in skill level and attitude towards the work. Inclusion workers can facilitate and achieve meaningful processes and



outcomes when facilitating inclusion if they are adequately skilled, motivated and relationship-focused. On the other hand, there are practitioners that are not listening to people or communities and their attitude or lack of motivation towards the work results in outcomes that are not sustainable or empowering. Inclusion workers currently may or may not be supported by their organisation. With the present unsystematic approach, inclusion workers' experiences range from feeling supported and valued by their organisation to being completely unsupported, undervalued and exhausted. Consistency, recognition, and aligned investment into supporting practitioners' work will generate more dependable outcomes engendering greater respect and trust for inclusion workers amongst people with a disability, families and communities.

A systematic, consistent approach to inclusion work is urgently required. Inclusion work must be explicitly planned, resourced and staffed.

### **Current issues with practice**

The themes discussed above are explored below in more detail. This discussion identifies current issues relating to inclusion work that recurred throughout the research data. The discussion focuses on the remaining difficulties in, and barriers to, inclusion work and therefore does not highlight the range of positive work that is being undertaken, examples of which are provided in sections two and three of this report. This is followed by a discussion of the key areas for, and ingredients of, change towards comprehensive and embedded inclusion work.

### **Inclusion as community tourism**

Whilst inclusion has been on the agenda, and formally in government policy documents, for many years, there is a lack of clarity about parameters, practices and outcomes of this work. There is a long standing discussion about the extent to which inclusion work focuses on 'presence' or 'participation' (e.g. O'Brien, 1987; Smull & Sanderson, 2001; Clements et al, 2008). Recent research (Clements et al, 2008) suggests that there has been a strong focus on community 'presence', notions of 'filling in' time with 'activities', and a focus on re-venueing activities in community venues. Less attention has been paid to building meaningful relationships between people in these venues, or on structural and attitudinal change that fosters further opportunities for meaningful and valued roles for people with a disability in a wide range contexts.

### **A de-valuing of communities of peers with disabilities**

There have been varied understandings of what 'community' means and which communities are valued as contexts for inclusion. In particular, there has been both an implicit and overt focus on community inclusion work as exclusively about connecting people with a disability to people *without* disabilities, and not on the building of communities comprised of people with

disabilities. This concept appears in some government documents stating that “segregation, isolation, marginalisation and ‘congregation on the basis of disability’ are damaging to all people” (DSC 2004:9).

### **Inclusion work is ad hoc and not systematically supported in organisations**

Further, whilst many organisations appear to have begun to re-orient their work towards inclusion, only a few organisations have systematically re-structured their work throughout their entire organisation. In section 3, practitioners discussed a lack of identified support and organisational processes for their inclusion work. For some, this means that necessary inclusion work gets done ‘off to the side’, or ‘if we have time’, or involves staff going significantly beyond the role identified for them by the organisation. In other cases, the most that could be expected from the organisation is that it would not actively hinder the work – a kind of benign neglect of staff’s role in inclusion work.

Similarly, individuals with a disability identify a lack of trust of staff and organisations (particularly around disclosing personal information, interests and aspirations), that suggests previous approaches have not respected individuals’ choices or have failed to follow through on support required. The data from section 3 suggests that people with a disability are currently subject to a range of inclusion workers, some with negative (and power holding) attitudes. Organisations and staff appear to be at different stages in ‘letting go’ of their control and allowing people with a disability to drive the work. Individuals’ aspirations and interests are subject to the whims and approaches of particular staff that can either support or block their inclusion goals. Whilst person centred approaches identify the importance of matching the interests, values and personalities of staff with individuals with a disability (Ritchie et al, 2003), this appears to be occurring only sporadically.

### **Lack of focus on resources and targeted work to overcome barriers**

Throughout the data of this report, staff at all levels report on the inadequate resources available both within disability agencies and mainstream community settings to enable inclusion to occur. Repeatedly, interviewees identified lack of staff time and lack of key physical resources (equipment, finances, etc), coupled with attitudinal and structural barriers. Overcoming these barriers required significant staff time, the involvement of key ‘champions’ (within services or the wider community), money and shared effort. These resource, infrastructure and attitude barriers were identified as operating at a number of levels: within an individual’s context, within services, and within broader community settings. Tackling these barriers appeared to be largely occurring on a case by case basis (often without clear organisational support), with a smaller amount of systemically focused work occurring. The extent to which these barriers were repeatedly reported by interviewees suggests that work to date has been only marginally successful in addressing these wide spread road-blocks to inclusion.

## **The silo effect**

The 'silo effect' has been a feature of disability practice both within and between disability agencies for some time. Interviewees in section 3 reported problems with lack of consistency across service silos that all provide different supports to an individual, yet should be acting with a consistent sense of the person's life goals and interests. This meant work done inside one silo may not be supported by another. Such silos occur both within a single agency (for example, between a day placement and residential service), and among disability and the range of wider community services with which an individual may be involved. Additionally, where inclusion work to address barriers was occurring, it appeared to be uncoordinated and highly individualised, so that there was no sharing of strategies for attitude or structural change.

## **What needs to change**

### **Inclusion is both personal and social change**

This report proposes that:

*Inclusion work involves supporting people to achieve, do and be in life in the ways they choose, as well as identifying and removing barriers to this in society, services and individuals.*

The notion of inclusion encompasses O'Brien's (1987) understanding of not just community 'presence' and 'participation' (with the focus on meaningful relationships), but includes the concepts of 'choice', 'respect' and 'competence'. For people with a disability to achieve valued roles and identities in different contexts, inclusion work involves removing a wide range of barriers both within and external to these individuals. These barriers can be understood as physical (e.g. physically inaccessible places and spaces), attitudinal, behavioural, and structural (including how policies are made and resources allocated). Inclusion work is sometimes described as creating *enabling* rather than *disabling* environments (Swain et al (Eds) 2004).

A significant amount of data discusses that services, staff and operating modalities need to change to ensure that people with a disability have more control and choice. The notion of people with a disability being drivers of this change needs to underpin inclusion work within all three Orientations, not just within the person-centred focus of Orientation One.

### **People are part of multiple communities – all are important**

Communities are formed on the basis of shared identity, interests, issues or culture as well as geography or location (Ife, 2002). Like all members of society, people with a disability should have the opportunity to choose to be members of many communities.

There is significant literature, both from people with a disability and from other commentators, recording the value of communities chosen by people with a disability from among their peers with a disability. This is consistent with person centred approaches that seek to empower people with a disability to express their choices and preferences. Additionally, this understanding of 'community' is critical to the work of mentoring and role modelling. Role modelling and mentoring were clearly articulated by interviewees as common outcomes for individuals resulting from inclusion work. Clearly, when governments or agencies discourage any type of congregation by disability, the opportunities for role modelling are severely reduced, despite a range of evidence to suggest these are valued activities by people with a disability.

Community is not an 'either / or' option, but an 'and /and' one. People with disabilities can be members of this community *and* that one *and* so on, and move in and out of these depending on life circumstances and choices. An individual with a disability may be simultaneously a part of an Italian community, a cerebral palsy community, a hobby sailing community, a professional community (linked to employment), a community of friends, and a community of locality (where they live). How they engage with these communities, the amount of time and energy they give to them, how they are valued within them, and what they take from them will be different and vary according to a wide range of factors.

Practitioners are required to support people with a disability to explore and choose the communities they feel most akin to. Some of these communities will be pre-existing or ready made (for example, the local photography club), others will need to be built or formed (for example, a cerebral palsy support group for women over 50 years). It is clear that additional support and resourcing is required for people with complex and multiple disabilities to enable them adequate levels of choice and participation in multiple communities of their choosing.

### **The work is both large scale and skilled**

This report proposed three dominant Orientations to inclusion work. Broadly these Orientations focus on individuals; on the creation of opportunities in community; or on larger systemic changes. Of course, some of the work involves combinations of these. For inclusion work to be successful, there needs to be sufficient attention paid to all of these Orientations, to ensure that barriers to inclusion are addressed across a range of levels in society.

The work involves a broad range of job roles (facilitative, educational, technical and representational, Ife, 2002:257) and is underpinned by a set of practice principles that ensure the work matches its purpose and is ethical.

The findings indicated that inclusion work is far more sustainable when carried out over a significant length of time. 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 are 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. The work requires substantial time allocations.

### **Inclusion is everyone's responsibility and needs to be organisationally embedded**

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. 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 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. With these in place, it was felt that organisations can then invest in equipping staff 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. 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 the 9 to 5pm hours (so that they can better support people with a disability) are all examples given to the 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.

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 of inclusion work**

As mentioned in section 2, practitioners 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. This is 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, 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? Do we ask individuals and families 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? Do we ask community members/leaders 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?

## **For Practitioners**

The work of inclusion is exciting but often complex. Practitioners need to constantly build their skills in this field.

### *Reflection on practice is critical to successful inclusion work*

Follow and regularly check the work against Ife's (2002) principles of community development. This will also ensure the inclusion work process and outcomes are empowering, meaningful and sustainable.

### *Be continually aware of power differences when working with people with a disability, their families and communities*

All participants in inclusion work hold skills, knowledge and expertise – to assume the inclusion worker holds more of these is to reinforce uneven power relations and demean people, families and communities. People with a disability and their families are experts in their own lives. Care is required not to assume the worker knows what is best or what the priorities are for an individual or family. Everybody works on different timeframes and within different contexts and pressures. Be flexible and adapt to this. Listen to people with a disability and their families.

### *Identify and address structural barriers collaboratively*

Be particularly mindful of structural barriers to inclusion that many people with a disability still encounter on a daily basis. Consciously work to remove these disabling policies, practices, structures and relations thereby creating opportunities for freedom that all people are entitled to. This is likely to require collaboration and alliances with other workers and organisations as structural change requires resources, energy, a wide set of skills and a longer time frame. None of this is possible without collaborative work with others.

### *Allow sufficient time to facilitate inclusion work*

There is no quick fix. Inclusion work is dependant on the quality of relationships that practitioners have built with individuals, families and communities. Trust takes time to develop.

### *Adjust your strategies and approaches based on changing contexts*

Individuals and communities are dynamic and fluid. Flexibility is required to adapt to these changes, catering for the diverse flavours that individuals and local communities

bring. What works for one context may be irrelevant for another. Listen to those with whom you work alongside.

## **Recommendations for further research**

Whilst existing research has documented case studies of inclusion, and some recent research has attempted to record the extent to which inclusion has occurred since deinstitutionalisation of some settings (e.g. Clements, et al 2008), little research has engaged with the factors associated with inclusion practice.

The following are suggestions for future research in this area.

1. Engage with people with a disability (and families where relevant) to determine what components of inclusion work have been helpful or detrimental to their aspirations for inclusion. Inquire about the outcomes of inclusion work. Gaining a better understanding of this would further assist government, organisations and practitioners to support people with a disability in more relevant ways.
2. Engage with the community sector to determine the benefits, challenges, changes and outcomes of inclusion from the community perspective. Gaining a better understanding of this would further assist government, organisations and practitioners to support the community sector in more relevant ways to create enabling environments and communities.
3. Identify and map the level of resources (human, physical, financial) currently allocated to bring about inclusion for identified populations of people with a disability (such as those in identified services, or experiencing particular needs).

## **Conclusion**

This report set out to identify how disability organisations can enhance their function in facilitating inclusion. The research drew on a wide body of literature, recent research evidence, as well as the experiences of practitioners and disability organisations in undertaking successful inclusion work.

This evidence show that inclusion work is varied but can be largely categorized as consistent with the three Orientations proposed in this report. The dominant practice is located within Orientation One, perhaps due to the government's and sector's adoption of person centred planning and approaches. Perhaps as a consequence of this, practitioners report significant barriers to inclusion work related to overcoming systemic and attitudinal barriers both within disability agencies as well as within wider community and social systems. Practitioners report that their work is frequently not understood, they are under-resourced, under significant time

pressures and lacking in organisational support. Successes in inclusion work appear to be largely the result of exceptional relationships among parties involved, energetic champions (including people with a disability and their families as well as community members), and skilled practitioners.

Without explicit, strategic and significant commitment to inclusion work by governments, disability and mainstream organisations, little will change. Inclusion successes will be of limited duration and depth. This report proposes that inclusion work be identified and affirmed as the *core* business of disability agencies and undertaken with the rigour and dedicated expertise applied to other service modalities.

Finally, the examples provided by practitioners in this report identify a host of creative responses to the inclusion aspirations of people with a disability. From enabling a family to maintain its status in its own community, to transforming a disability service provider into a 'community' organisation, each example identifies one of the many changes required to achieve inclusion across the whole of society. Importantly, the report also documents the outcomes of inclusion work, evidencing that it has significant impact on people with a disability, their families, organisations and communities with whom they are associated. There is no doubt that inclusion work is difficult, nor is there a doubt that it is necessary, repeatedly called for by people with a disability as a pre-requisite for change in their lives. The examples provided in this report also leave no doubt that inclusion work can lead to real and significant change. Our challenge is to better resource, embed and make sustainable these currently ad hoc results.

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## **Further information**

For further information about various organisations mentioned, contact:

Access for All Abilities (AAA):

<http://www.sport.vic.gov.au/web9/dvcsrv.nsf/headingpagesdisplay/active+communitiesaccess+for+all>

Centre for Cerebral Palsy:

<http://www.tccp.com.au/Home>

Deaf Access:

[http://www.dhs.vic.gov.au/\\_data/assets/pdf\\_file/0003/152463/deaf\\_access\\_vb\\_181103.pdf](http://www.dhs.vic.gov.au/_data/assets/pdf_file/0003/152463/deaf_access_vb_181103.pdf)

Fremantle Connections:

<http://www.fremantle.wa.gov.au/facilities/html/services.cfm>

Local Area Coordination (LAC):

<http://www.disability.wa.gov.au/publication/lacsupport.html>

Local Area Coordination:

[www.dsc.wa.gov.au](http://www.dsc.wa.gov.au)

Leisure Action:

[http://www.scopevic.org.au/everyday\\_leisure.html](http://www.scopevic.org.au/everyday_leisure.html)

MetroAccess/RuralAccess/DeafAccess:

[http://www.dhs.vic.gov.au/data/assets/pdf\\_file/0015/152412/metroaccess\\_info\\_sheet20050605.pdf](http://www.dhs.vic.gov.au/data/assets/pdf_file/0015/152412/metroaccess_info_sheet20050605.pdf)

My Place:

<http://www.myplace.org.au/>

Nulsen Haven:

<http://www.nulsenhaven.com.au/>

Planned Individual Networks:

[www.pin.org.au](http://www.pin.org.au)

ReCharge, Scope:

[http://www.scopevic.org.au/ReCharge\\_brochure.pdf](http://www.scopevic.org.au/ReCharge_brochure.pdf)

Recreation and Sport Network Inc:

<http://www.rec.net.au/>

Speech Therapy Initiative, Scope:

[http://www.scopevic.org.au/therapy\\_crc\\_news\\_ccb.html](http://www.scopevic.org.au/therapy_crc_news_ccb.html)

The Lost Generation Project, Disability Services Commission and DADAA WA:

<http://www.dadaawa.org.au/ageing-disability/lost-generation-1/>





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