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Organising Inclusion Work: Key Factors for Success

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

Introduction

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

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

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

For the purposes of the Scope research, inclusion work was defined as supporting people to achieve, do and be in life in the ways they choose and identifying and removing barriers to this in society, services and individuals. In this way, inclusion work selected for the research encompassed a range of individuals, practitioners or organisations that used a range of strategies to enable:
• people with a disability and their family to achieve their life priorities and / or
• community / communities to include and welcome people with a disability.
• The definition adopted here suggests that inclusion work involves a broad set of change actions that may focus on individuals, families, services, groups, communities and systems.

**Orientations to Inclusion Work**

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

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

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

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

**Case Study: Orientation 1**

Joe, a 32 year old male, spent the second half of his life in an institution. There came a point, according to the interviewee, that the institution decided Joe could live on his own. The institution set Joe up with limited support in a flat and never saw him again. Joe went from having 24 hour support, to a 1 hour visit every fortnight by a support person to assist him with budgeting. Joe felt frightened and became sad. He stopped going out. The only friends he knew were in the institution and he had lost them. Joe couldn’t communicate easily, he didn’t know what he wanted and within a year and a half a mental illness developed and he was accessing the mental health system. Joe met the local inclusion worker who is based in Joe’s suburb. They met weekly to talk, and develop a relationship. Gradually, the inclusion worker drew in people to support Joe to achieve his goals to own his own home, gain employment, become a DJ and be involved in the football club. The inclusion worker linked Joe to different people that supported him with various interests. One included a mentor from the local church. Joe met a few men his age and identified the person he felt most comfortable with. The mentor was a similar age and they started going out together. As Joe came to trust the mentor, they went to the pub regularly, had a meal and played pool. Joe attended a modified DJ course through a University and he completed the course and was presented with a certificate. He was then linked with a DJ mentor for a few hours every week to build up his DJ skills. He is now a DJ once a week for a local community radio station and has become well known in his area. Joe’s story covers a five year period.

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

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

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

**Case Study: Orientation 2**

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

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

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

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

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

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

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

Orientation 3: Broad Level Community Change.

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

Inclusion workers foster opportunities for inclusion by focusing on overarching structures, allocation of resources, skill sets and knowledge of various groups. While this work is most powerful when it includes or is led by people with a disability it does not always, or even frequently, include people with a disability as actors. This work is general ground-breaking and foundation-lying work with organisations and communities. It may involve work to change policies and procedures that have extended effect (eg the funding allocations for staffing of classes at neighbourhood houses, or public transport facilities), or change practices and attitudes (for example, work to skill psychologists to provide appropriate services to people with intellectual disability and complex communication needs). In most cases it involves re-visioning notions of ‘disability’ and ‘community’ services in a range of ways.

Case study: Orientation 3

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

Breadth of the Work

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

We have already discussed above that inclusion requires addressing barriers that create exclusion. These barriers occur at all levels of society and across multiple environments in which people engage. Barriers can be found within attitudes, knowledge, skill sets, relations between people and groups or between individuals and organisations, behaviours and practices (such as professional or organisational practices), policies and other
structures. Within each Orientation, the inclusion worker focuses on whatever set of these barriers she/he finds.

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

Orientation 1 work focuses primarily on:
- personal and home barriers;
- barriers in disability services (e.g. residential or day services);
- barriers in non disability organisations (e.g. shops, neighbourhood house etc).

Orientation 2 work focuses primarily on:
- barriers and opportunities in non disability organisations / community.

Orientation 3 work focuses primarily on:
- barriers of policy, program delivery, facilities and infrastructure across non disability organisations and community.

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

What this analysis suggests is that inclusion work requires activity (and staff resources) to be focused across all dimensions of a person’s life, and to address the barriers to inclusion at a range of levels. Inclusion is a broad-scale activity that requires the combined focus of Orientations 1, 2 and 3 in order to ensure that barriers to inclusion are removed at all levels. However, data from the seventeen case studies in this research identified that by far the greatest majority of the work was operating within Orientation 1 (94%). Around one quarter of examples were situated in each of orientations of 2 and 3, with forty percent (40%) working across more than one orientation. Organisations took different approaches to structuring their work within each of these orientations. Within orientation 1, organisations largely took a ‘case management’ style approach, focusing their inclusion work around identified individuals and building responses to their needs and interests. Work within Orientation 2 tended to be structured around interest areas or service types (for example, leisure interests or respite services). In this Orientation, organisations became specialists in particular interest areas or fields and worked to build inclusion opportunities across the field as a whole (e.g. the field of arts participation, or the field of football). There was only one example of an organisational approach to Orientation 3. This involved total service re-design and re-conceptualisation.

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

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

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

Each of these four clusters contain numerous roles that exist within community work. Ife reports that “community work tends to be about doing lots of things at once, and in any single activity or project a community worker is likely to be filling several of these roles, and will move between one and
The following summary identifies key changes needed in order for organisations and governments to effectively progress inclusion work, drawing together the data presented by respondents about barriers and enablers to inclusion work, and the key organisational factors required to sustain it.

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

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

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

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

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

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

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

Resources were also needed in flexible formats and to support flexible approaches such as small funding packages that could be approved and utilised in a timely manner.

Inclusion Relies on Collaboration, Partnerships and Co-ordination
Disability agencies cannot do the work of inclusion alone. It requires a combined focus with an inter-dependent partnership with people with a disability, community members, disability services and mainstream agencies to bring about change. Consistent with previous studies, the attitudes present in the community were seen to be critical to successful inclusion work. Positive attitudes were characterised by a commitment to interact, a willingness to seek appropriate resources, and openness to flexibility and adaptation. Leadership by key individuals who championed inclusion was identified as important as were partnerships between groups and organisations that unlocked resources and support.

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

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

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

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

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

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

**Implications**

*For government departments*

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

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

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

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

*Clarify the practice of inclusion work*

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

*Actively develop cross-sector collaboration in inclusion work*

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

*For Organisations*

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

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

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

Resource all staff to undertake inclusion work.

Inclusion work needs to be the job of all staff as it requires consistent activity towards the identified goals of people with a disability. To achieve this, significant skills development is required for existing staff, along with targeted recruitment strategies that equally value staff attitudes and values along with inclusion skills. Professional development programs need to include community development training as a core base to build staff capacity. Staff require skilled supervision and management processes that affirm and support inclusion work. Specialist staff with advanced skills in inclusion work (possibly drawn from the disciplines of community development and social work, among others), are needed to mentor and support the work as well as leading larger and more complex activities across the three Orientations. Organisations need to ensure they value and resource staff that enact the practices identified in the next section detailing the implications for practitioners.

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

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

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

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

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

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

Questions to Ask our Organisations

1. What do we understand from the terms ‘community’, ‘inclusion’, ‘participation’ and ‘presence’?
2. In which Orientations does our current inclusion work sit? Is this adequate?
3. Are we explicitly interested in supporting people with a disability to lead a life that is important to them as defined by them (and those who know them best)?
4. Is inclusion work our core business? Are our mission, strategic plan, budget, job roles and job descriptions aligned with this?

5. Are we genuinely listening to people with a disability and their families?

6. What do we do once we have listened? Does this information guide our practice or is it overlooked and simply a process of courtesy that remains too difficult to act on?

7. How well do we know the individuals and families we are working with? Do we invest enough time with the individuals and families to build a solid relationship and gain a sense of trust? What would individuals and families say if we were to ask them these questions?

8. How well do we know the communities we are working within? Can we really say we have good relationships with the community sector? What would community members/leaders say if we were to ask them these questions?

9. Who are we accountable to in regard to inclusion? What processes are in place to ensure accountability occurs?

10. How well do we value inclusion work? Are systems in place to ensure workers can carry out their tasks as a priority and in a flexible manner? What are they?

11. How well do we support inclusion workers? What policies and processes are in place to ensure practitioners are adequately supported and encouraged to develop skills and improve practice?

12. What principles do we work by? Are all practitioners consistent in applying these principles? How do we supervise and support them to do so? Do our supervisors have these skills?

13. Do inclusion workers collaborate together? What processes are in place to ensure regular communication and collaboration occurs? Is there enough engagement with others in the disability sectors that may be doing similar work?

14. Who do inclusion workers learn from? Are they supported with mentors? What other processes are in place to ensure reflection and ongoing learning is a valued and consistent practice? What external forums could we connect with to support professional development around inclusion?

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

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

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

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

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

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

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

'Due to the fact that C is far more involved, visible and interactive, she is better known in the community and this reduces safety concerns.'
Finally, while respondents reported increased community presence, this was linked to a range of other benefits and in many cases was also linked to expanding social relationships. Around half of respondents discussed people going out more, having more conversations with people they know from a range of activities as their paths cross outside these activities, and having ‘connections’ with particular groups or retailers as a result of frequent engagement and knowledge of a shared interest. One interviewee stated the individual was ‘now a valued member’ of a specific community.

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

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

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

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

Conclusion

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

References


