

Living with Disability

RESEARCH CENTRE

Supporting inclusion of people with cognitive disabilities



Full report

Designing effective support for community participation for people with intellectual disabilities

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Executive Summary

Designing effective support for community participation for people with intellectual disabilities

Community participation of people with intellectual disabilities is a longstanding policy aim and a key objective of the Australian National Disability Insurance Scheme. Despite significant investment since the 1980s, it remains elusive for many people with intellectual disabilities, whom researchers continue to describe as being present rather than participating in communities. The reasons for limited progress are often associated with a lack of conceptual clarity about the purpose of community participation and the limited evidence about effective interventions. Community participation takes many forms as individual success stories demonstrate (see for example <https://www.19stories.org>). However, such narratives hide underlying assumptions about types of participation, strategies to facilitate it, skills of support workers and supporting organisational structures. This type of knowledge is important in understanding good practice in order to replicate it and design person-centred interventions or programs to support community participation. This is especially the case for the many people with intellectual disabilities who do not have resourceful families or strong informal networks that support participation (Bigby, 2008).

The overarching aim of this study was to develop conceptual clarity and a typology of different types of community participation and interventions to support it, to inform decisions about funding, planning and purchase of person centred supports to facilitate community participation for people with intellectual disabilities.

The research questions were:

- what are the key elements of community participation for people with intellectual disabilities;
- what are the diverse ways in which community participation is manifested;
- what staff practices and organisational strategies are effective in supporting community participation of people with intellectual disabilities, and;
- what are the implications of the findings for the disability sector in terms of service models, organisational forms and the disability workforce?

Design

The study had two components:

- A systematic scoping review of international peer reviewed literature published between 2000-2015 about interventions to support community participation for people with intellectual disabilities. Seventeen articles reporting 13 separate studies of interventions to support community participation were identified and reviewed.
- Five in-depth case studies of organisations supporting community participation of people with intellectual disabilities. Cases were purposely selected on reputation of success, and as exemplars of the typology developed from the literature review. Data were collected using mixed methods about the host organisation, the embedded theory of change that informed staff practice, experiences of staff in supporting community participation and of adults with intellectual disabilities and their families in being supported to participate. Analysis used inductive qualitative methods and a detailed program logic and assessment of outcomes prepared for each. A cross case analysis was used to identify common and different aspects.

A project reference group made up of representatives from across the disability sector, and a consumer advisory group that comprised representatives from the Our Voice committee of Inclusion Australia, provided input at key stages of the project. The research was led by La Trobe University Living with Disability Research Centre in partnership with National Disability Services.

Findings

Literature review

The scoping review was published in the Journal of Applied Research in Intellectual Disabilities and available as open access (Bigby, Anderson & Cameron, 2018). Different ways of conceptualising community participation were summarised and the new ideas considered from urban studies that are disrupting traditional thinking about place based communities and long term relationships as the bedrock of community. Interventions to support community participation differed according to the way it had been conceptualised, and fell into three different types. Community participation as:

- Social relationships - the development of social relationships between adults with or without intellectual disability. Interventions to develop social relationships prioritised social interactions, and matching with volunteers or support to meet people with similar interests. Promising strategies were those used by community builders (Harlan- Simmons et al. 2001),

- Convivial encounters - support for social interactions that are neither free mingling in public places nor based on long term relationships, where there is a shared identity or activity with others and a sense of pleasantness or warmth. Interventions to support convivial encounters prioritised place (mainstream community groups) and activities (based on individual interest) and pleasant social interactions in for example, community groups, where a person is known and recognised. Promising strategies were active mentoring (Stancliffe et al. 2015), active participation in community groups (Craig & Bigby, 2015), facilitative support worker practices (Bigby & Wiesel, 2015),
- Belonging –activities and places where subjective feelings of a sense of attachment and belonging to close and more distant others develop. Interventions to support a sense of belonging prioritised participation in activities with the potential to lead to a new social identity and valued role as for example an artist, in a mix of segregated and mainstream places. Promising strategies were arts based programs (Stickley et al. 2011).

The intervention studies were predominantly small scale and qualitative, with the most rigorous evidence about strategies to support convivial encounters. Despite the differing conceptualisations and strategies adopted, outcomes of community participation were commonly framed as:

- personal development such as skills, self-esteem or confidence;
- increased social networks, or;
- subjective experiences such as enjoyment or happiness.

Case studies

Case study organisations are identified but names of all informants were changed to ensure confidentiality. Each case study consisted of a one page summary, program logic diagram and a longer descriptive piece about processes used by staff and participant outcomes.

Gig Buddies - Community participation as social relationships.

Theory of change. Matching people with intellectual disabilities with volunteers with similar interests will provide opportunities for friendship, expanding their social networks and participation in activities and choices about their social lives.

Activities. Interest-related activities in the context of matched relationships or as part of a bigger group organised by the program.

Place. Mainstream community places.

Social interaction. Fleeting and convivial encounters and friendships with matched volunteer, peers and others involved in the program and at mainstream.

Outcomes. Friendships with matched volunteer and experience convivial or fleeting encounters with people without intellectual disabilities. Enjoyment of going out either in a group or with their volunteer and development of social skills and competence.

Participants. People with intellectual disability, with low support needs and able to use public transport.

Melba Support Services Community Connections - community participation as convivial encounters with people without disabilities in mainstream community places.

Theory of change. Supporting individuals with intellectual disabilities to engage in activities of their own choosing in the local community will mean they live more interesting and fulfilling lives and develop a greater sense of belonging to that community.

Activities. Skills training, sport, group activities such as cooking, food distribution with peers or others in locality, individual activities as part of social enterprises or micro businesses.

Place. Locality based. Mixture of segregated and mainstream community places.

Social interactions. Fleeting and convivial encounters with peers and others without disabilities in the local community.

Outcomes. Regular and convivial with people in the locality who know or recognise them, whilst others may be intermittent or fleeting. Sense of belonging and contributing to the locality through their engagement in a range of activities.

Participants. People with intellectual disabilities with moderate to high support needs.

Shepparton Access - community participation as convivial encounters with people without disabilities in mainstream community places.

Theory of change. Creating opportunities for individuals with intellectual disabilities to participate in a range of activities in a variety of highly visible settings will mean they experience a sense of belonging to a community which embraces people from diverse backgrounds.

Activities. Skills training, sport, group activities such as cooking, food production with peers or others in locality, individual activities, as part of social enterprises, micro businesses or paid employment.

Place. Locality based. Mixture of segregated and mainstream community places.

Social interactions. Fleeting and convivial encounters with peers in the program, and people with and without disabilities in the local community.

Outcomes. Friendships with peers and regular convivial or fleeting encounters with a wide range of others in locality. Being recognised and known by community members beyond those met as part of specific activities and a sense of belonging to the local community.

Participants. People with intellectual disabilities with support needs ranging from low to high.

Arts Project Australia - community participation as belonging and identity.

Theory of change. Creating a space in which individuals with intellectual disabilities are supported to produce art will develop their sense of belonging to the arts community, and an identity as a working artist.

Activities. Create, display and sell pieces of art.

Place. Segregated and some mainstream community places.

Social interactions. Fleeting and convivial encounters with peers in the program, artists and the wider arts community. Friendships with peers.

Outcomes. Development of strong identities as working artists and enjoyment in practising as an artist and developing their skills. Sense of belonging to the artistic community, friendships with peers, and convivial encounters with peers, others in the arts community and shopkeepers in the local neighbourhood.

Participants. People with intellectual disabilities with low to moderate support needs.

The Ringwood Spiders - community participation as belonging and identity

Theory of change. Creating a formal structure that enables people with intellectual disabilities to train and play football will allow participants to develop friendships with peers and a sense of belonging to the broader group of sports people in the community.

Activities. Training and playing football, social activities, social skills training.

Place. Mainstream community places

Social interactions. Fleeting and convivial encounters with peers in the program, and people without disabilities such as committee members, volunteers, players' family members and others interested in football.

Outcomes. Friendships with peers who are members of the club, and convivial or fleeting encounters with others involved in the club, and members of mainstream football clubs and the general public. Enjoyment of playing footy and sense of belonging to the club and the wider community interested in footy and sport. Development of confidence and social skills.

Participants. People with intellectual disabilities with low to moderate support needs.

Cross case study

The five case studies give a detailed understanding of the different approaches to supporting community participation, making explicit embedded assumptions, design, strategies and practice. They can act as blueprints to inform development or refinement of programs aiming to support community participation for people with intellectual disabilities.

The case studies demonstrate the value of the typology of approaches to supporting community participation, and a common language. This is particularly evident in the Melba Community Connections and the Shepparton Access programs which at first glance may appear as simply locality based 'day programs'. Using the typology to frame these programs as supporting convivial encounters, made the aims and strategies clearer and drew out similarities. It also helped in thinking about how such programs could be replicated in urban places where local place based communities are less important.

These two convivial encounters case studies were the only ones that included people with high support needs, suggesting this group has limited choices. Notably, newer and perceived innovative programs that frame community participation as building relationships, such as Gig Buddies, primarily served people with milder intellectual disabilities who could travel independently. This suggests there may be a need to direct funding for innovation or demonstration pilots towards people with more severe disabilities to this group to ensure they have choices comparable to other groups.

The two convivial encounter case studies that supported people with more severe disabilities also raised issues about differences between support for community participation and support that simply provides 'care' to ensure a person's safety, provide respite for unpaid carers, or fill gaps in support available at a group home. The support provided by both Melba Community Connections and Shepparton Access involved both types of support without clear boundaries. The typology developed may help thinking about the differences between

support for participation v ‘day support’ that poses a challenge to the NDIA and funding community participation. Similarly, ‘work’ was used in two of the case studies to refer to various activities, both paid and unpaid. This is indicative of the growing spectrum of activities that include; unpaid work experience, volunteering, and low paid work in micro businesses or community enterprises. Further thought needs to be given to whether there should be differences in the support and funding for community participation compared to supporting people with intellectual disabilities to find and sustain paid employment that provides income and independence, as well as social connections.

The case studies also suggest the potential difficulties of support for community participation in rural or remote areas, where there are likely to be limited potential groups and organisations to negotiate opportunities for shared activities (for convivial encounter programs) or too narrow range of events available (for relationship programs such as Gig Buddies) or insufficient numbers to create a critical mass of people with a particular focal interest (for identity and belonging programs such as Spiders or Arts Project). This suggests further exploration is required to identify and analyse the type of support for community participation that is effective in rural and remote places.

There was much similarity between outcomes and levels of satisfaction across the case studies, despite some participants not spending all their time in mainstream places. This suggests that place may not be a major factor influencing outcomes and should warn against potentially stereotypical views derived from social role valorisation that are blind to the potential advantages of using segregated places for some time, for supporting some types of community participation. In particular, the Arts Project case study demonstrated that developing skills and identity through specialist support in a segregated place can act as a catalyst for belonging to wider groups or communities based on interest, or a springboard for use and enjoyment of mainstream places such as galleries or museums, which hold the potential for convivial encounters with others who use these places.

Peer friendships were an outcome from 4 of the 5 case studies which was not acknowledged in program aims. Such friendships were clearly important to the participants with intellectual disabilities and their families. This is also reflected the growing body of research suggesting the loneliness of people with intellectual disabilities and long held knowledge about their desire for friendships. It must be acknowledged that support for community participation programs other than those that specifically aim to build relationships, can support the development of peer friendships.

There is much support in current debates for individual support and a notable backlash against the idea of programs. These case studies demonstrate that individualised support can and does occur in the context of a program. The programs in these case studies delivered person centred support, underpinned by individual planning processes that required staff to know each participant well. Families of participants were included in planning and for many participants, families were partners in negotiating the type of activities they preferred and support they needed. Importantly the provision of direct one to one support ‘in the moment’ was only a small fraction of the overall work associated with supporting each individual’s community participation. A significant proportion of total staff time was spent behind the scenes, establishing the infrastructure to create opportunities for convivial encounters and engagement, or supporting and ensuring the competence of natural supporters in community places. This must be recognised, and embedded in funding rates, together with recognition of the centrality of staff knowledge about individual participants, and importance of individual planning processes.

An initial mapping of staff skills necessary to support community participation shows that these span community mapping and development, evidence-based disability support worker practice such as Active Support, and various newer approaches for which evidence is emerging, such as Active Mentoring, Risk Enablement and Support for Decision Making. Further mapping of skills and competencies of staff is required as well as bringing together these various approaches into a coherent practice framework. Recruiting staff with preferred attitudinal attributes and ensuring they have the training and ongoing supervision to be competent practitioners is a major challenge for disability support organisations as the demand for support for community participation grows with the additional funding available from the NDIS.

Conclusions

The knowledge developed from this study can inform future design of support for community participation and the typology will be useful in finding a common language for people with disabilities and their families, the NDIA and disability support organisations to talk about these programs of support. The typology can also be helpful in informing individual NDIS planners, and broader decisions by the NDIA about types of effective support for community participation. Setting out the common characteristics and differences between promising community participation programs will also be useful to people with intellectual disabilities and their families in making decisions about planning and purchase of services. There is

significant room for further development of this material into more accessible guides to thinking about support for community participation for people with intellectual disabilities, their families, NDIA planners and local areas coordinators.

Recommendations

- These findings reinforce the diversity of experiences that might be described as instances of community participation and the attendant dangers of vague or ill defined approaches to support. Planning and funding for community participation should be closely attuned to identifiable types of participation, include a clearly articulated and evidence based logic for the type of support provided.
- Support for community participation can be typically represented as either:
 - Social relationships - the development of social relationships between adults with or without intellectual disability. Interventions aims to develop social relationships prioritise social interactions, and matching with volunteers or support to meet people with similar interests.
 - Convivial encounters - support for social interactions that are neither free mingling in public places nor based on long term relationships, where there is a shared identity or activity with others and a sense of pleasantness or warmth. Interventions to support convivial encounters prioritise place (mainstream community groups or community organisations) and activities (based on individual interest) and pleasant social interactions in for example, community groups, where a person is known and recognised.
 - Belonging –activities and places where subjective feelings of a sense of attachment and belonging to close and more distant others develop. Interventions to support a sense of belonging prioritise participation in activities with the potential to lead to a new social identity and valued role as for example an artist, in a mix of segregated and mainstream places.
- Expected outcomes of community participation should be defined for each individual and measures should include some or all of the following and be tailored to reflect the primary goal of the individual;
 - personal development such as skills, self-esteem or confidence;
 - increased social networks, including peer relationships;

- subjective experiences such as enjoyment or happiness.
- The benefits of peer relationships for people with intellectual disabilities should not be underestimated and are often an unnoticed outcome of community participation programs.
- Community has multiple meanings, and can be based on place, locality, ideology or interest. A community of peers which is based on choice, common interest or talent is a legitimate form of community participation that should not be devalued and may also facilitate inclusion other communities that include people with and without disabilities.
- Visible direct one to one support is likely to be a small fraction of the work of supporting a person with intellectual disability to participate. Individual person centred support for community participation can be delivered by identifiable programs which are likely to enable better client outcomes ensuring support is developmental rather than simply paid companionship. Programs facilitate behind the scenes support, that involves key elements such as developing opportunities for community participation, recruiting volunteers, supporting natural supporters in groups or organisations, sharing of practice wisdom about community places and training and supervising staff.
- Supporting community participation requires skilled staff who are competent in a range of community development skills, such as analysis of community groups and community mapping, as well as disability support practice such as Active Support, Active Mentoring, Risk Enablement and Support for Decision Making.
- Particular attention should be given to developing interventions or programs that support community participation of people with more severe and profound intellectual disabilities, as some of the new innovative programs exclude this group.
- Further exploration is necessary of interventions or programs to support community participation for people with intellectual disabilities in rural or remote areas where small populations may be too small to support the three types identified in this study.
- Support for community participation should be distinguished from support for every day care, respite or support that compensates for gap in support in a person's accommodation.

- The success of strategies to support community participation of people with intellectual disabilities depends on partnerships and collaboration between specialist disability services and the broader community, including the availability, design, accessibility and inclusiveness of community groups, mainstream and the general population. Potential strategies and roles of local government authorities in designing places conducive to convivial encounters, facilitating inclusivity of community groups and public places in respect of people with intellectual disabilities requires further exploration.

Designing effective support for community participation for people with intellectual disabilities

Introduction

Furthering the social inclusion of people with intellectual disabilities has been an enduring aim of disability policy since the mid 1970s when deinstitutionalisation and community living were first mooted in Australia. As a result, people with intellectual disabilities are increasingly likely to be present in communities, but progress to advance community participation has been slow (Clement & Bigby, 2010; Gray et al. 2014; Overmars-Marx et al. 2014). Data from the National Disability Insurance Agency (NDIA) echoes a significant body of research in this arena, and highlights the continuing low levels of community participation of scheme participants (NDIA, 2017 yr 5 qtr 1 p.17). Not surprisingly, community participation is a key objective of the National Disability Insurance Scheme; included as a goal in approximately 50% of NDIS participants' plans, and ranking third in types of support funded.

Reasons for limited progress are suggested to be weak program design, poor implementation, and omission of specific support for community participation in accommodation services (Beadle-Brown et al. 2015; Bigby, Bould & Beadle-Brown, 2016). Some of these issues originate from the conceptual maze surrounding community participation which hinders interventions through a lack of clarity about the intended purpose or outcomes and the absence of shared meaning and language among stakeholders (Clifford-Simplican et al., 2015).

There is no shared conceptual framework and little evidence about the design elements and capabilities necessary to support community participation for people with intellectual disabilities. Community participation has many guises, and a growing body of written and multi-media material is portraying individual success stories (see for example <https://www.19stories.org>). These stories hint at the significance of informal support networks in orchestrating participation. However, they rarely articulate the underpinning assumptions, strategies and supporter skills that combine to deliver participation. Knowledge such as this is fundamentally important in replicating good practice or designing more formal programs to support community participation required by those without resourceful families or informal networks (Bigby, 2008).

There is considerable potential to learn from successful programs by identifying systemic details of design and practice, and the organisational and workforce implications of

these. Some small scale short term demonstration programs are beginning to provide insights into the complexities of the task and breadth of skills required to facilitate community participation (see for example, Stancliffe et al., 2015; Craig & Bigby, 2015). Studies such as these also suggest that approaches to supporting community participation may differ depending on an individuals' severity or type of impairment, raising issues about the pitfalls of a differentiated approach to support (Clegg & Bigby, 2017).

The limited successes of the past suggest that a common nomenclature and language for describing different types community participation, and a stronger evidence base about interventions to support participation are required to realise the objective of the NDIS and effectively utilise the increased availability of funding. The aim of this study was to bring greater conceptual clarity to the diverse manifestations of community participation for people with intellectual disabilities, by developing a typology and identifying the promising staff practices and organisational strategies for supporting different types of community participation. In doing so, it helps to drive policy design and shape regulatory settings to support scalable models for supporting community participation of people with intellectual disabilities. Developing greater conceptual clarity about community participation will support the NDIS in funding decisions and people with intellectual disabilities and their families in individualised planning about participation and purchasing appropriate supports.

Overview of design and methods

The research questions were: what are the key elements of community participation for people with intellectual disabilities; what are the diverse ways in which it is manifested; what staff practices and organisational strategies are effective in supporting community participation of people with intellectual disabilities, and; what are the implications of these for service models, organisational forms and the disability workforce? The study had two components, a systematic scoping review of international peer reviewed literature about interventions to support community participation for people with intellectual disabilities, and five in-depth case studies of best practice in supporting community participation of people with intellectual disabilities.

The scoping review was published as a journal article during the course of the study, and a word version of this forms the first part of this report. The paper reviewed different conceptualisations of community participation, analysed papers published in peer reviewed journals between 2000-2015 about interventions to support participation and developed a typology of interventions (Bigby, Anderson & Cameron, 2018). The case studies used mixed methods to collect data about the organisation and experiences of each program from staff,

people with intellectual disabilities and their families and program documents. A report of each study detailed the nature of community participation, for whom and the practices and strategies in place to achieve it. A cross case analysis identified the common and different aspects of community participation, practices and strategies.

A project reference group made up of representatives from across the disability sector, and consumer advisory group that comprised representatives from the Our Voice committee of Inclusion Australia, provided input at key stages of the project. This included discussion of research design, workshopping findings of the literature review, identifying good practice providers to participate in case studies, and discussion of overall findings and a plan for dissemination.

The first section of this report is the literature review, the second section presents the five detailed case studies and the third section the cross-case analysis. A policy commentary on the finding from NDS is included in the final section and also forms part of the executive summary.

Identifying conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review

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Background: Little progress has been made towards community participation of people with intellectual disability despite it being a policy aim since the 1980s. We aimed to identify the features of programmes designed to support community participation.

Method: A scoping review was conducted of peer-reviewed literature between 2000 and 2015, about interventions to support community participation for adults with intellectual disability.

Results: A small body of evidence relates to the design and effectiveness of interventions to enhance community participation. Seventeen studies reported programmes reflecting three conceptualizations of community participation (as social relationships, as convivial encounter and as belonging) that used strategies such as active mentoring, facilitative support worker practice and arts-based programmes.

Conclusions: Studies showed the diverse and person-centred nature of community participation and demonstrated the need for larger-scale studies of promising interventions that include details of costs, and strategies to guide implementation of policies to support community participation.

KEYWORDS

adults with intellectual disability, community participation, effective interventions, national disability insurance scheme, programme design

1 | INTRODUCTION

Community participation is a central theme in policies seeking to create a better life for people with intellectual disabilities. In Australia, the landmark 1986 Australian Disability Services Act aimed to support people with disability to live “as valued and participating members of the community.” Similar aims are replicated in more recent national policies and international treaties (Commonwealth of Australia 2011; National Disability Insurance Scheme Act 2013; United Nations 2006). Nevertheless, community participation is a contested and ambiguous concept. It exists within a terminological forest (Sinason, 1992) where

prefixes such as “social” and “community” to words such as “inclusion,” “integration,” “participation” are interchangeable (Simplican, Leader, Kosciulek, & Leahy, 2015). Definitions of community participation range from expansive to narrow, encompassing multiple or single life domains (e.g., domestic, leisure, work), or arenas (e.g., social, political, economic), and the term is used both as an overarching concept or as a subcomponent of social inclusion. The absence from empirical research of consistent conceptual frameworks (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014; Simplican et al., 2015; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009) combined with interchangeability of terms has created a

conceptual maze. This means that policymakers and those who design and deliver interventions to support community participation are offered little clarity about intended purpose or outcomes of programmes.

In this article, the present authors focus on adults with intellectual disability, briefly describing different ways that community participation has been conceptualized, and review the small body of literature about interventions designed to support community participation, exploring the theories of change and conceptualizations that unpin these. Empirical evidence overwhelmingly suggests that significant progress has been made towards supporting the presence of adults with intellectual disabilities in mainstream communities as consumers in public and commercial spaces, or as residents in neighbourhoods (Verdonschot et al., 2009). The literature is, however, replete with conclusions that despite increased community presence, several decades of policies have not achieved community participation for adults with intellectual disabilities, irrespective of the particular definition that is adopted (Amado, Stancliffe, McCarron, & McCallion, 2013; Bigby & Fyffe, 2010; Gray et al., 2014; Overmars-Marx et al., 2014; Walker, 1999).

These conclusions reflect one of the most common understandings of community participation which is based on the principle of normalization (Wolfensberger, 1972) and distinguishes between community presence, as the use of facilities or services available to everyone, and community participation, as being part of a growing network of relationships that include people with and without intellectual disability (O'Brien & Lyle, 1987). This conceptualization of community participation places importance on particular kinds of places and personal relationships. Presence in mainstream places is regarded as a precursor to the formation of personal relationships (Ager, Myers, Kerr, Myles, & Green, 2001; Amado et al., 2013). In turn, personal relationships provide opportunities to participate in formally organized or informal activities in public and private places. Often particular types of relationships that people with intellectual disabilities have, or might have, are seen as more important than others, such as those with people who do not have disabilities (Cummins & Lau, 2003), those that are freely given rather than paid (Amado, 2014) or those that involve reciprocity (van Alphen, Dijker, van den Borne, & Curfs, 2010).

Other conceptualizations of community participation are based on the World Health Organization's (2001) International Classification of Functioning (ICF) framework. For example, in Verdonschot et al.'s (2009) review of empirical findings about community participation, it is defined as "the performance of people in actual activities in social life domains through interaction with others in the context in which they live" (p. 304). Similarly, Dusseljee, Rijken, Cardol, Curfs, and Groenewegen (2011) define community participation as "performing daytime activities while interacting with others" (p. 4). These conceptualizations are broader and less prescriptive than the presence/participation binary based on the principle of normalization. They also give significance to activities in addition to place and social interactions. However, approaches based on the ICF definition (World Health Organization, 2001) do not consider the qualitative aspects of activities, where they occur or with whom, or subjective experiential elements of community participation.

As it has become clearer that experiences of being in mainstream places, often simply referred to as "the community," are not

"unambiguously virtuous" (Bates & Davis, 2004; p. 201), more attention has been given to choice and the subjective aspects of community participation (Milner & Kelly, 2009; Simplican & Leader, 2015). Hall (2013, p. 259) for example, considers community participation to entail subjective feelings, a sense of belonging and social relationships, which he views as a transformative process where a person "moves towards a sense of attachment and belonging to proximate and distant others." Hall (2013) and others (Anderson & Bigby, 2017; Darragh, Ellison, Rillotta, Bellon, & Crocker, 2016; Frawley & Bigby, 2015) illustrate how segregated groups, based around activities such as drama, sports or self-advocacy may be places of community for people with intellectual disability, where through participation they gain a sense of belonging. While participation in a community of peers is important in its own right, the sense of belonging or identity derived, as an artist or sports person, for example, may also facilitate participation in other, perhaps more mainstream communities, through activities such as exhibitions or sports carnivals. In some ways, this conceptualization of community participation links conceptually back to the principle of normalization and the privileging of socially valued roles such as artist or sportsman.

More recently, researchers have begun to disrupt the binary between community presence and participation using ideas about *encounter* and the diverse and fluid social networks that characterize modern cities (Bigby & Wiesel, 2011, 2015; Bredewold, Tonkens, & Trappenburg, 2016; Laurier & Philo, 2006; Wiesel, Bigby, & Carling Jenkins, 2013). Convivial encounters are a particular type of encounter-social interactions that are neither free mingling in public places (presence) nor based on long-term relationships (participation as understood by O'Brien & Lyle, 1987) but where there is a shared identity or activity and a sense of pleasantness or warmth (Fincher & Iveson, 2008). They can be fleeting and singular, such as an exchange in the supermarket queue, intermittent, such as recognition and greeting by the proprietor or other patrons at a local shop, or longer and episodic, such as regular exchanges with other participants in a yoga class. There is potential for such convivial encounters to develop into lasting or deeper relationships (Bigby & Wiesel, 2011); however, encounters are important in themselves. Gestures such as a nod or a wave "contribute to a sense of recognition and of 'feeling at home' in a neighbourhood" (Bredewold et al., 2016; p. 3381). Convivial encounter as a fluid conceptualization of community participation brings together core components identified in other perspectives without embedded normative assumptions. Seen by Simplican et al. (2015, p. 25) as a way to "modernize" community participation, the concept of convivial encounter avoids reference to the kind of continua frequently relied on by other understandings of community participation. It accords equal value to diverse combinations of place, interaction and activities but incorporates an experiential element of conviviality or pleasantness.

The failure to make significant headway with community participation has occurred despite significant investment in programmes to support community living, employment, daytime activities, leisure and recreation. For example, in Australia in 2014–2015, the Federal Government spent eight billion dollars on specialist disability services (Parliament of Australia, 2016), and in the State of Victoria, as institutions closed, relocated residents were guaranteed a place in a

small group home and day programme, both with mandates to support community participation. In the UK, for example, the person-centred planning processes designed to support community participation, that were implemented as part of the Valuing People policy, have not significantly changed the composition of the social networks of people with intellectual disability (Ratti et al., 2016).

This limited progress is typically understood through the binary of presence and participation and explained as due to weak programme implementation or service design (Beadle-Brown, Bigby, & Bould, 2015; Clement & Bigby, 2009; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008). Commonly identified factors include poor staff practices, such as group-based outings and use of anonymous public spaces (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Walker, 1995); inadequate staff training or supervision; misinterpretations of policy intent by staff (Beadle-Brown et al., 2015; Bigby & Wiesel, 2015; Clement & Bigby, 2009); or design problems such as omission of support for building social relationships (Bigby, Bould, & Beadle-Brown, 2016).

Simplican et al. (2015) suggest that lack of conceptual clarity may be an explanatory factor that impedes effective service design and delivery by hindering communication, understanding of goals and agreement among stakeholders. In programme logic terms, making clear the underlying theory of change—the central proposition about the way change comes about for target/s of the intervention that informs its strategies or actions is important to success (Clement & Bigby, 2011; Funnell & Rogers, 2011; Rossi, Lipsey, & Freeman, 2004). Rogers' diffusion of innovation theory posits that observability of outcomes and absence of complexity about meaning are important to policy and programme implementation (Reidy, Swerisson, & Bigby, 2010; Rogers, 2003). For example, the multiple and often unclear purposes, without measurable outcomes, of day centre programmes may account to some extent for their limited success in facilitating community participation (Simons & Watson, 1999; Simpson, 2007). Moving beyond programme design, a socio-ecological approach can also be used to analyse the plethora of obstacles and facilitators of the interactions between people and their environments at the core of community participation (Amado et al., 2013; Simplican et al., 2015).

The implementation of the National Disability Insurance Scheme and accompanying growth of individualized funding in Australia is likely to have a similar impact to the personalization policies in the UK, which reduced reliance on day centres to support community participation and opened possibilities for more dispersed and individualized interventions (see, e.g., Whitaker & McIntosh, 2000). Evidence about the effectiveness of interventions; clarity about purpose; underlying assumptions; and intended outcomes will assist in the design of innovative programmes or interventions to support community participation.

This article reports the findings from a literature review that was the first stage of a study to investigate promising interventions to support community participation of people with intellectual disability. In undertaking the review, the present authors aimed to identify how interventions (or individualized interventions delivered in the context of a programme) conceptualized community participation and the features of promising interventions. The present authors also aimed to develop a framework that could be applied in the second stage of

this programme of research for identifying and evaluating potentially effective innovative programmes. This article reports on three key questions: (i) "How do interventions designed to facilitate community participation for people with intellectual disability conceptualize their aims and community participation?" (ii) "What theory of change and facilitation strategies do interventions have?" and (iii) "How effective are interventions in achieving anticipated outcomes?"

2 | METHODOLOGY

2.1 | Design

The review followed the approach for scoping reviews suggested by Arksey and O'Malley (2005), which facilitates an iterative process of review to ensure the literature is comprehensively covered, producing both in-depth and broad results. The starting point was the ICF (World Health Organization, 2001) conceptualization of community participation, used by Verdonchot et al. (2009, p. 304), "the performance of people in actual activities in social life domains through interaction with others in the context in which they live," and our focus was on the social rather than political, educational or economic domains.

2.2 | Search strategy

A systematic search was undertaken of the following databases which include all the major journals in the fields of disability and social work: CINAHL, PsycINFO, MEDLINE and PubMed. Keywords for searching included the following: cognitive impairment, intellectual disability, developmental disability, learning disability, intellectual disability, PIMD, participation, community participation, social participation, community engagement, social engagement, active engagement, inclusion and day service. This search yielded 4,534 results after duplicates were removed. Due to the volume, items published prior to 2,000 were removed, leaving 1,424 items. Inspection of abstracts revealed large numbers of articles pertaining to acquired brain injury and other cognitive impairments such as dementia which, when removed, left 175 items. Book chapters were removed as these are not peer reviewed and consolidate existing knowledge rather than report empirical data about interventions, which left 103 articles. An additional search, undertaken using the term "friendship," yielded five additional items and hand searching identified another 12, bringing the total to 120 articles.

The abstracts of these remaining articles were read so that our final inclusion criteria could be refined to reflect the research questions about the nature of specific interventions designed to facilitate community participation. The inclusion criteria were as follows: report of empirical research about the nature and effectiveness of a specific intervention (programme or practice) to facilitate community participation; regardless of the specific terminology used, the intervention aimed to facilitate Verdonchot et al.'s (2009) broad definition of community participation; the intervention was in respect of adults with intellectual disabilities; written in English language published in a peer-reviewed journal between 2000 and 2015. To determine inclusion of articles, the second author read all 120 abstracts and proposed the inclusion

or exclusion of each. Proposals to remove articles were reviewed by the first author, and where there was disagreement, both authors read the full article again and discussed any differences in order to reach a consensus. The articles removed fell into the following groups: reporting of broad empirical data about or an aspect of community participation for particular subgroups or from broad multifaceted initiatives (e.g., Andrews et al., 2014; Power, 2013; Sullivan, Bowden, McKenzie, & Quayle, 2016); conceptual articles theorizing the nature of community participation (e.g., Bates & Davis, 2004; Bigby, 2012; Hall, 2010; Simpican et al., 2015); analysis, commentary or reviews of policies or strategies to support community participation without empirical data about outcomes (Amado, 2014); general articles describing perspectives of people with intellectual disability about community participation (e.g., McClimens, Partridge, & Sexton, 2014; Welsby & Horsfall, 2011); and, describing broadly, factors associated with or barriers and facilitators to community participation (Abraham, Gregory, Wolf, & Pemberton, 2002; Beart, Hawkins, Kroese, Smithson, & Tolosa, 2001). Decisions about some articles involved considerable discussion about whether data about a specific intervention was reported. For example, the decision was made to exclude "Social inclusion through football fandom: opportunities for learning disabled people" (Southby, 2013) as this reported on participants experiences of being football fans and the phenomena of fandom rather than a specific intervention to support people with intellectual disability to be fans. One hundred and three articles were removed following this process leaving 17 articles that reported empirical research on specific community participation programmes or interventions. These articles are summarized in Table 1.

2.3 | Analysis

Articles were aggregated according to the aims of the programmes they discussed, under three key conceptualizations of community participation—drawn from the broader theoretical literature—as social relationships, convivial encounters and belonging. Strategies used to achieve aims were identified, and the ICF framework (World Health Organization, 2001) that defines participation as about *activities*, *place* and *interactions* was used to describe further the components of each programme (see Table 1). The aims and methods of the reported research about each of the interventions/programmes and evidence about outcomes were summarized in Table 2.

3 | FINDINGS

Data about 13 separate interventions were reported in the 17 articles, as four articles reported research about the same Transition to Retirement (TTR) programme (Bigby et al., 2014; Stancliffe, Bigby, Balandin, Wilson, & Craig, 2015; Wilson et al., 2013, 2015), and two reported on the same Friendship and Dating programme (Ward, Atkinson, Smith, & Windsor, 2013; Ward, Windsor, & Atkinson, 2012). Three articles reported on the international Special Olympics programmes, but the focus of these was sufficiently different for them to be treated separately. Of the 13 programmes, three were

time limited and established for research projects (Craig & Bigby, 2015; Lante, Walkley, Gamble, & Vassos, 2011; McClimens & Gordon, 2009) rather than as ongoing programmes. Table 1 summaries the way each programme was categorized, its facilitative strategies and the key components of its approach to community participation. Table 2 summaries and comments on the findings about outcomes for each programme.

3.1 | Conceptualizations of community participation

3.1.1 | Community participation as social relationships

Four programmes conceptualized community participation as the development of social relationships between adults with or without intellectual disability. The theory of change underpinning these programmes was that if support is offered to people with intellectual disabilities to make and develop relationships with others then, as well as enlarging their social network, it will lead to opportunities for them to participate in a wide range of activities, community groups and social interactions. The strategies used by these programmes varied, and in ICF terms (World Health Organization, 2001), the primary component was social interaction rather than activities or place.

Heslop (2005) reported research on five UK befriending services that focussed on building relationships between people with and without intellectual disability. The primary strategies used in these programmes were to recruit volunteers, match them individually, by personal interests, to a person with intellectual disability and support the developing friendship. The community membership project described by Harlan-Simmons, Holtz, Todd, and Mooney (2001) had similar aims to the befriending services but employed different strategies and used staff trained as "community builders" to work with individuals to support the creation of "community connections and meaningful relationships" (Harlan-Simmons et al., 2001, p. 171). In one respect, this programme may appear similar to the TTR programme as in some instances it involved connecting people to a community group but, unlike the TTR programme, the primary aim of community builders was to find community places that would act as a catalyst for longer-term relationships to develop.

Programmes with a similar purpose of building relationships, but with a slightly different focus, were described in the two articles by Ward et al. (2012, 2013). These programmes were confined to supporting development of relationships between people with intellectual disabilities, including extending intimate partnerships as well as friendships. Aimed to expand social networks as well as promote healthy relationships, they were developed in Alaska to "teach the social skills needed to develop healthy, meaningful relationships and to prevent violence in dating and partnered relationships" (Ward et al., 2012, p. 22). This programme's conceptualization of community participation was based on the notion that within a disability support programme, or other less segregated settings, establishing, supporting and developing relationships between peers with intellectual disability is the key to expanding the social networks of individuals, and increasing their

TABLE 1 Summary of articles included in review

	Conceptualization of community participation	Primary strategy	Description of ICF components		
			Activities	Place	Social interactions
Ward et al. (2013, 2012), UK	Relationships	Support to meet and establish friendships or more intimate relationships with peers with disability	Incidental reliant on decisions made in context of matched relationships	Segregated, mainstream or private places	Friendship/partners people with disability
Heslop (2005), UK	Relationships	Recruitment of befrienders and matching for friendship of person with intellectual disability to person without disability	Incidental reliant on decisions made in context of on matched friendships	Mainstream or private places	Friendships with people without disability
Harlan-Simmons et al. (2004), USA	Relationships	Community builder matching person to community group and supporting interaction with others and participation in activities—with view to longer-term friendships	Interest related activities	Mainstream community groups	Convivial encounters and friendships with people without disability
Bigby and Wiesel (2015), Australia	Convivial encounter	Individual support for positive social interactions with people in mainstream places	Range from every day commercial transactions to activities in community group	Mainstream places, commercial, public, community groups	Convivial encounters with people without disability—regular, intermittent or singular
Lante et al. (2011), Australia	Convivial encounter	Individual support to undertake physical activity in mainstream gym	Physical activity	Mainstream gym	Convivial encounters with people without disability—regular, intermittent or singular
Craig and Bigby (2015), Australia	Convivial encounter	Facilitative support to community group members and individual to participate in social group and interact socially with other participants	Activity in a community group reflecting individual's interest	Mainstream community group	Convivial encounters with people without disability—regular in group context
Stancilffe et al. (2015), Bigby et al. (2014), Wilson et al. (2013), Australia	Convivial encounter	Facilitative support to community group or volunteer organization and voluntary mentor to support individual's participation in activities and social interaction with other participants	Activity in a community group or volunteer organization reflecting individual's interest	Mainstream group as member or volunteer organization with age peers	Convivial encounters with people without disability—regular in group or volunteer context
Wilson et al. (2015), Australia	Convivial encounter	Facilitative support to community group and volunteer mentor to support participation in activities and social interaction with other participants	Activity in a community group reflecting individual's interest	Mainstream community group which is gender specific	Convivial encounters with people without disability—regular in group context
Tedrick (2009), USA	Belonging	Establishment of segregated sports programmes with connection to mainstream sports	Sport	Segregated with some boundary crossing initiatives	Convivial encounters with other people with disability—regular in group context and intermittent with associated others without disability
Harada et al. (2011), USA	Belonging	Establishment of segregated and integrated sports activities, and support to take part	Sport	Segregated and integrated	Convivial encounters with other people with disability—regular in group context and intermittent with associated others without disability

(Continues)

TABLE 1 (Continued)

	Conceptualization of community participation	Description of ICF components		
		Primary strategy	Activities	Place
McConkey et al. (2013), Europe	Belonging	Establishment of segregated sports programmes with deliberate pairing to peers without disability in other programmes	Sport	Segregated but boundary crossing initiatives
Darragh et al. (2016), Australia	Belonging	Establishment of segregated arts activity. Support to develop talents, as catalyst for interaction with other artists and public	Arts and music	Segregated but boundary crossing initiatives through exhibitions, performances and sales
Stickley et al. (2012), UK	Belonging	Establishment of segregated arts activity. Support to develop talents, as catalyst for interaction with other artists and public	Arts	Segregated, boundary crossing initiatives through performances and visits from mainstream students
McClimens and Gordon (2009), UK	Belonging	Individuals matched to students as trainers in a university setting to support blogging	Internet blogging	Mainstream places, virtual and real used by value peers without disability

social interactions and participation in activities in various mainstream or segregated places.

3.1.2 | Community participation as convivial encounter

Our analysis suggested that, although not explicitly, four programmes conceptualized community participation as convivial encounter, that is as social interactions, that are neither free mingling in public places nor based on long-term relationships, where there is a shared identity or activity with others and a sense of pleasantness or warmth. The distinguishing feature of these programmes was that the encounter occurred in public non-segregated places, or community groups or volunteer organizations with others who do not have disability. The theory of change evident in these programmes was that supporting people with intellectual disability to join mainstream community groups, undertake volunteer work or engage in social interactions in commercial or public places would lead to episodic, intermittent or singular convivial encounters. In these programmes, the ICF (World Health Organization, 2001) elements of activities and place were the means for facilitating positive social interactions.

Craig and Bigby (2015) described the case study of Helen who participated in many shared activities as part of a cooking group, primarily comprised of older men, who accepted her and interacted with her in a friendly way. Not all of the case studies described in this article involved this type of shared activities, or acceptance or warm interactions by group members. Craig and Bigby (2015) identified *active participation* (which broadly equates with convivial encounter) as occurring only when the person with intellectual disability had equal membership status in the group, participated in mutually rewarding activities and worked cooperatively with other members towards a common goal, and where the group utilized advice about supporting access for people with disability. The four articles about various aspects of the TTR programme described very similar types of participation by individuals with intellectual disability in community groups or as volunteers in organizations. A common feature of these programmes was that the person with intellectual disability did not join the group with a peer or small group of other people with intellectual disability.

The strategies employed to facilitate participation were described in the action research project reported by Craig and Bigby (2015). Individual support was given to individuals with moderate intellectual disability to join and participate in a community group that reflected an understanding of their interests. Support extended beyond face-to-face work with the individual including scanning the community for groups for their potential participation, negotiation with group leaders about initiation and ongoing attendance, as well as training and advice to group members. A similar approach was used, though with a participant group with milder levels of intellectual disability, in the TTR programme (Bigby et al., 2014; Stancliffe et al., 2015). This programme was targeted at older workers in a supported employment setting and had a clearly articulated set of processes which are described as, “promoting the concept of retirement, laying the groundwork for inclusion

TABLE 2 Summary of evidence about outcomes from reviewed community participation programmes

Type and aims of study	Methodology	Findings	Comments	
Ward et al. (2012)	Document the “treatment fidelity” of the Friendship and Dating Program conducted for 20 sessions, twice per week for 10 weeks, aimed to prevent violence in dating and partnered relationships and teach social skills for healthy relationships for adults with intellectual disability	Mixed methods process evaluation. 31 participants with intellectual disability and 11 facilitators. Self-report completion of measures of Social Networks and Interpersonal Violence and interview	Increase in participants’ social network size. Measure of comprehensiveness showed that agency staff delivered content of the programme successfully with minimal training	Small-scale rigorous study, larger sample size needed for efficacy evaluation
Ward et al. (2013)	Evaluate impact of the Friendship and Dating Program on size of participants’ social networks and incidents of interpersonal violence experienced	Mixed methods process evaluation. 31 participants with intellectual disability and 11 facilitators. Self-report completion of measures of Social Networks and Interpersonal Violence and interview	Increase in size of participants’ social network and reported incidents of interpersonal violence had reduced. Ten-week follow-up post-programme showed increase in network size maintained	Small scale some drop out in completion of post-programme questionnaires. No outcome measure of participants’ knowledge about sexuality, sexual health and healthy relationships
Heslop (2005)	Identify key issues faced by befriending services, factors which may contribute to good practice and make recommendations for future good practice	Qualitative. Interviews and questionnaire with 15 workers from 7 services, and interviews with 34 people with intellectual disability, 42 befrienders and 46 parents/carers from the same 7 services	Many activities engaged in by the participants and their befrienders were home based such as watching a video. Difficulties with the recruitment, training and retention of befrienders. People with intellectual disability had limited choice about nature and frequency of contact with their befrienders	No mention in methodology of how data were analysed, little supporting evidence for conclusions such as qualitatively the services in the study were a good thing
Harlan-Simmons et al. (2001)	Provide stories illustrating the intentional strategies and concerted effort necessary to support creation of community connections and meaningful relationships for people with intellectual disability	Qualitative, longitudinal case study (3 years) using observation and informal interviews with 3 older participants with intellectual disability, family and community members	The community building process made a positive impact on social networks, bringing “a variety of community relationships into their (participants’) lives.” (p. 179)	In-depth case studies findings potential for testing with larger sample

(Continues)

TABLE 2 (Continued)

Type and aims of study	Methodology	Findings	Comments
Lante et al. (2011) Examine the physical and psychosocial benefits of engagement in a programme of physical activity	Mixed methods evaluative case study. 2 participants with intellectual disability. Accelerometer to measure physical activity. Interviews conducted with participants and support staff	Neither participant recorded recommended levels of moderate intensity physical activity. Qualitative data indicated programme gave opportunities for social contact with other gym users and had social/emotional benefits for participants who enjoyed social praise as a result of their engagement	Small-scale case study—little depth to qualitative analysis
Craig and Bigby (2015) Identify the nature and impact of group processes on the active participation of people with an intellectual disability in community groups	Action research and participant observation over 10 months in 5 community groups. 5 participants all aged over 45 years with moderate intellectual disability each in a different community group selected to represent their interests. In-depth field notes of interactions and social processes in groups. Critical realism guided analytical approach used inductive and abductive techniques	3 of the 5 cases met the criteria of active participation; being afforded equal membership status; members working together to achieve common goals around a shared activity. Factors affecting active participation were positive leadership response to inclusion, participants with intellectual disability who had friendly dispositions and relatively good social skills, access and acceptance by the group to expertise about disability, the groups' use of an integrating activity and flexibility and capacity to deal with difference among members	In-depth case studies, theoretically driven, conceptual findings potential for testing with larger sample
Standcliffe et al. (2015) Evaluate the success of the Transition to Retirement programme and its model of active mentoring support for participation in community groups by assessing participants' loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts and work hours before and 6 months after joining a community group	Mixed methods. Two matched groups of 29 participants, most with mild intellectual disability. Self-report and proxy reliable and validated measures: health-related quality of life, UCLA Loneliness Scale, Worker Loneliness Scale (modified), Glasgow Depression Scale, Mini Psychiatric Assessment Schedules for adults with Developmental Disabilities Checklist. Weekly logs of participation and social contact. [linked to Bigby et al., 2014; Wilson et al., 2015, 2013]	Positive outcomes - relative to pre-test. Six months post-test intervention participants had made significant gains in terms of making new inclusive social contacts, spending time with new acquaintances, participating for more time in mainstream community activities and reducing their weekly work hours as planned	Small-scale but rigorous design
Bigby et al. (2014) Describe the programme logic and implementation challenges of the Transition to Retirement programme	Descriptive. Data on implementation process collected for 24 participants in 24 groups or volunteer situations. Data included field notes, filed notes, time logs and minutes of discussions among team members. [linked to Standcliffe et al., 2015; Wilson et al., 2015, 2013]	Logic model described as: promotion of retirement, laying the groundwork, involving identifying appropriate community groups for retirees to join, constructing the reality, involving a person-centred approach to getting individuals involved in the group (being sure of their interests, helping map a new routine for them and supporters, training and supporting mentors in the group and offering ongoing monitoring and additional support was necessary)	Logic model description of Standcliffe et al. (2015)
Wilson et al. (2015) Examine the participation of older men with lifelong disability in community-based Men's Sheds	Mixed methods collective case study. Subset of data from Transition to Retirement Program. [linked to Standcliffe et al., 2015; Bigby et al., 2014; Wilson et al., 2013]	No significant changes from pre- to post-tests in self-reported health-related quality of life measures but significant post-test increase in social satisfaction for those engaged with Men's Sheds. Mentors expressed a willingness to include people with disability in the Shed and also reported that they felt that they had themselves benefitted from being a mentor	Subset of data from Standcliffe et al. (2015)

(Continues)

TABLE 2 (Continued)

Type and aims of study	Methodology	Findings	Comments
Wilson et al. (2013) Explore the experience of being a mentor supporting a previously unknown person with an intellectual disability	Qualitative. Subset of data from Transition to Retirement Study. Interviews with 14 mentors who supported 11 different individuals with intellectual disability in 11 Men's sheds. Analyse using constant comparative approach. [linked to Stancliffe et al., 2015; Bigby et al., 2014; Wilson et al. 2015]	Positive finding re use of mentors to support participation of an individual with intellectual disability in community group or volunteer situation (see main study findings). Mentors trained using the "no different from us" model see past the disability to the person, they are community leaders and offer natural support in the group context. Mentors self-selected so may have already held positive attitudes about the inclusion of people with intellectual disability	Subset of data from Stancliffe et al. (2015)
Tedrick (2009) Explore the meaning and benefits of participation in Special Olympics for people with intellectual disability, and analyse the impact of age-related change on the athletes and their parents	Qualitative case study. Three participants with intellectual disability aged over 65 years and their parents	Participants developed sports skills and fitness, described having enhanced self-esteem, having met a lot of others through Special Olympics. Some had formed friendships with other participants, acted as mentors. Age-related changes in the athletes may impact on their future participation. Reliance on parents to facilitate involvement meant future participation be limited due to parental ageing or ill health	Small-scale case study - little depth to qualitative analysis
Harada et al. (2011) Describe and compare examples of Special Olympics and Unified Sports programmes in different countries	Descriptive programme data	Three million individuals with intellectual disability in 180 countries participate in Special Olympics programmes and 150,000 people participate in Unified Sports in seven regions. no outcome data, provides a "chance to play sport... be a part of society.. a platform for the development of social relationships..."	Descriptive
McConkey et al. (2013) Evaluate outcomes of the Unified Sports programme across five countries (Serbia, Poland, Ukraine, Germany and Hungary) in terms of participant's personal experiences, impact on social inclusion and processes perceived to enhance social inclusion	Qualitative, phenomenological. Short (average 15 min) individual and group interviews with athletes, partners, coaches, community representatives from 4 teams in each country designed to gather personal experiences and insights into the programme (no information re overall number of participants). Collected on one day to coincide with event	Outcomes included, personal development of athletes and partners, formation of inclusive and equal bonds, alliances with families, schools and community and sports organizations, and broader positive perception of athletes with disability in community. Suggested as impacting on bonding and bridging aspects of social capital	Weak design, re sampling, data collection and no information re participant numbers or characteristics
Darragh et al. (2016) Examine the impact of participating in the Tutti Arts day programme on the social and emotional well-being of young adult participants with intellectual disability	Qualitative. Five participants with intellectual disability aged between 21 and 27, purposively sampled. Semi-guided interviews with participants, family members, support workers Thematic analysis	Participants felt happier and more confident. Enjoyed activities, public approbation for their work, had developed friendships with others at the group which meant participation had expanded individual social networks	Small-scale descriptive study

(Continues)

TABLE 2 (Continued)

Type and aims of study	Methodology	Findings	Comments
Stickley et al. (2012) Describe the effects upon people who are engaged with arts programme	Qualitative, ethnographic Interviews, focus groups, observations. 50 participants over 2 years. Six participants, 3 artists/facilitators, 4 support workers, 3 organizers and 20 family & friends of participants interviewed	Personal and group benefits, greater confidence, development of relationships with other participants, increased in confidence and self-esteem. Increased interactions with community members, for example, with local college students who filmed the group	In-depth qualitative evaluative study
McClimens and Gordon (2009) Determine the utility of "blog-related technology" for people with intellectual disability, to increase social capital of participants and relationships	Qualitative. Used Social Capital Question Bank as basis for focus group with participants. Document analysis of on line blogs Adults with intellectual disability and varying levels of literacy and keyboard skills	Participants found social activity generated around the blogging exercise valuable rather than blogging per se which was concluded has "little do with social capital" (p. 28)	Exploratory, few details re participants or data collection and analysis

of would-be retirees with intellectual disability in the community, and constructing the reality. The third component comprised five stages: planning, locating a group, mapping a new routine, recruiting and training mentors, and monitoring and ongoing support" (Bigby et al., 2014; p. 117). A key feature was active mentoring, developed from person-centred active support and co-worker support (Wilson et al., 2013), and utilized to ensure not only presence in the group but the occurrence of convivial encounters between the individual and group members. Active mentoring aimed to ensure provision of the right type and amount of individual support to enable the individual with intellectual disability to participate in the group. It involved identifying one or more volunteers from the group, and training them to use active support to help pinpoint group activities the person with intellectual disability might participate in, facilitate their engagement in activities and support social interaction with other group members. This approach was illustrated in Men's Sheds (Wilson et al., 2015) and a wide range of community groups and volunteering situations (Bigby et al., 2014; Stancliffe et al., 2015). Mentors are reported to have had positive experiences of this role, demonstrating the reciprocity that can occur when people with intellectual disability participate in community groups (Wilson et al., 2015). Significantly, however, as already described, in both these programmes, the support provided for participation extended well beyond individual face-to-face support provided in the group, either by the supporter (Craig & Bigby, 2015) or by the mentor (Stancliffe et al., 2015).

Places more anonymous than community groups, where people with intellectual disability may be known or recognized, were the site of the shorter convivial encounters described by Bigby and Wiesel (2015). This study investigated the support to people with intellectual disability in shops and other public facilities provided by direct support staff attached to accommodation services. It identified the nuanced judgements and skills involved in support that facilitated convivial encounters between people with intellectual disability and community members, and the way staff actions have the potential to facilitate and obstruct encounters.

The final article exemplifying this type of conceptualization was a case study of two people supported to participate in an exercise programme in a community gym (Lante et al., 2011). By locating the programme in a public facility, the programme aimed—in addition to providing physical and psychosocial benefits of engagement in physical activity to participants—to provide opportunities for social interaction with other gym users with and without intellectual disability.

3.1.3 | Community participation as a valued sense of belonging and identity

Five programmes represented Hall's (2013) conceptualization of community participation, as a sense of belonging to proximate or distant others. The theory of change informing these programmes was that participation in certain types of activities would create new identities such as artists, craftspeople, singers, actors or athletes for people with intellectual disability, and consequential opportunities for social interactions with peers as well as people without disability who may

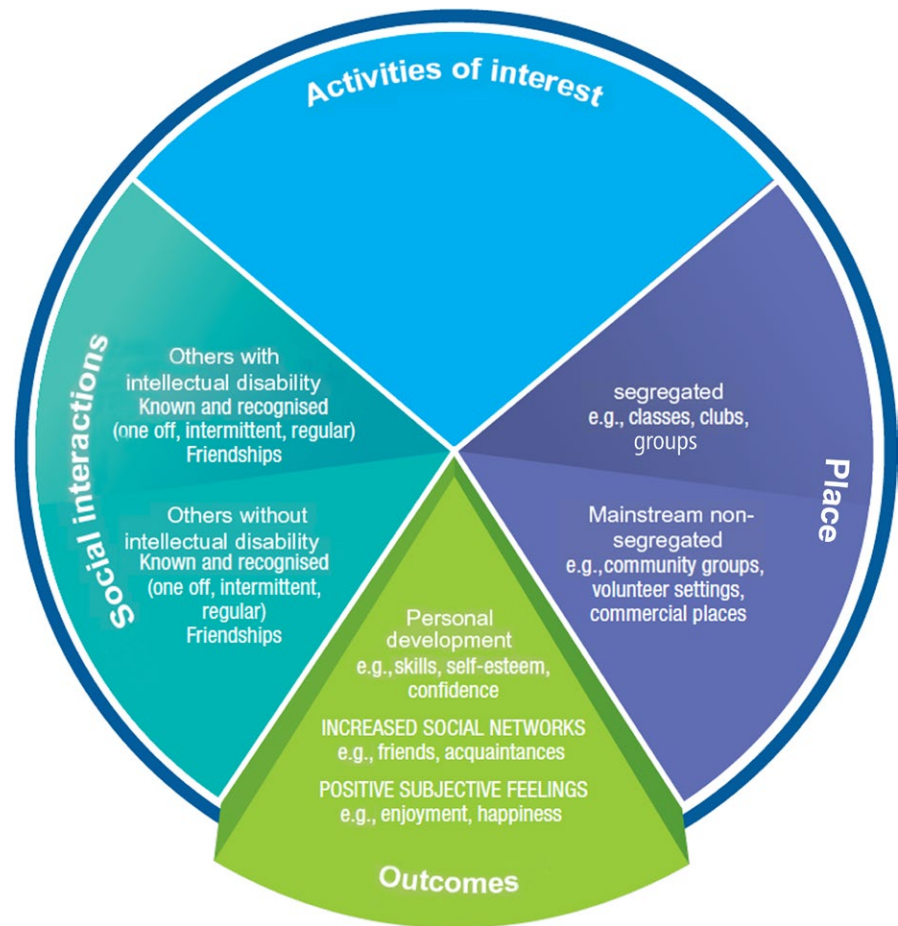


FIGURE 1 Heuristic of components and outcomes of community participation

have similar interests, be members of an audience or purchasers of artworks. The two most common types of activities were associated with the arts or sport, and one programme involved blogging. The ICF (World Health Organization, 2001) element of activities was prominent in these programmes, place was less important and often segregated, while social interaction was seen as the beneficial consequence of engagement in activities and the derived sense of belonging or new identity.

Similar arts programmes were described by Darragh et al. (2016) and Stickley, Crosbie, and Hui (2012). Both offered “day options” for young adults with an intellectual disability as an opportunity to engage in art and music-based activities. Tutti Arts, for example, aimed to “provide opportunities for artists with intellectual disabilities to create visual art and engage in theatre and drama and to make music.” (Darragh et al., 2016, p. 2). A central strategy of both programmes was the creation of a segregated group that enabled participants to develop artistic skills. Parallel strategies were to develop external connections to other artists or the public that enabled creative work to be exhibited or sold, and or brought participants into contact with others, often without intellectual disability with similar interests. For example, the location of the programme described by Stickley et al. (2012) in a disused cinema gave scope for interaction with students from the local area who filmed some of the activities.

The three sport-centric programmes had similar intent and strategies to the arts programmes. Harada, Siperstein, Parker, and Lenox

(2011) described two international programmes. The first, Special Olympics, ran groups and competitive events for athletes with intellectual disabilities often alongside mainstream events. The other, Unified Sports programmes, aimed to include people with intellectual disabilities in community sports teams where they trained and competed alongside peers without intellectual disability, known as “partners.” Both programmes have very large numbers of participants and offer opportunities to play sport as well as “to be a part of society” (p. 1142).

Tedrick's (2009) case study of three older participants in Special Olympics programmes demonstrates the potential benefits of this type of programme for all ages. McConkey, Dowling, Hassan and Menke's study (2013) offers insights into strategies used by Unified Sports programmes, such as “pairing” athletes with and without disabilities, and development of alliances with local sporting clubs and facilities, to create a sense of identity and provide opportunities for socializing with other sports people.

Based on a different type of activity, McClimens and Gordon (2009) described a programme aimed to create new identities for people with intellectual disability in the online world as bloggers. Participants were supported to develop blogging skills by students who acted as trainers. The programme was situated in a mainstream place (a university), but the group could be considered segregated as it comprised solely people with intellectual disability. Nevertheless, the activity of blogging and the identity of blogger subsequently formed was a potential social

role that, like sportsperson or artist, could be adopted by anyone in society.

3.1.4 | Summary of approaches to community participation

As Table 1 shows, each programme adopted one of three dominant conceptualizations of community participation and differing strategies for achieving its goals. Importantly, however, the common threads of community participation were also evident in each. As Table 1 and Figure 1 show, these programmes illustrated the differing ways that the ICF (World Health Organization, 2001) components of activities, place and social interaction were constructed, combined and given varying degrees of prominence. For example, the TTR programme prioritized place (mainstream community groups) and activities (based on individual interest) and sought pleasant social interactions in a community group where the person was known and recognized as an individual, rather than longer-term friendships. The same three components are present but emphasized differently in the Tutti Arts programme which prioritized participation in activities (with the potential to lead to a new social identity and valued role as an artist). Less important for this programme were place, which was segregated, and social interaction, which was usually with other people with intellectual disability and intermittently with others without intellectual disability who had a shared interest in art.

3.2 | Programme outcomes

Overall, as Table 2 shows, studies of community participation programmes have been predominantly small scale and qualitative and produced little robust evidence about outcomes, programme effectiveness or detailed descriptions of the programme logic or costs. Some of the general positive claims about outcomes made in these articles were not backed up by data (Harada et al., 2011; Heslop, 2005; McConkey et al., 2013). For example, the statement by Heslop (2005, p. 33) that “qualitatively the services in the study lived up to their reputation as being a good thing” was not supported by evidence about the success of achieving its aim of developing friendships between people with and without intellectual disability. Despite the differing conceptualizations of community participation and strategies adopted, outcomes were commonly framed in terms of personal development such as skills, self-esteem or confidence, increased social networks and subjective experiences such as enjoyment or happiness.

Several in-depth qualitative studies described both positive outcomes, and the concepts and processes underpinning these, providing a sound basis to scale up the programme or intervention and conduct larger more rigorous outcome studies (Bigby & Wiesel, 2015; Craig & Bigby, 2015). In two of the five case studies described by Craig and Bigby (2015), the participant was judged to be actively participating, regarded as an equal and a welcomed member of the group. These authors identified five influential social processes in these cases: positive leadership response to inclusion; participants with intellectual

disability who had friendly dispositions and relatively good social skills; acceptance by the group of advice about including a person with disability; the existence of an integrating activity, and flexibility and capacity to deal with difference among members (see Craig, 2013 for further details). These factors require further investigation and could be further tested in demonstration initiatives with other non-segregated community groups.

The practices that supported convivial encounters described by Bigby and Wiesel (2015) were very similar to those used in person-centred active support which is an enabling relationship between a person with intellectual disability and a supporter that facilitates engagement in meaningful activities and social relationships (Mansell & Beadle-Brown, 2012). There is significant evidence about the positive effects of active support on engagement of people with intellectual disability but the vast majority of research has been conducted in group home settings focussed on domestic rather than community arenas (Bigby & Beadle-Brown, 2016). Further research on the nature and effectiveness of this approach to practice in public or community places would help to identify the challenges and difficult judgements involved in providing this type of support in the community and ways in which practice might need to be adapted for various types of place.

The strongest design was the mixed methods, matched group approach used by Stancliffe et al. (2015) which, though small scale, provided positive evidence about outcomes for individual programme participants and perspectives from mentors involved in supporting participation. The collection of articles about the TTR programme provides insights into both the overall programme logic and the practices used within groups to support individual participation (Bigby et al., 2014; Stancliffe et al., 2015). This programme was focussed on the transition of older workers into retirement, but there is no reason why this approach to supporting participation in community groups could not be applicable to younger people, given that the initial phases of the intervention aim to understand individual preferences and seek out groups with activities that align with these.

The Special Olympics and Unified Sports programmes are large-scale international programmes offering opportunities for people with intellectual disabilities to train for, and compete in athletic events. The studies of these programmes, however, have weak methodologies and provide little evidence to substantiate claims that they provide; “access to the community” or “develop social relationships with their teammates which often carry over into their lives off the playing field” (Harada et al., 2011, p. 1135–1136).

Although many of the programmes aimed to have both proximal and distal outcomes (immediate and longer-term consequential outcomes), there was little evidence of the latter. For example, interviewees observed that Tutti (a segregated arts programme in a mainstream place, Darragh et al. 2016) offered opportunities for engagement in meaningful and purposeful activities, created the chance for participants to assume valued roles as artists and, through performance opportunities, to receive public accolades. However, there was little evidence about more distal outcomes such as increased opportunities for social interactions or convivial encounters with community members without disability.

Outcomes of the programme described by McClimens and Gordon (2009) were a little different from those intended. While the programme sought to create identities for the participants as bloggers, a lack of "social capital" (described as the background characteristics of poor education, youth, and low wealth) made this difficult. The university environment, however, offered participants activity in a non-segregated place where they felt comfortable. There was also some evidence of the positive interactions with student trainers. Although it was not a central intention, this programme created opportunities for intermittent convivial encounters in a mainstream place, connected to attendance at the activity rather than a new identity as a blogger or friendships.

The studies by Ward et al. (2012, 2013) suggest the Friendship and Dating programme successfully led to more social relationships for participants with other people with intellectual disability, although there are no data about the durability or quality of these friendships. Similarly, there are few data about the relationships formed between people with and without intellectual disabilities supported by the befriending or community connections programmes (Heslop, 2005; Ward et al., 2012, 2013).

4 | DISCUSSION

The aim of this review was to identify promising interventions or programmes that support community participation of people with intellectual disability. In order to understand the nature of these programmes, the analysis sought to identify the assumptions made about the nature of community participation and the theory of change that informed programme design and strategies. The 13 programmes represented examples of the three dominant ways of conceptualizing community participation found in the broader literature reviewed in the first part of this paper, as social relationships (O'Brien & Lyle, 1987), as convivial encounter (Bigby & Wiesel, 2011) and as belonging (Hall, 2013). The differing designs and strategies employed by these programmes illustrate the diversity, both of approaches to community participation and its manifestation for individuals. The common threads of community participation were also evident, and the review has illustrated the differing ways that the ICF (World Health Organization, 2001) components of activities, place and social interaction were constructed, combined and given varying degrees of prominence in these programmes. Figure 1 is a useful heuristic for understanding the design of community participation programmes and generating discussion about the possible features and relative importance of each of the three components—activities, place and social interactions. It may help to avoid binaries such as presence and participation, and judgements that prioritize mainstream places and relationships between people with and without disabilities. The heuristic also captures the way programme outcomes were reported in the articles. In the main, these were subjectively, cast in terms of feelings of happiness or enjoyment, or changes to the individual in terms of skills development, self-esteem, confidence or increased social networks.

These findings reinforce the diversity of experiences that might be described as instances of community participation. They also highlight the importance of a person-centred approach in thinking about and supporting community participation for a person with intellectual disability, one that takes into account their individual preferences and choice. Individuals will combine the three components differently, perhaps emphasizing one more than others and preferring different types of place or social interactions. Importantly, one individual may seek out different types of community participation, piecing them together into a regular routine. For example, an individual could have membership of a segregated art group, participation in a bike riding club run at the local community centre, and a monthly pub meal with a group of friends with intellectual disability. Figure 1 might also be a useful tool for discussing with an individual their preferences about community participation or the different types of experiences that various programmes might offer them.

This review demonstrates the relatively small body of evidence pertaining to the design and effectiveness of programmes to support community participation. It has identified some promising approaches, particularly in the series of studies describing the use of active mentoring (Stancliffe et al., 2015), active participation in community groups (Craig & Bigby, 2015), facilitative support worker practices (Bigby & Wiesel, 2015), community builders (Harlan-Simmons et al., 2001) and the arts-based programme described by Stickley et al. (2012). The findings about the efficacy of these programmes, and the availability of well-described programme logics, though not so with respect to cost, suggest there is the potential for replication, larger-scale implementation and conduct larger more rigorous outcome studies.

These studies are also beginning to describe the type of microlevel practices, such as active support and active mentoring, as well as the need for skills such as locating and analysing social contexts such as community groups that are likely to be required of staff who work in community participation programmes. Importantly, some studies also illustrate the broader set of tasks involved in community participation programmes that do not involve face-to-face contact with the individual but are needed to build the foundations for their participation with a group or a person's support network. Language such as "individualized" or "person-centred" runs the risk of rendering invisible hidden tasks of interventions to support community participation such as identifying and evaluating groups with the potential to accept a person with intellectual disability as an equal member. Tasks such as these are connected to supporting a particular individual to participate rather than preparing the community in general, which is the province of broader community development/change type of work.

Nevertheless, these findings illustrate, an individual intervention can be delivered in the context of a programme such as the TTR programme that serves more than one person. This suggests that when investigating the efficacy of interventions to support community participation, attention must be given to microlevel practices and the work associated with the intervention that does not involve direct contact with the individual such as analysis of potential community groups. It also suggests that delivery of individual interventions can be brought together into programmes which, while still offering

individualized support, may enable better client outcomes by providing, on a more collective and economically sound basis, staff training, supervision, sharing of practice wisdom about community places and things such as human resource and accounting functions.

Notably, the findings suggest there is little rigorous evidence about programmes that give prominence to participation in sports-related activities as a means of building new identities and a sense of belonging. This may reflect the limited volume of research or absence of strong research methodologies about this type of programme. The cultural significance of sport as a means of breaking down social and racial barriers for other minority groups such as refugees, apparent in the grey literature and mainstream media sources (BBC, 2016; Human Rights Commission, 2006), suggests the potential of these programme in building a sense of identity and belonging that should be further explored. This is a potential area for further research and perhaps too, the implementation of demonstration programmes accompanied by rigorous evaluation.

The unintended outcomes of the blogging programme described by McClimens and Gordon (2009) suggested the potential of universities as places where convivial encounters between young people with and without intellectual disability could be fostered. Although usually cast in the arena of education rather than community participation, the inclusive higher education programmes found in the USA and Canada that support young people with intellectual disability to monitor classes and match them with student mentors may be worthy of further exploration (Jones & Goble, 2012).

The majority of the programmes identified in this review were not designed to fill people's days or provide respite care for parents or carers as had often been the case for more traditional day centres in the past (Bigby, Fyffe, Balandin, Gordon, & McCubbery, 2001). Rather, they offered support for singular, intermittent or regular but relatively short episodes of community participation, which may also have acted as a catalyst for further opportunities outside of the programme. Understanding more about programmes that effectively support community participation may help to tackle some complex questions, such as how to fill the daytime lives of people with intellectual disability who do not work; replace full-time attendance at day programmes/centres; or what constitutes a meaningful ordinary life of a person with intellectual disability. Such questions are particularly pressing for people with higher and more complex support needs for whom supported paid work may never be an option that society is willing to fund. These issues, however, are much broader and should not be confounded with understanding ways to support community participation.

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REFERENCES

- Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self-esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community & Applied Social Psychology*, 12(6), 430–443.
- Ager, A., Myers, F., Kerr, P., Myles, S., & Green, A. (2001). Moving home: Social integration for adults with intellectual disabilities resettling into community provision. *Journal of Applied Research in Intellectual Disabilities*, 14, 392–400.
- van Alphen, L. M., Dijker, A. J., van den Borne, B. H., & Curfs, L. M. (2010). People with intellectual disability as neighbours: Towards understanding the mundane aspects of social integration. *Journal of Community & Applied Social Psychology*, 20, 347–362.
- Amado, A. (2014). Building relationships between adults with intellectual disabilities and community members: Strategies, art and policy. *Research and Practice in Intellectual and Developmental Disabilities*, 1, 111–122.
- Amado, A., Stancliffe, R., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, 51, 360–375.
- Anderson, S., & Bigby, C. (2017). Self-advocacy as a means to positive identities for people with intellectual disability: 'We just help them, be them really'. *Journal of Applied Research in Intellectual Disabilities*, 30, 109–120. <https://doi.org/10.1111/jar.12223>
- Andrews, J., Leonard, H., Hammond, G. C., Girdler, S., Rajapaksa, R., Bathgate, K., & Downs, J. (2014). Community participation for girls and women living with Rett syndrome. *Disability and Rehabilitation*, 36(11), 894–899.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Research Methodology*, 8, 19–32.
- Bates, P., & Davis, F. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability & Society*, 19, 195–207.
- BBC (2016). Rio Olympics 2016: Refugee Olympic team competed as 'equal human beings'. Retrieved from <http://www.bbc.com/sport/olympics/37037273>
- Beadle-Brown, J., Bigby, C., & Bould, E. (2015). Observing practice leadership in intellectual and developmental disability services. *Journal of Intellectual Disability Research*, 59, 1081–1093.
- Beart, S., Hawkins, D., Kroese, B. S., Smithson, P., & Tolosa, I. (2001). Barriers to accessing leisure opportunities for people with learning disabilities. *British Journal of Learning Disabilities*, 29(4), 133–138.
- Bigby, C. (2012). Social inclusion and people with intellectual disability and challenging behaviour: A systematic review. *Journal of Intellectual and Developmental Disability*, 37(4), 360–374.
- Bigby, C., & Beadle-Brown, J. (2016). Improving quality of life outcomes in supported accommodation for people with intellectual disability: What makes a difference? *Journal of Applied Research in Intellectual Disabilities*. <http://onlinelibrary.wiley.com/doi/10.1111/jar.12291/full>
- Bigby, C., Bould, E., & Beadle-Brown, J. (2016). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual and Developmental Disability*. <https://doi.org/10.3109/13668250.2016.1253051>
- Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 363–376.
- Bigby, C., & Fyffe, C. (2010). More than community presence: Social inclusion for people with intellectual disability. *Proceedings of the fifth annual roundtable on intellectual disability policy*, 3–11. La Trobe University, Bundoora.
- Bigby, C., Fyffe, C., Balandin, S., Gordon, M., & McCubbery, J. (2001). *Day support services options for older adults with a disability*. Melbourne, Vic.: National Disability Administrators Group.

- Bigby, C., & Wiesel, I. (2011). Encounter as a dimension of social inclusion for people with intellectual disability: Beyond and between community presence and participation. *Journal of Intellectual and Developmental Disability*, 36, 263–267.
- Bigby, C., & Wiesel, I. (2015). Mediating community participation: Practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 28, 307–318.
- Bigby, C., Wilson, N., Stancliffe, R., Balandin, S., Craig, D., & Gambin, N. (2014). An effective program design to support older workers with intellectual disability to participate individually in community groups. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 117–127.
- Bredewold, F., Tonkens, E., & Trappenburg, M. (2016). Urban encounters limited: The importance of built-in boundaries in contacts between people with intellectual or psychiatric disabilities and their neighbours. *Urban Studies*, 53(16), 3371–3387. <https://doi.org/10.1177/0042098015616895>
- Clement, T., & Bigby, C. (2009). Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 22, 264–275.
- Clement, T., & Bigby, C. (2011). The development and utility of a program theory: Lessons from an evaluation of a reputed exemplary residential support service for adults with severe intellectual disability and challenging behaviour in Victoria, Australia. *Journal of Applied Research in Intellectual Disability*, 24, 554–565.
- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action*, 2, 75–84.
- Commonwealth of Australia (2011). *2010–2020 National Disability Strategy*. Canberra: Commonwealth of Australia.
- Craig, D. (2013). "She's been involved in everything as far as I can see". *Supporting the active participation of people with intellectual disabilities in community groups*. Unpublished doctoral dissertation, La Trobe University, Bundoora, Australia.
- Craig, D., & Bigby, C. (2015). "She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disability in community groups. *Journal of Intellectual & Developmental Disability*, 40, 12–25.
- Cummins, R., & Lau, A. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16, 145–157.
- Darragh, J., Ellison, C., Rillotta, F., Bellon, M., & Crocker, R. (2016). Exploring the impact of an arts-based, day options program for young adults with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 3, 22–31.
- Disability Services Act 1986 (Cwth). Austl.
- Dusseljee, J., Rijken, P., Cardol, M., Curfs, L., & Groenewegen, P. (2011). Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research*, 55, 4–18.
- Fincher, R., & Iveson, K. (2008). *Planning and diversity in the city: Redistribution, recognition and encounter*. Basingstoke: Palgrave Macmillan.
- Frawley, P., & Bigby, C. (2015). Reflections on being a first generation self-advocate: Belonging, social connections, and doing things that matter. *Journal of Intellectual and Developmental Disability*, 40, 254–264.
- Funnell, S., & Rogers, P. (2011). *Purposeful program theory: Effective use of theories of change and logic models*. Hoboken, NJ: John Wiley & Sons.
- Gray, K., Piccinin, A., Keating, J., Taffe, J., Parmenter, T., Hofer, S., ... Tonge, B. (2014). Outcomes in young adulthood: Are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*, 8, 734–745.
- Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(Suppl 1), 48–57.
- Hall, E. (2013). Making and gifting belonging: Creative arts and people with learning Disabilities. *Environment and Planning A*, 45, 244–262.
- Harada, C., Siperstein, G., Parker, R., & Lenox, D. (2011). Promoting social inclusion for people with intellectual disabilities through sport: Special Olympics International, global sport initiatives and strategies. *Sport in Society*, 14, 1131–1148.
- Harlan-Simmons, J., Holtz, P., Todd, J., & Mooney, M. (2001). Building social relationships through valued roles: Three older adults and the community membership project. *Mental Retardation*, 9, 171–180.
- Heslop, P. (2005). Good practice in befriending services for people with learning difficulties. *British Journal of Learning Disabilities*, 33, 27–33.
- Human Rights Commission (2006). *What's the score? A survey of cultural diversity and racism in sport in Australia*. Retrieved from <https://www.humanrights.gov.au/our-work/race-discrimination/publications/whats-score>
- Jones, M., & Goble, Z. (2012). Creating effective mentoring partnerships for students with intellectual disabilities on campus. *Journal of Policy and Practice in Intellectual Disabilities*, 9, 270–278.
- Lante, K., Walkley, J., Gamble, M., & Vassos, M. (2011). An initial evaluation of a long-term, sustainable, integrated community-based physical activity program for adults with intellectual disability. *Journal of Intellectual and Developmental Disability*, 36, 197–206.
- Laurier, E., & Philo, C. (2006). Possible geographies: A passing encounter in a café. *Area*, 38, 353–363.
- Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley.
- Mansell, J., Beadle-Brown, J., Whelton, B., Beckett, C., & Hutchinson, A. (2008). Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 398–413.
- McClimens, A., & Gordon, F. (2009). People with intellectual disabilities as bloggers: What's social capital got to do with it anyway? *Journal of Intellectual Disabilities*, 13, 19–30.
- McClimens, A., Partridge, N., & Sexton, E. (2014). How do people with learning disability experience the city centre? A Sheffield case study. *Health & Place*, 28, 14–21.
- McConkey, R., Dowling, S., Hassan, D., & Menke, S. (2013). Promoting social inclusion through Unified Sports for youth with intellectual disabilities: A five-nation study. *Journal of Intellectual Disability Research*, 57, 923–935.
- Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24, 47–62.
- National Disability Insurance Scheme (NDIS) (2013). Act 2013 (Cth). Austl.
- O'Brien, J., & Lyle, C. (1987). *A framework for accomplishment*. Decatur, GA: Responsive Systems Associates.
- Overmars-Marx, T., Thomése, F., Verdonschot, M., & Meininger, H. (2014). Advancing social inclusion in the neighbourhood for people with an intellectual disability: An exploration of the literature. *Disability & Society*, 29, 255–274.
- Parliament of Australia (2016). *The National Disability Insurance Scheme: A quick guide*. Retrieved from http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/DisabilityInsuranceScheme
- Power, A. (2013). Making space for belonging: Critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion. *Social Science & Medicine*, 88, 68–75.
- Ratti, V., Hassiotis, A., Crabtree, J., Deb, S., Gallagher, P., & Unwin, G. (2016). The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, 57, 63–84.
- Reidy, R., Sweris, H., & Bigby, C. (2010). Increasing social inclusion in local settings: priorities for disability policy. *Proceedings of the fifth annual roundtable on intellectual disability policy*, pp. 52–57. La Trobe University, Bundoora.

- Rogers, E. (2003). *Diffusion of innovations* (5th ed.). New York, NY: Free Press.
- Rossi, P., Lipsey, M., & Freeman, H. (2004). *Evaluation: A systematic approach* (7th ed.). New York, NY: Sage Publications.
- Simons, K., & Watson, D. (1999). *New Directions? Day services for people in the 1990's: A review of the research*. Exeter: Centre for Evidence-based Social Services.
- Simplican, C. S., & Leader, G. (2015). Counting inclusion with Chantal Mouffe: A radical democratic approach to intellectual disability research. *Disability & Society*, 30, 717–730.
- Simplican, S., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, 38, 18–29.
- Simpson, M. K. (2007). Community-based day services or adults with intellectual disabilities in the United Kingdom: A review and discussion. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 235–240.
- Sinason, V. (1992). *Mental handicap and the human condition: New approaches from the Tavistock*. London: Free Association Press.
- Southby, K. (2013). Social inclusion through football fandom: Opportunities for learning-disabled people. *Sport in Society*, 16(10), 1386–1403.
- Stancliffe, R., Bigby, C., Balandin, S., Wilson, N., & Craig, D. (2015). Transition to retirement and participation in mainstream community groups using active mentoring: A feasibility and outcomes evaluation with a matched comparison group. *Journal of Intellectual Disability Research*, 59, 703–718.
- Stickley, T., Crosbie, B., & Hui, A. (2012). The Stage Life: Promoting the inclusion of young people through participatory arts. *British Journal of Learning Disabilities*, 40, 251–258.
- Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2016). The close relationships of people with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 29(2), 172–184.
- Tedrick, T. (2009). Growing older in Special Olympics: Meaning and benefits of participation – selected case studies. *Activities, Adaptation & Aging*, 33, 137–160.
- United Nations (2006). *Convention on the rights of persons with disabilities*. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- Verdonschot, M., De Witte, L., Reichrath, E., Buntinx, W., & Curfs, L. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53, 303–318.
- Walker, P. (1995). Community based in not community: The social geography of disability. In S. Taylor, R. Bogdan, & Z. Lutfiyya (Eds.), *The variety of community experience. Qualitative studies of family and community life* (pp. 175–192). Baltimore: Paul H. Brookes.
- Walker, P. (1999). From presence to sense of place: Community experiences of adults with developmental disabilities. *Journal of the Association for Persons with Severe Handicaps*, 24, 3–32.
- Ward, K., Atkinson, J., Smith, C., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities*, 51, 22–32.
- Ward, K., Windsor, R., & Atkinson, J. (2012). A process evaluation of the friendships and dating program for adults with developmental disabilities: Measuring the fidelity of program delivery. *Research in Developmental Disabilities*, 33, 69–75.
- Welsby, J., & Horsfall, D. (2011). Everyday practices of exclusion/inclusion: Women who have an intellectual disability speaking for themselves? *Disability & Society*, 26(7), 795–807.
- Whitaker, A., & McIntosh, B. (2000). Changing days. *British Journal of Learning Disabilities*, 28, 3–8.
- Wiesel, I., Bigby, C., & Carling Jenkins, R. (2013). 'Do you think I'm stupid?': Urban encounters between people with and without intellectual disability. *Urban Studies*, 50, 2391–2406.
- Wilson, N., Bigby, C., Stancliffe, R., Balandin, S., Craig, D., & Anderson, K. (2013). Mentors experiences of using the Active Mentoring model to support older adults with intellectual disability to participate in community groups. *Journal of Intellectual and Developmental Disability*, 38, 344–355.
- Wilson, N., Stancliffe, R., Gambin, N., Craig, D., Bigby, C., & Balandin, S. (2015). A case study about the supported participation of older men with lifelong disability at Australian community-based Men's Sheds. *Journal of Intellectual and Developmental Disability*, 40, 330–341.
- Wolfensberger, W. (1972). *The principle of normalisation in human services*. Toronto, Canada: National Institute on Mental Retardation.
- World Health Organization (2001). *International Classification of Functioning, Disability and Health*. Retrieved from <http://www.who.int/classifications/icf/en/>

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Case Studies of Promising Programs

Five case studies of Australian programs supporting community participation were undertaken to test the applicability of the program typology developed from the literature and to understand more about program design, delivery and outcomes. A case study approach enables an understanding to be gained of the multiple variables and ways in which they combine to achieve particular outcomes. Criteria to select the case studies were: inclusion of at least one of each of the three types of programmatic approaches to supporting community participation identified in the literature; inclusion of a mix of regional, inner and outer urban locations, and; positive perceptions about each of the programs' quality and effectiveness from different sources.

Decisions about the programs included were based on the researchers' own knowledge about programs from previous research, and suggestions from members of the project reference group and consumer advisory group. The data collection methods included observations and interviews with program participants and interviews with staff, and family members of participants, as well as review of program and organisational documents. For each program five program participants were invited to participate based on the advice of the senior program staff. All interviews were transcribed, and observations written into field notes. Data were analysed qualitatively using similar categories for each program that were based on elements of a program logic.

The qualitative data about participant's experiences supported initial perceptions that these programs were enabling good outcomes for participants. Data about program and unit costs was not comprehensive, as for some organisations this is commercial in confidence and there are also likely uncalculated cross subsidies between programs within delivery organisations. At the time of writing, funding mechanisms and prices are changing as the NDIS is being implemented, and organisations' program costs as well as accounting systems are in a state of flux.

The study received ethics approval from the LaTrobe Human Research Ethics committee, and all participants gave informed consent, or in the case of observations of people with more severe intellectual disabilities, consent was given by the person who usually makes decisions with them. Data were collected during 2017 and checked for accuracy at the end of 2017. Drafts of the case study were shared with senior personnel in each organisation and errors of fact or omission corrected. Organisations were given the

choice of being identified or remaining anonymous. The senior staff member from each organisation agreed to their organisation being identified. Nevertheless, the names of all informants have been changed so that individuals are not identified.

A one page description of the key program dimensions and a program logic diagram was prepared for each program. A longer descriptive piece of approximately 5000 words was written for each program setting out key characteristics and components of the program logic. Table 1 summaries the 5 case study programs, and the next sections include the summary and detailed write up of each one.

Table 1 Primary conceptualisation of community participation and nature of ICF domains of each program

	Gig Buddies	Melba	Shepparton	Arts Project	Spiders
Primary conceptualisation	Social relationships	Convivial encounter	Convivial encounter	Belonging and identity	Belonging and identity
Primary Strategy	Recruitment of buddies, and matching for shared likes and interests of person with intellectual disability with person without disability.	Creation of tailored mixture of daytime activities and engagement in specific tasks in collaboration with groups and organisations in the locality that maximise social interaction with others and reciprocity.	Creation of tailored mixture of daytime activities with an element of interaction with community members, also skill development, supported voluntary work with broader goal of paid work and greater independence	Support to create, display and sell pieces of art.	Creation of opportunities to belong to an active football club with a distinct identity and associated social activities
Activities	Interest-related activities in the context of matched relationships or as part of a bigger groups organised by the program.	Skills training, sport, group activities such as cooking, food distribution with peers or others in locality, individual activities as part of social enterprises or micro businesses.	Skills training, sport, group activities such as cooking, food production with peers or others in locality, individual activities, as part of social enterprises, micro businesses or paid employment	Create, display and sell pieces of art	Training and playing football, social activities, social skills training
Place	Mainstream community places	Locality based. Mixture of segregated and mainstream community places.	Locality based. Mixture of segregated and mainstream community places.	Segregated and some mainstream community places	Mainstream community places
Social interaction	Fleeting and convivial encounters and friendships with matched volunteer, peers and others involved in the program and at mainstream venues.	Fleeting and convivial encounters with peers and others without disabilities in the local community.	Fleeting and convivial encounters with peers in the program, and people with and without disabilities in the local community. Friendships with peers.	Fleeting and convivial encounters with peers in the program, artists and the wider arts community. Friendships with peers.	Fleeting and convivial encounters with peers in the program, and people without disabilities such as committee members, volunteers, players family members and others interested in football. Friendships with peers.

Gig Buddies – summary model of community participation

Theory of change

Matching people with intellectual disabilities with volunteers with similar interests will provide opportunities for friendship, expanding their social networks and participating in activities and making choices about their social lives.

The primary conceptualisation of community participation is about building and supporting social relationships.

Place

Gig Buddies group and pair activities take place in a wide range of non-segregated settings such as at sports events, concerts, gigs and the cinema.

Activities of interest

Gig Buddies enables people to attend social activities that reflect their interests. This may be music, theatre, sporting or more informal social events in private homes or restaurants. They may go in pairs or with a larger group of participants in the program who are people with and without intellectual disabilities.

Social interactions

Participants have regular opportunities to interact with their matched volunteer as well as other program participants with and without intellectual disabilities, and others who are present at the events or venues they attend.

Outcomes

Participants develop friendships with the volunteer they are matched with and experience convivial or fleeting encounters with people without intellectual disabilities. They enjoy going out either in a group or with their volunteer and develop social skills and competence.

Logic model: Gig Buddies

Theory of change: Matching participants with volunteers with like interests will increase participants' opportunities for expanding their social networks and participating in activities and making choices about their social lives.

Inputs/Resources

Local government funding
Grants, donations
Sponsorship
Pro bono services
Staff 2.5 EFT, volunteer interns
Staff meetings
Database of volunteers and participants
Training for volunteers
Participant Advisory Group
Social media resources
Gig Buddies merchandise
NDIS costing 3 hours per month per participant @ \$57.71
Typical participation 2-3 hours a month after hours.
45 matched pairs and 190 unmatched volunteers and potential participants

Program Components

Screening applicants and volunteers
Matching gig buddies with volunteers
Supporting volunteers
Organising program wide events
Negotiation with sponsors

Outputs

Shared activity and social interaction at mainstream venues with matched volunteer
Participation in social events and social interactions with other program participants and the general public in mainstream venues.

Outcomes

Friendships, convivial or fleeting encounters with people without intellectual disability.
Enjoyment
Social and independence skills development.

Context: A befriending organisation designed to facilitate pairings between those with intellectual disabilities with volunteers for the purpose of participating in social activities.

Detailed Case Study: Gig Buddies

Gig Buddies was established in Sydney in 2015. It is managed by Assisted Community Living (ACL), a not-for-profit organisation that supports people with intellectual disabilities who live independently or in shared supported accommodation. The Gig Buddies office is co-located with ACL in an inner suburb of Sydney.

Gig Buddies matches volunteers with people with intellectual disabilities (gig buddies) in order to support the development of friendships through sharing activities of mutual interest; primarily attendance at music or sporting events. It also runs social events to which matched pairs and unmatched volunteers and potential gig buddies are invited. Participants range in age from late teens to sixties, despite the initial belief that participants would be mainly comprised of young people. They have mild or moderate intellectual disabilities, reflecting the client group of ACL. It is estimated that 75% of participants do not need personal care, and most live with family members. There are no rules about eligibility, but staff were unsure about whether the program would be viable for people with higher support needs.

In an ideal world you would include everybody, and there have been times where we've had to say if there's no communication, it makes it really hard. Because one thing we say to volunteers is we don't ever want you to be a support worker, because that changes the relationship. The relationship is a friendship. (David, staff)

The program employs two full time staff and a part time staff member (25hrs). The 2015 annual report indicated there were 45 pairs, and at the time that data were collected (February 2017) there were 190 volunteers and 190 participants who were waiting to be matched.

The program is modelled on the UK Gig Buddies program that operates in south eastern coastal towns and in Scotland, the purpose of which is to give adults with intellectual disabilities an opportunity to enjoy the same kind of nightlife that their peers without disabilities enjoy.

Gig Buddies is funded by grants from the City of Sydney but anticipates that in the future funding will come from individualised NDIS packages of participants.

This case study is based on data obtained from semi-structured interviews with five participants; four matched volunteers and one prospective volunteer; three parents of participants and a support worker who knew a participant well; four staff members and a board member. Observations were also undertaken at a music event organised by the

program, an advisory group meeting and a volunteer training session. Program documents such as annual reports were reviewed. All names have been changed to ensure confidentiality. Tables 1 and 2, in the appendix, summarise the characteristics and quality of life indicators for these five participants. Notably, their scores on part 1 of the Adaptive Behaviour Scale ranged from 173-289, where a score of 151 or below is indicative of a more severe level of intellectual disability.

Aims

The principles that underpin the program are those of the original UK Gig Buddies, to provide people with intellectual disabilities with: increased meaningful participation in various cultural activities and gigs; improved opportunities and capacity to make their own choices about how they lead their lives, and; opportunities for developing informal support networks and friendships in their communities.

Gig buddies and volunteers conceptualised the program as both revolving around doing fun things and being an easy concept to relate to. It was also seen as flexible from the perspective of volunteers.

When you break it down, it's simply about two people going to have some fun and getting to know each other and getting the other person out into the world and getting to do stuff that they might not get to do otherwise. It's just the ease of it. I love that I can just text [participant's] mum and just say, 'Hey, what is [participant's] week looking like next week. Let me know and I'll book something then'. I don't have to jump through hoops or, like, regulation. (Kim, volunteer)

Inputs

The program was originally funded by \$20,000 grant from the City of Sydney, which has been followed by further small grants and donations. In the first nine months of 2017 it has received \$63,874 in grants and donations. It is sponsored by several organisations such as the Cronulla Sharks Football Club and the Sydney Festival from which it receives subsidised tickets for events. The program also receives pro bono legal and business services from other companies. The overhead costs are covered by ACL and the building is leased. In the future, the program is likely to be funded through participants' individual NDIS packages. Support from the program fits under the NDIS category of 'increased social and community participation' and an item about establishing volunteer assistance which is costed at \$57.71 an hour (as at October 2017 (see <https://www.gigbuddiessydney.org/faq-ndis>). If it is to be included in an NDIS package, Gig Buddies' charge is 3 hours per month at \$57.71 per hour.

There are two full time staff members (the CEO and social media co-ordinator) and a part time staff member who works 25 hours a week which is equivalent to 2.5 EFT. The program also draws on volunteer labour through an internship program. The staff have a diverse skill set and bachelor degree level or vocational qualifications in journalism, graphic design, music production, speech pathology, social science, law, teaching, community services and disability studies. Only the CEO and one of the coordinators had prior experience in the disability sector. They work flexible schedules including nights and weekends. Volunteers, participants and parents of participants commented about the positive attitude of staff towards people with intellectual disabilities and their commitment to the program.

I guess there's an underlying passion there to help those who experience some sort of disadvantage or isolation in the community. So that definitely came across for me and that got me quite motivated and engaged. (Jas, volunteer)

...wonderful, great people...very understanding. (Sue, participant)

...really friendly and respectful. (Thomas, participant)

...don't try to fob you off. (Mark, participant)

Participants hear about Gig Buddies through staff from other programs such as Ability Links, and their parents or friends. Volunteers find out through the media or searching for volunteering opportunities. Promotion of the program through the mainstream media and street presses means that it has to do little active recruitment.

Volunteers are expected to commit to the program for at least a year and to see their gig buddies 8-10 hours a month, although interview data suggested that this is more likely to be fewer hours. All volunteers must have a police check. Little information is collected about the socio-demographic characteristics of participants or volunteers, but it is estimated that volunteers range from early 20s to late 50s and come from a range of different backgrounds. Those interviewed, for example, included a person who worked two jobs, a university student and a retiree. Staff suggested that requisite qualities for volunteers were patience, being observant and caring. Volunteers generally said they were motivated by a desire to help others to have experiences they took for granted and had been looking for volunteer roles that would be fun as they believed that this element would help them to stay committed to the program.

Volunteers are required to undertake a day's training before meeting their gig buddies. Training is provided to volunteers in groups of five or six people. It is run by staff members together, where possible, with a program participant who offers their own

perspective on the program. It covers topics such: as the NDIS Safeguarding framework; abuse; program goals; processes and code of conduct; developing friendships; distinctions between volunteer and support worker roles; significance of friendship and participating in new activities for people with intellectual disabilities; potential challenges such as harassment, discrimination and difficulties with alcohol use, and; types of travel.

The training is designed to help volunteers reflect on how best to build the relationship and to deal with problems that might arise with their gig buddy, especially around going out with them to public venues. One said,

The training definitely put my mind at ease and I was like, oh this is something I guess I have the capability to do. It was really good and I think I felt reassured. (Jas, volunteer)

A prospective volunteer said she had wanted to join Gig Buddies in part because of the excellent reputation of the training program around going out at night.

A participant advisory group, named Soul Fly Band by one of its members, comprises four gig buddies and is supported by staff. The advisory group is currently co-facilitated by a volunteer and staff member. The long-term aim, however, is for members to operate quite independently of other assistance. The group helps to identify events that might appeal to Gig Buddies participants and their volunteers, suggests changes to program processes and seeks out promotional opportunities.

One staff member said about the group:

We needed to recognise that and also utilise that [expertise of participants], because if it's always just us saying, 'this is what you're doing next' or 'this is what we'll do now', we're kind of defeating the purpose of the program. I'm really pleased to see that people are stepping up and taking ownership, because it's - we're the facilitators but we don't want to be the owners of the program. (Anna, staff)

Program components

The program divides its components into the following tasks for the purpose of funding: recruiting and training of the volunteer, including reference & police checks; interviewing participants and significant others in their lives; facilitating the initial meeting between the participant and volunteer once a match is made; supporting the pair on the initial first outing; ongoing mentoring and support for the pair; facilitating Gig Buddies social events; sourcing venues, building relationships with sporting clubs, entertainment locations, often resulting in

discounted tickets; liaising with disability organisations, local councils and advocate groups, and; maintenance and continual review of the database.

Recruiting and matching

Entry into the program for both volunteers and gig buddies follows an agreed process. Having identified an interest in the program and gone to the Gig Buddies website or called the program, prospective participants and volunteers are invited to fill out a form about themselves. This information then goes into a database. The forms have been modified over time to allow various additions including, for Gig Buddies, more information about personality and what things make them feel uncomfortable. Upon receiving a completed form, staff make contact to find out more about individuals' motivations for joining the program. Staff usually contact participants directly to avoid assumptions about others making decisions for them and to ensure they are not being pushed into joining by well-meaning family members or support workers. Conversations often take place by telephone but prospective participants, in particular, are often invited to come into the office to meet staff or a staff member will visit them at home.

The interview is followed by a search of the database to find a match. Matching participants to volunteers can take several months. Staff see this stage, and the care they take with matching, as the linchpin of the program. They do not want to match individuals who have very different interests or personalities or who live some distance from each other,

We're not going to find a volunteer who lives at the other end of town because we want this to be a long-lasting friendship, and probably with another person who can get around the town [otherwise] it becomes sort of an obligation. And then you're sort of heading towards support work there where you'll feel obliged to help out the person with a disability. (David, staff)

Staff were also aware of potential emotional consequences of a poor match, where the likelihood of a volunteer dropping out were greater. For the same reason, when a possible match was identified, staff always contacted the volunteer before the participant. One staff member explained the next part of the process,

I phone the volunteer first because it's probably easier to let down a volunteer than it is a gig buddy. ...there may be a chance that we may not have spoken to the volunteer for a number of weeks or months. So, I'll say, 'do you still live in this area?' [And if they say yes, I would say something like] 'Brilliant. Well, we've potentially found a match. Now I've found a female gig buddy, she lives nearby, she's a certain age'... I

don't go into the exact details but [say something like] she's into this music, she may need assistance from A to B. So, I just go through based on the profile that we ascertained through the interview and then I find out the volunteer's interests, but even then, I put a massive emphasis on saying, 'don't feel obliged, don't tell me what you think I want to hear'. (David, staff)

One volunteer commented that he thought the thorough selection process aided the flexibility of the program and the organic way in which participants and volunteers were able to develop their relationship. He felt the process precluded the 'need for them to be heavy handed or always checking in or anything'.

Supporting initial meetings and ongoing relationships

If the volunteer is keen to meet the prospective participant, staff contact that person, similarly emphasising there is no obligation to meet the volunteer. Very few would-be volunteers or participants decline an offer to meet or decide not to take the relationship further after a first meeting. The initial meeting is supported by a staff member and then it is up to the pair as to how their relationship proceeds.

There are no program records kept of contact that pairs have, but staff estimated most pairs meet once a month. Staff provide support if either party requests help with the relationship. Three of the four volunteers interviewed stated, without prompting, that they felt they had all the support they needed from program staff and would be comfortable talking to staff about anything. One issue for which volunteers sometimes request help is the frequency with which their gig buddies contact them. The volunteers interviewed, however, rarely contacted program staff for advice and were more likely to ask family members or paid support staff if they had questions about their gig buddy's preferences or behaviour.

Volunteers identified some of the challenges they faced. These included: concern about embarrassing their buddies through over or under estimating their abilities; difficulties with identifying times to go out; balancing spending time with their buddy alone with attendance at group events; choosing between doing a broader range of activities and those that could be reached by public transport (the latter is encouraged by the program as a way of increasing participants' independence), and: forming a close relationship with a person with communication difficulties.

A final part of the process staff facilitate is bringing to an end a pair relationship if there is an irresolvable problem. To date this has only occurred once and related to the volunteer being uncomfortable about the alcohol consumption of her gig buddy.

Facilitating program wide social events

The program supports or directly organises different types of social activities: outings initiated by gig buddy pairs for just themselves or involving other gig buddy pairs; outings organised by staff exclusively for those involved in the program (matched and unmatched gig buddies and volunteers and their friends and family) in booked venues, and; outings facilitated by staff for gig buddy participants to events open to the general public.

The activities of Gig Buddies pairs extend beyond attending music gigs or sporting events together to things such as dining out, bowling, karaoke, going to bars and going to theatre shows. One volunteer said, for example,

We've been to comedy shows, we've been to gigs, we've been to music halls, so very much in the performing arts, yeah. We've been bowling. One night we just went out, just in the local area, and just went and had dinner together, and then just went to a few clubs. (Sim, volunteer)

Group activities for participants are held bi-monthly and help to maintain pair relationships. As one volunteer said,

...if you didn't get your act together and arrange catch-ups on, let's call it, a monthly basis Gig Buddies are creating and providing an umbrella where you would do something at least quarterly (Kim, Volunteer).

We observed one of these events, a country rock band playing the Spiegeltent as part of the Sydney festival. It was attended by a staff member, four gig buddies (aged between early 20s and early 60s), a friend of one of the gig buddies and a prospective volunteer. The group met for a drink in an outdoor bar before moving to the venue a few metres away. The staff member made sure that everyone who had indicated they were coming arrived, and each person was warmly greeted into the group. He was non-directive, leaving people to sit where they chose. After the performance, the group chatted briefly together outside the venue and the staff member ensured everyone had arrangements for getting home.

The program is becoming more focused on sport, and has signed a memorandum of understanding with the Cronulla Sharks. They have formed the Shark Buddies group, who are program participants interested in sport who will receive discounted tickets and are expected to attend at least four games a year.

Outcomes

The program has supported development of new friendships and social connections, access to cultural activities and gigs, and enhanced participants' independence skills confidence and self-esteem.

Friendships and social connections

Some gig buddies had developed significant friendships with their volunteer which were characterised by shared activities, easy conversations and regular contact.

My feelings for [volunteer] are that I feel like I can be myself. And have fun and go out and that. So, I'm not with Mum and Dad all the time... I always wanted to have a friend to hang out with and do things with and enjoy the world out there. (Sue, participant)

[He] is a bit of a handful, but [volunteer] just does it easily. [He] goes, 'come on buddy, let's go, off we go', and off they go. They start off with their favourite restaurant and then they move on and go somewhere else... even though we moved away, [participant] just loves [volunteer] so much, and that was a like a year ago, and they still see each other constantly... The excitement he gets about having a friend! Because he didn't have a friend before Gig Buddies...he's never had a friend before, and now he's got a friend. (Rachel, parent)

I think that [participant] is very comfortable with her. And I'll ask her about what did you talk about, what did you do and it sounds to me like they've had some fairly deep kinds of conversations. She's asked her about boys and these sort of things. She might say, 'I've got a problem with this one or that one' and [volunteer] been really good to be able to say, 'Don't worry about that one'. (Chris, parent)

Some volunteers saw their friendship with their gig buddy as different from their other friendships, and involving a greater sense of obligation or looking out for the person and a little less reciprocity.

I don't feel like I have to go and do this. I mean, that's not it at all. It's just that there's a stronger sense of that than in your typical friendship. (Siobhan, volunteer)

I still do feel a sense of responsibility. It's not as much. I feel now we're just, it's like meeting up with a friend, going out... Yeah, we sing in the car... I hate being called a volunteer. It really doesn't sit well with me and... It's not a burden on my time. I'm

doing it because I want to socialise with [participant] or the rest of the Gig Buddies group. (Simone, volunteer)

But I guess, we are definitely heading towards that space, a friendship that would be, not identical to, but quite similar to some of my other friendships. (Jas, volunteer)

The ambiguities in many of these friendships was captured in the comments of one volunteer who first compared his gig buddy friendship with his other friendships but then talked about its lack of reciprocity.

I would say that [participant] is close to that friendship spectrum. I often think of including [participant] in different things and we've gone well beyond the Gig Buddies context anyway...To be honest, I probably see [participant] more often than I would any other person in my friendship group...

But then:

I don't ever get back from [participant] in terms of conversation or intellectual stimulation. I mean he is a companion, but I'm not a person that needs to see a band with a companion. So, for me I see it very much as a giving relationship and for me it's an easy give. (Kim, volunteer)

Even when relationships were not described as friendships, gig buddy pairs shared activities and pleasant interaction with each other, and participants had opportunities to meet a wider circle of people without disabilities. One parent described how important it was for her son to feel part of a group and that both he and his volunteer always wore their Gig Buddies wrist bands when they went out. A staff member also commented on the opportunity to feel part of a wider social group.

I noticed when we went to the Cronulla Sharks game people would start cheering along the same cheers they'd hear someone else shout out, so they'd feel like they were more part of it because everyone's cheering the same thing. (Connor, staff)

Being paired with a volunteer opened up opportunities for participants to meet other people without disabilities as well.

[Participant] came over and watched the rugby league grand final here with my son and we had a barbeque dinner. I've been out with [participant] and his girlfriend, and they came with my wife and I when we went to have a meal. (Kim, volunteer)

People I haven't met before; I talk to them. And I have a drink here and have tea there. Mix with other people. I'm the sort of person, I like to meet other people. (Mark, participant).

I like the fact that we are able to go out in the evenings and socialise and everything. And just able to have fun with our buddies. And get to know each other. I'm going to a Christmas party on Friday night with my gig buddy so we're going to meet up and go to the city. (Mel, participant)

Enjoyment of new experiences, skills and independence

The opportunities to be regarded as an adult, go out without their parents and try new experiences was an important outcome for many participants. First time experiences for participants included going to karaoke, live theatre, the Sydney Opera House, live music and sports events. One volunteer spoke of the determination of her Gig Buddy to keep pushing himself to have new experiences:

We could easily default, go to the movies. Like he is an absolute movie buff, loves movies. But he said to me... you know, the reason I'm doing this is to try and get out of my comfort zone. (Simone, volunteer)

Another volunteer felt that he was routinely offering his buddy new experiences, reporting:

I think that [participant] has definitely had experiences with me that he wouldn't have had otherwise, the bands we go and see and the venues that we go to. (Kim, volunteer)

Both participants and parents talked about the opportunities the program afforded participants to be regarded as an adult.

The other social activities I've done have been very rule bound. And you weren't allowed to go out at night. You weren't allowed to have boyfriends or girlfriends. We weren't even allowed to bring our partners along. They were very, very strict on all of that. I found that very annoying... Not very nice people. They treated us like we were babies, like we were at pre-school. But we're not. We're adults. (M, participant)

I think what she really enjoys is not being out with us – you know, Mum and Dad all the time – and just off with someone her own age. That's just incredible for her. To go off with her friends [in usual circumstances], there's always little bit of parenting involvement somewhere along the line. Whether it's a drop off or a pick up, there's always someone hovering or – not hovering – but you know, there's always some

parent thing involved. Whereas with her and [volunteer] she can just go off like. It's just her and another person. (Rebecca, parent)

Some volunteers were aware of the importance of enabling their buddy to be as independent as possible rather than doing everything for them.

I'll determine when I come in... I know there's certain things that he might struggle with. So, money, he struggles a little bit with how much to give. So, I'll stand next to him at the bar and let him order and they'll tell him. I'll say, you've got a \$10 there, just give them a \$10'. So just trying to help but not take over... Yeah, rather than take over and go, 'here, give me your wallet, I'll go order for you'. It's like no, you know, he's old enough to do that. He can do it. (Simone, volunteer)

Vignette

The following vignette illustrates outcomes for one Gig Buddies participant:

Sue is a softly spoken but reasonably confident young woman of 25 with a strong interest in the arts. She lives with her parents but has her own bungalow attached to their house. Sue works as an administrative assistant four days a week at an office in the inner city. She is involved in various regular activities including a performing arts group, social tennis and a film club, all of which are for young people with a disability. She doesn't see her friends from these groups outside of attending the groups.

Sue had been matched with her volunteer for about 18 months. She says that she was lucky enough to have only waited a few months to be matched. Sue and her volunteer, Jas, are the same age and as they enjoy the same kinds of live performances they find it easy to identify activities to do together. They see each other once or twice a month. On their first outing they went to a karaoke bar. They have since gone to films and a number of theatre shows but sometimes just go out for dinner and a drink. They also attend some of the Gig Buddies group events but Sue particularly enjoys just going out with Jas.

Sue says that she loves having someone to go out with aside from her mother and father, commenting 'I always wanted to have a friend to hang out with and do things with and enjoy the world out there.' She feels that, with Jas, she can be herself.

Sue participates in the Gig Buddies participant advisory group which she describes as 'pretty cool, kind of interesting'. Although it was early in the life of the group, she

thought it was good that participants could come together and decide on activities the other participants might enjoy doing on their group activities. She thinks that the Gig Buddies staff are 'really friendly and respectful'.

Her mother believes that it has been really important for Sue's development and happiness for her to have a friend her own age she can go out with independently, and talk about issues that concern those in her age group. She has noticed a general improvement in her social confidence since she started going out with her Gig Buddies volunteer.

Jas, Sue's volunteer, thoroughly enjoys spending time with Sue. She has particularly enjoyed watching Sue become more confident. She feels that she and Sue are slowly becoming good friends.

Melba Support Services Community Connections program- summary model of community participation

Theory of change

Supporting people with intellectual disabilities to engage in activities of their own choosing in the local community will mean they live more interesting and fulfilling lives and develop a greater sense of belonging to that community.

The primary conceptualisation of community participation is concerned with convivial encounters with people without disabilities in mainstream community places.

Place

Community Connections is locality based and operates within identifiable local communities. It operates in a segregated building at its main Lilydale Campus (located on the Lilydale TAFE campus) and two smaller venues, situated close to, or within mainstream community places, such as the TAFE college and town centre. As well as the segregated places, participants take part in activities in mainstream non-segregated settings including businesses, community group and volunteer settings.

Activities of interest

Community Connections offers a wide range of activities for participants. These include paid and volunteer work, creative, leisure and skill development. Support for participation in activities is often broken down to the micro task level.

Social interactions

Participants have regular social interactions with peers in the program at various sites and community based activities. They also have interactions with people without a disability in the course of various activities, some may be regular and convivial whilst others may be intermittent or fleeting.

Outcomes

Participants enjoy participating in a mix of preferred and individual activities. They have regular convivial encounters with range of people in the locality who know or recognise them. They have a sense of belonging and contributing to the locality through their engagement in a range of activities.

Logic model: Community Connections Program, Melba Support Services

Theory of change: If people are supported to engage in activities of their own choosing in the local community then they will live more interesting and fulfilling lives and develop a greater sense of belonging to that community.

Inputs/ resources

Funding - State Government
In-kind service provision
Facilities at main Lilydale
Campus and two smaller sites,
equipment, resources
Board of management
Staff 35 EFT
Supervision
Staff meetings
Training
Recruitment
ARROW self-advocacy group
Provision of transport (mainly
minibuses)
Typical attendance 5 days a
week from 9.00am to 3.00pm
Total number of participants 97

Program Components

Individual Planning
Program level planning
Creating opportunities for
individual or group shared
activities with other community
members in classes, volunteer or
paid work places, activities in
community places for facilities and
peer activities
Attention to micro task level
engagement.
Collaboration and negotiation with
other groups
Adapting environments and
support to people with severe
cognitive impairments

Outputs

Social interaction and
participation in a mix of
preferred and individual
activities and less
preferred ones.
Contribution to other
groups in the community.
Modelling social
interactions with people
with severe and profound
intellectual disability who
occupy values roles to
others in the locality.
Social enterprises,
community service
activities.

Outcomes

Regular convivial
encounters with range of
people in the locality and
peers.
Enjoyment
Sense of belonging and
contributing to locality

Context: The mission of Community Connections is to provide support to people with intellectual disabilities to 'lead everyday lives' through participation in individualised activities which are planned to take place in the local community.

Detailed Case Study: Melba Support Services, Community Connections Program

Melba Support Services began in the early 1970's and was very much a service of its time; providing congregate care for children with intellectual disabilities and a support network for their parents. It has since grown in size and altered considerably both the type and range of its services. It now employs 35 equivalent full time staff and has some 70 volunteers. The management team comprises the CEO, COO, other senior managers and team leaders supported by administration and finance staff. The organisation has a strong emphasis on individualised support, measured quality outcomes and creating and developing local community connections. The Community Connections program is one of the programs it offers, others are community living, respite and recreation services. Some of the participants in the Community Connections program also use some of these other programs.

Melba is based in Lilydale in the Yarra Valley. The Lilydale district is about 34km from the centre of Melbourne and whilst it is suburban in character it retains some of the feel of a small rural community. The local community is composed of predominantly Australian born people who speak English at home. The median age is 37. The program operates from several sites around Lilydale. The majority of program participants live within a 12-15-kilometre radius of the service.

The main site is on a TAFE college campus. It is a large, low rise building indistinguishable from the other buildings on this large undulating campus that has many trees and a small lake. The campus is a busy and pleasant place. The Melba building is easily reached by car from the main campus access road. Public transport is available to the site via buses from the local Lilydale railway station. The reception area is open and bright and there are photos on the walls showing all of the program participants and the staff who are going to be supporting them that day. Staff and participants share the space, including kitchen and bathroom facilities. Everyone is encouraged to interact with one another across the shared spaces including those areas identified as belonging to particular staff or programs. Staff office doors remain open and others are free to wander in and say 'hello' at any time. All staff, including those in financial management and human resources have regular interactions with program participants. The building has a relaxed but purposeful atmosphere. The environment is stimulating and interesting with lots of noise, friendly banter, music and visual aids. Taking account of the limited literacy skills of most participants a 'colour and scent of the day' is always displayed in the central reception area. The number of participants on site varies from day to day and from hour to hour.

A total of 97 people, many of whom have severe to profound intellectual disabilities and complex support needs participate in the program. Participants come for varying periods dependent on each person's goals, aspirations and interests. Most attend 5 days per week (75), and 22 attend on a part time basis. The program hours are flexible but typically, individuals are supported between 9.00 am and 3.00 pm. As additional or more individualised funds become available the hours are likely to extend beyond this.

Each participant has an individual plan and program and is engaged in a mixture of different activities reflecting personal preferences. Most spend a significant portion of the day engaged in various individually supported activities off site, out in the local community. The proportion of time that participants spend on site and off site varies each day for each participant, but a typical pattern would be 2 hours on site and 4 hours offsite. On-site activities are group based and educational or recreational such as having a pub lunch or craft activities, whilst off site activities are more varied, including fitness for example swimming, and leisure, voluntary work, participation in community groups, social enterprises and micro-businesses.

The program at the time of the research is funded by the State Government Department of Health and Human Services based upon each person's Support Needs Assessment (SNA) level. The social enterprises and micro-businesses established as part of the program such as the Able Bakehouse generate some income, but do not make a profit. In the future, the program will be funded through the NDIS and participants' individualised funding packages.

This case study draws on data gathered from semi-structured interviews with five program participants, Melba Support Services senior managers, and all levels of Community Connections staff (11). It also draws on observations of these participants at the local pool and the social enterprise Able Bake House, and review of organisational and program documents. With the exception of one, the program participants had very limited verbal communication skills. Support workers were therefore significant contributors to the interviews conducted with participants. All names have been changed to ensure confidentiality. Tables 1 and 2, in the appendix, summarise the characteristics and quality of life indicators for these five participants. Notably, their scores on part 1 of the Adaptive Behaviour Scale ranged from 60-265, where a score of 151 or below is indicative of a more severe level of intellectual disability.

Aims

The program has a coherent design. Its mission is to provide support to people with intellectual disabilities to ‘lead everyday lives’. It aims to offer “...week day support to people with a range of interests and abilities in the Yarra Ranges and surrounding communities in small group or 1:1 arrangements.” (The Melba Way document, 2016). Staff across the organisation very clearly understand the program’s purpose, though use their own language to express it. For example,

Community Connections is all about people being part of the community and doing stuff. (Nathan, staff)

Community Connections is about giving people real options... being able to participate in a way that’s meaningful for you – for the individual. (Charlotte, staff)

...good engagement, a quality engagement. (Nathan, staff)

...and enjoy the time together with other people out and about in the local area, the social banter that goes on. (Karen, staff)

Staff saw community participation as multi-dimensional but strongly emphasised local places, and developing a sense of belonging and acceptance. For example, they talked about;

...people feeling comfortable in their local community, having valued roles in the community and being accepted and respected in community. (Heather, staff)

Community Connections is all about people interacting with other members of their community. The people we support are out and about in the community every day; importantly they are known by name. People have valued roles and connections based on their interests, skills and abilities. These connections are born out of people interacting with their local community. (Melba Support Services, Annual Report, 2016)

The program is built on the understanding that it is not enough for people to have a presence in the local community, they need to be participating in programs and activities that are of their own choosing;

You can be in the community and still be isolated, but it is how you feel connected to your community and how you are engaged. (Charlotte, staff)

Achieving the program aims are perceived as neither ‘easy nor straightforward’, and it is acknowledged that what constitutes community participation is likely to look different for each participant, reflecting their choices and individual preferences. Each individuals’ goals,

aspirations and interests are the starting point for staff who then work intensively with the local community to build opportunities for engagement.

Community participation [is] really central to what we seek to do. Not necessarily easy or straight forward, if it was everyone would be leading better lives than they are, but it's an important focus for us. (James, staff)

Objectives and the goals definitely are around what the person is wanting. Objectives of course I think sits underneath that in regards to how will we achieve that for a person. Whether that's paid employment, a socially valued role, it could even be physical activity like swimming, gym, we have people who are swimming on a regular basis once a week and they've connected with a whole lot of other people in the local community who use the pool at that particular time and day. (M, senior staff)

I think community participation is very much the way that we look at it as Melba has a very much individual approach. And for some people, what would be classified as community participation for them may not be the same for somebody else. I'll give an example. Somebody who likes to walk around the lake, then they may sit down, and someone may sit next to them. And for them, that may be being part of this community. For somebody else, that could feel quite isolating. So, I think a lot of it comes back to the individual, and how they choose to participate. (Charlotte, staff)

Program inputs

The program operates from a large site in Lilydale in outer suburban Melbourne as well as a number of smaller sites in surrounding localities, including a community kitchen, and a shopfront in a shopping centre in the neighbouring suburb of Mt Evelyn. An additional small site has recently opened in Mt Evelyn which offers day activities in a quiet environment for five people with very high complex support needs.

Funding for the program is from the State Government with most participants having individualised packages through Department of Health and Human Services. The organisation is currently working to introduce new systems to manage the transition to funding through the NDIS and program participants' individualised packages. Additional income is generated through sales of products through social enterprises which operate under the Community Connections umbrella including the 'Able Bakehouse' bakery and the 'Yarra Ranges in a Box' food delivery service. The Community Connections program is led by a Manager who reports to the COO and three Team Leaders. These staff are involved in

planning and organising programs and activities in supervision of direct support staff who work with participants.

Thirty-five effective full time staff work on the program, of these 12 are full time, 59 part time and 23 casual. Qualifications and experience vary among the staff. Some have a TAFE Certificate 4 in Disability Services, and most have participated in Melba's in-house training program. Their length of service varies between 6 months-40 years, and their age from 18-60 years. Four information sessions are held across the year to recruit staff. These are advertised in local newspapers. When staff with specific skills are needed, ethical jobs and seek careers websites are used.

The Board of Management is voluntary and made up of 12 people; some of whom are parents of service users and others from the disability sector, law and finance backgrounds. There is a participant advisory committee ARROW (Advocacy, Rights, Representation, Outcomes, Worth) which reports directly to the Board of Management through the CEO. The ARROW group meets regularly to discuss issues of importance and interest to Melba participants. The group was a finalist in the 2016 Victorian Disability Sector Awards for the work it has done in advocacy and awareness raising in the local community and the promotion of the human rights of people with intellectual disabilities.

Melba Support Services' organisational chart is proudly upside down, with program participants described as 'people we support' at the top of the chart and the Board of Management, its sub-committees and the CEO at the bottom. The organisation believes that this is symbolic of the priority given to the needs and wishes of the users of the service and a strong individual planning and delivery model which pre-dates the implementation of the NDIS.

Senior staff describe Melba as having a strong 'quality' culture stemming from the use of the Personal Outcomes framework of the US based Council of Quality Leadership, as part of the organisation's quality system.

So, the 21 outcomes sets up a framework for discussions with individuals and depending on the person, some of those 21 outcomes will be more important than others. And so yes, we are guided by individuals and what they see as more important or less important, but nevertheless that is part of our quality framework and community participation, sits at the heart of that. (James, staff)

Private transport is a priority for the program as access to public transport is very difficult for most of the people who use the program. Providing a 'transport service' is a significant but essential expense.

...we run a fleet of buses that reflect the fact that it's not easy for many of the people we support to use public transport. And you know we have wrestled with that because you know your starting point is great to take advantage of public transport, and if people can then we support people to do that. But it is not a realistic option for many people that we support. So, if we didn't provide a form of transport then it would absolutely be a barrier to people's participation and the funding that is made available for that in no way meets the costs of that particular service. And I think it's fair to call it a transport service that we provide. But if people are going to get out and about, if they are going to participate in community life they can't do it sitting in this building. They have to have a means of getting around. (James, staff)

There is no waiting list for the program, and most new participants are school leavers.

Program components

Individual planning

Being person-centred and tailoring activities to individual choice and preference underpin all the program components and staff practice – this means that in effect each participant has their own program;

It's very, very personal, and it's flexible around that person. It needs to be what they need it to be, but then we need to develop the program around that. Yes, it's flexible, but around that person. We try and look at everything that is going to make it a success for that person. (Prue, staff)

The activities each person does are based around their interests, preferences, and guided by imperatives for creation of a mix of different types of activities over a week. Other imperatives that guide planning are making a valued contribution to the local community, maximising interaction with others in the locality, and being recognised and known in the locality by others.

Knowledge of the person from multiple sources informs planning. Staff share their interpretations of the person's preferences, gain insights through observation and talk to others in the person's life. Close relationships developed over time between staff and participants provide the context for an ongoing conversation about preferences and interests

which may mean that activities evolve and change. This close knowledge is used to meticulously plan activities.

We are guided by individuals and what they see as more important or less important... to direct us in terms of what really matters to them. (James, staff)

Creating opportunities for activity, interaction and participation in tasks.

Creation of opportunities to participate in activities is informed by individual planning, and the knowledge and networks of staff and the organisation. Significant attention is given to planning at a program level and translation of individual plans into the maximum possible opportunities for each person. Micro level planning down to task level is undertaken so that the person is involved in specific tasks rather than just being there. Breaking down tasks into component parts in this way is an important way of enabling people with more severe intellectual disabilities to participate and creates opportunities for each individual to be engaged and contribute as a person with a valued role and according to their interests and preferences.

The program is flexible but robust due to the rigour of the planning which underpins it, a rigour which is sometimes not obvious to others;

It's very purposeful very planned but it looks to other people like it's not. We don't try to fit people in, we build things for them from the ground up. (Prue, staff)

It's an enormous amount of thinking and planning, but once it is thought out and planned out, there's no reason it should stop. (Prue, staff)

It's quite a high degree of support documentation and instruction and delivery and planning and preparation that goes into these programs. (Peter, staff)

Community Connections works to connect participants to the community by 'bringing in' the community where possible, to enable interactions and engagement. Planning is also based on knowledge of the local community, for example other local groups or facilities and tapping into the skills, hobbies and personal connections of staff, volunteers and their social networks.

It's really important that when we think of community participation, we think about the ability of all the people that we support, and how we can bring the community to them, rather than, always, the other way around. Rather than trying to fit people, that have quite significant needs, into a community project or something that's already

been up and running, we build one from the ground up based on the skillset of the specific person we're looking at, and bring community members in. (Prue, staff)

The Able Bakehouse illustrates the way that strategies are developed from individual planning processes to create opportunities for preferred activities. The bakehouse was developed in response to one participant's interest in one particular task in the biscuit making process, and is now an enterprise that offers many people many different tasks and provides differing opportunities for interaction and engagement with peers, staff and the local community. The staff member who manages the Able Bakehouse described its origins;

The Able Bakehouse was an idea that started around one lady's like for chopping chocolate - not just any chocolate - the round buddy [chocolate piece]. It was right down to the shape of the chocolate. (Prue, staff)

Someone with a severe disability, but someone who enjoyed chopping, and so the chopping up of chocolate chips in particular was an essential part of making chocolate chip biscuits. Five years ago, might be almost – no it'd be more than five years ago the Able Bake House started. So, one day a week in our community hall in Mount Evelyn the bakery operates. (James, staff)

Other participants are involved in all stages of the process of making the biscuits; mixing, rolling, baking, packaging, making up orders and delivery to local cafes and businesses.

Similar approaches to creating activities that facilitate interaction and contribution to the local community are the 'Yarra Ranges in a Box' fruit and vegetable box delivery service and a free fruit program run in conjunction with Second Bite, a food reclaiming community organisation and a local primary school. Here, too, breaking down tasks into smaller tasks is used as a strategy to engage as many participants as possible in implementing the fruit program and making sure that each person has a valued role which fits their abilities and interests. Community Connections participants, in small groups, are involved in collecting fruit from Second Bite, preparing the fruit, delivering the fruit to the school classrooms, collecting the empty containers and travelling to a local chicken owner to drop off scraps. Each of these stages involves regular interaction with peers, staff, volunteers and members of the local community.

A number of participants are involved in growing herbs and vegetables at a local farm. Produce is planted, watered and harvested. Members of the local community are invited to come and join in mass chutney making days utilising the produce grown on the farm, and other donated produce.

We have people from the community coming in and working alongside us, just because they want to be there for that day. It's kind of fun. (Prue, staff)

Participants who 'enjoy driving' are involved in delivering chutney and other tasks such as collecting jars and delivering and returning crates.

Community Connections also organises drama and art classes, gardening and cookery workshops. These are run by local artists, gardeners and chefs in community halls and kitchens and are advertised to the local community with the goal of creating classes which have a mixture of people with disabilities and those without. Other activities include the 'Drinkers and Thinkers', a small group who enjoy having coffee in local cafes and writing reviews about them rating their accessibility, friendliness, food and drinks.

Working from their knowledge of each individual, staff negotiate opportunities for participants to engage in short periods of voluntary work or paid employment. One participant has a long-standing job at a local supermarket. Others undertake voluntary work in local organisations and businesses including a child care centre, op shop, meals on wheels service and the State Emergency Service (SES). These are opportunities much valued and enjoyed by participants;

On that one day of the week he spends time volunteering and assisting at the SES, he might do things like washing trucks which is a job that would need to be done by someone else so it's significant, it's important, absolutely. And this young man knows that he is doing something of significance and importance and the fact that he's got his SES kind of jacket on which is one of those fluoro outfits. Yeah, he understands that yes he is volunteering, he is working as part of the SES volunteer cohort and there are many people who volunteer as part of the SES, he's no different in that respect.

(James, staff)

One participant has been supported to develop her own 'micro-business' as a result of her interest in cooking. She has been supported to find a supplier with whom she works to supply a range of salts which she sells to friends, family and others she encounters, including the researchers on this case study!

The ARROW group, created as part of the governance structure for input from consumers provides opportunities for members to interact with each other and with members of similar groups. One participant was an active member of this self-advocacy group and said;

My [Arrow] group is a group that we get together every Thursday and we talk about advocacy rights and stuff and responsibility and we get together with another group and we sit together and we talk. I go on the radio to talk about my ARROW group.

(Hannah, participant)

It is not always feasible to provide opportunities for individuals to participate solely in their most preferred activities. Due to funding constraints people often participate in activities in community settings in groups of four to six. Staff seek to regularly review activities to maximise the enjoyment of those they are supporting;

Kind of across the week everyone participates in things that they enjoy, or they've shown that they seem to enjoy. It kind of at the end of the day, if four people out of six enjoy it then we do that this time and then we try and do something for the other people another time. (Maureen, staff)

Being flexible

The flexible approach acknowledges that preferences can change and therefore staff need to be responsive to individual choices about participation. This approach depends on staff working closely with participants, including those with complex needs and communication difficulties, to develop a deep knowledge of the person's interests and a willingness to adapt activities and tasks within those activities at short notice and in sometimes unexpected ways. The Community Connections staff seek to respond;

...minute by minute, hour by hour, day by day. This incredible flexibility where people bend and meld to suit what the person wants to do that day. (Charlotte, staff)

Putting this approach into action has given rise to a range of innovative responses to individual participants' preferences and choices and led to the creation of some tailored programs such as microbusinesses.

Outcomes

Participation in Community Connections has a range of outcomes for individuals. This might be characterised as a shift for each individual from anonymous other or stranger to a person who is known by others in shared places that others use, and who contributes to others in the local community.

Convivial encounters with people in community places

Participants developed a sense of belonging to a local community through their activities. Trudi described the kinds of positive interactions that arise for Chloe, the person she supports, when she does voluntary work at the local library;

It's not a long time but it's just enough to do what we can do while we're there and for Chloe to have a bit of a presence there. Off and on kids will come up and have a chat, won't they, Chloe? Yeah, there's been a few participants over the years that go to the kids' program that have come up and asked questions and had a bit of a chat with you. (Trudi, staff)

The same worker described Chloe's level of comfort and enjoyment when she attends the local swimming pool. Over many years of regular attendance, she has developed friendships with community members and others who recognise and acknowledge her as a community member herself.

She becomes quite social and she's made some great friendships there. There's a few friends. Jim, who you've known for quite some years, and we'll go and say, "Hi," to Jim when you first get there. He does an exercise program at the pool nearly every day. You'll take his hand sometimes, Chloe, and you'll go and walk the length of the pool with him. And then you have another gentleman that you see, Robin, who she's formed a great friendship with. And she will actually wait, and knows about roughly what time he gets there and she'll be watching to see. (Trudi, staff)

A sense of belonging and contributing to the local community

Part of the sense of belonging to the local community came through the idea of 'contribution'. Melba positions itself as a provider of services to its own service users but in turn with the labour, engagement and enthusiasm of program participants and staff, as a provider of services to its local community. This happens through businesses such as the Able Bakehouse and the Yarra Ranges in a Box and also through programs such as the collaboration with Second Bite and the array of workshops and classes which are offered to all in the local community.

Participants developed identities as contributing members of their local community through their involvement in the Community Connections program. Their visible involvement in a range of activities within the community has a 'ripple effect' in the ways that people are perceived and in the way that the programs become embedded in the fabric of the local community.

I think it's really important to think about all the other ripple effects that go on from that thought process. I think the ripple effects in the community are the big ones that we always think about. (Prue, staff)

A senior staff member Nathan described the outcomes for participants in terms of the recognition they received in the local community as people who were providing valued products and services. Through the reliable delivery of those products and services they were building strong positive identities as people who were social and economic contributors to their community.

Then they loved the fact that – and so this is particularly the cafes – they loved the fact that, not only were they getting this sort of product and doing stuff that they couldn't do or didn't have the time to bake, but the entire process. They saw the people we support engaged in the community. They love the fact that these people are out there in the community; they're doing stuff; they're doing meaningful activity, you know and mostly they love the fact that it was our crew that gave them the invoice of payment to make and that sort of stuff there. So, they saw our crew being involved in their business, as equals in their business. You know, and enjoyed the fact they chat to someone and that sort of stuff, doing that sort of stuff, then. So, to me that's the success of it coming through. (Nathan, staff)

For a participant who is supported in paid employment;

... his community participation really sits around the work that he does and as a result of his work, the friendships that he's made in the workplace, he is truly a valued member of the workforce of which he is part. (James, staff)

Community Connections participants gain a sense that they are making contribution to their local community which is valued by themselves and others;

...people are contributing in some way, shape or form that is valued by others. So, whether they're paid for that or whether they volunteer their time and their labour, what we're seeking to achieve is that their efforts, work is valued and appreciated by others and the sense that they are contributing something of worth is understood by themselves. (James, staff)

A participant who has been supported to develop her own micro-business says;

I've got my own business when I go out in the community, I sell things...People know I do stuff. (Hannah, staff)

Prue, a support worker, described the nature of the interactions within the school fruit program as being reflective of an acknowledgement that people were contributing something important and that they derived pleasure and satisfaction from that.

You know like if we're talking specifically again about the food preparation program, we get the social reward of working together on a goal that is important that the kids get fresh fruit every Thursday afternoon and then it connects us, you know like we wouldn't have fruit if wasn't for Second Bite. And then at the end of it not only are the kids getting something valuable but we get something valuable back and maybe the kids do too, maybe they love seeing us. So, it's, you know you have this, a reciprocation of social enjoyment. (Prue, staff)

Enjoyment of activities which reflect personal choice

There were many examples of participants, sometimes through their support workers, expressing enjoyment about the activities in which they had chosen to participate;

Chloe joins in, in that when they have different music and singing and dancing. They all get involved in whatever they like. (Trudi, staff)

We do a nice walk along the Warby Trail and we have a drink and then a nice walk back along the Warby Trail. (Trudi, staff)

Aileen just loves volunteering at the op-shop. (Tess, staff)

What makes Aileen smile? It's Baking. (Tess, staff) Aileen: Yeah

As one participant commented;

This program has helped me to aspire to what I'd like to do and to go out into the community and do other things. (Hannah, participant)

Vignettes

The following vignettes illustrate outcomes for two Community Connections participants:

Chloe is a 27-year-old woman who lives in a group home. She has an intellectual disability, is non-verbal and also has low vision. She is involved in a wide range of activities through Community Connections and is closely supported by staff who know her very well. Over the course of the week, Chloe goes swimming at the local pool, is part of a small team which delivers newspapers, has lunch or morning tea at a favourite local café and works at a farm which grows produce used in Community Connections cooking activities. On Wednesdays, she does voluntary work at a local primary school library re-shelving books that the children have borrowed and

returned. She has been doing this work for four years and loves being in the school environment. On site at Melba, Chloe has what her support worker described as 'down time' and participates in music and dancing sessions as well as enjoying having her hair and nails 'done' and sometimes a relaxing foot massage.

Chloe's support workers say that she enjoys a variety of activities and likes to participate in 'come and try' days. Recently Chloe tried all abilities sailing for the first time and really liked it. Chloe has an iPad which she uses for things like looking at photos taken of the week's activities.

Chloe has regular convivial encounters at the primary school where she enjoys the children 'saying hi' to her and at the pool where she has made a connection with another person who is also a regular attender. They often walk up and down the length of the pool together holding hands. Chloe's support workers say that she has made 'lots of good friends' at the pool and that she is always greeted warmly. Delivering newspapers to the same businesses each week has created an opportunity for Chloe to interact with the staff in those businesses which Chloe's support workers say she enjoys.

Hannah is a 32-year-old woman who lives with her mother. She is the eldest in her family which includes three brothers and two step brothers including a 'very cheeky' one. Hannah spends four days a week at Melba and is involved in a wide range of Community Connections activities. The remaining weekday is spent with her mum on leisure activities.

Hannah described her current program of activities which includes cooking meals with ingredients sourced from the Second Bite organisation on Mondays, swimming at the local pool on Tuesdays, activities with the ARROW self-advocacy group on Thursdays and selling eggs collected by other Community Connections participants and having a pub lunch on Fridays. During the week Hannah was interviewed for this case study, she had enjoyed the experience of doing a radio interview about the ARROW activities including its human rights roadshow. Hannah has, with support from Melba staff, developed her own micro-business. She loves cooking and trying different ingredients and sells packages of salt to staff, other community members and to two cafés in the Lilydale area.

Hannah enjoys bowling and loves planning trips and holidays. She will soon be going to Mildura for four days. 'It's all booked'. She has been there once before and

managed to meet one of her culinary idols there, the chef Stefano Manfredi. She is financing a part of the trip from her salt business which gives her 'extra money'.

Hannah says that she really enjoys Community Connections and that it has helped her to 'aspire to what I'd like to do and to go out into the community and do things'. She says that she really likes the support staff and that they are friendly and 'always around'. Hannah also commented that she has made some good friends at Melba, 'people I get on with' and in other community places such as the pool where she has built relationships with others who, like her, are regular attenders.

Shepparton Access - summary model of community participation

Theory of change.

Creating opportunities for individuals with intellectual disabilities to participate in a range of activities in a variety of highly visible settings will mean they experience a sense of belonging to a community which embraces people from diverse backgrounds.

The primary conceptualisation of community participation is as convivial encounters.

Place

Shepparton Access offers a range of programs. These take place in three dedicated segregated sites and in many non-segregated sites in the Shepparton community and Goulburn Valley district. The main sites are located close to shops and businesses, and community members are welcomed into these sites. The program is highly visible in the local community.

Activities of interest

Shepparton Access offers educational, vocational and leisure and recreation programs tailored to individual support needs and interests.

Social interactions

Program participants have regular social interactions with peers in the program and most have long term peer friendships. They also have social interactions with a range of others without intellectual disability in the Shepparton community. Some of these are regular interactions around transactions or shared activity, such as serving customers in the Eco Store or working with volunteers at Eco Park, others are with staff or other community members at community facilities or who attend the same interest based classes.

Outcomes

Participants developed friendships with peers in the program and had regular convivial or fleeting encounters with a wide range of others in locality. Many were recognised and known by community members beyond those they met as part of specific activities and had a sense of belonging to the local community. Participants enjoyed their participation in activities and developed skills through their engagement with the program.

Logic model: Shepparton Access

Theory of change: If Shepparton Access creates opportunities for individual participants to participate in a range of activities in a variety of highly visible settings then they will experience a sense of belonging to a community which embraces people from diverse backgrounds.

Inputs/Resources

Funding: State Government, moving to NDIS packages in 2019
Sponsorship local businesses
Donations
In-kind service provision - volunteers
Buildings and equipment, resources
Staff 18.8 EFT
Staff supervision
Staff meetings
Training
Recruitment
Typical attendance 5 days a week, from 9am – 3pm.
Total number of participants 98
Total budget \$2.5m

Program Components

Individual and program level planning
Imperatives for mix of on-site and in community activities with long term goal of inclusion without staff support
Creating opportunities for outside community members to come into program spaces and opportunities for participants to go out and participate in activities in mainstream places either as a separate group or with other community members, or in individual volunteer or workplaces.
Skill development and work experience opportunities with the aim of paid work.
Maximum use of natural supports with goal of independent inclusion.

Outputs

Social interactions and participation in a mix of individual and group activities in local community.
Certificate 1 courses.
Social enterprises.
Work experience and paid work.
Exposing local community to people with intellectual disability, emphasising their place within it.

Outcomes

Friendships with peers.
Regular convivial or fleeting encounters with wide range of others in locality.
Confidence and skill development
Enjoyment.

Context: The mission of Shepparton Access is creating pathways into the community. Shepparton is a regional town with a growing population and Shepparton Access is seeking to be a disability service which is highly visible in the community creating opportunities for its service users to engage in all aspects of community life.

Detailed Case Study: Shepparton Access

Shepparton Access is a disability service based in the regional city of Shepparton in Victoria. It was established in 1992, providing innovative support to eight adults with disabilities to participate in community life. The service quickly grew in size and expanded the range of supported day programs and activities. Shepparton Access now provides support to 98 participants and has remained focused on ensuring people are supported to participate in the communities of their choice and developing their skills and confidence to engage in paid or voluntary employment in the future.

Support is coordinated from three main sites in the Greater Shepparton region, two in the business centre of Shepparton. In the main building, the reception area and the CEO's office are positioned close to the entrance, making it easy for staff and participants to welcome visitors. The entrance leads down a narrow hallway, which buzzes with activity when participants and staff arrive in the morning and depart in the afternoon. This activity spills out onto the pathway on the main street, where participants and their family converse with Shepparton Access staff, staff from other disability services, and bus and taxi drivers. On the hallway walls hang large framed photos of participants engaged in activities at local restaurants and accounting firms. The hallway leads to a series of meeting rooms, office spaces and the staff kitchenette, and opens into a room at the back of the building where participants place their belongings. Participants commonly use spaces designated for staff activities. This building has a welcoming, positive and energetic vibe that suggests both participants and staff enjoy spending time in the space together.

Ninety-eight participants receive support at one or more of the service sites, and nine others are supported in other community settings. Most participants attend on a full time basis, between 9am to 3pm, 5 days a week. More than half of the participants have moderate to severe intellectual disability and complex support needs.

The program offers participants a combination of activities which take place on site and in community places, such as local neighbourhood houses, arts and recreational centres, with the aim that each person experiences a mixture of these each day. In the roster period during which the data was collected, the breakdown of time spent in different places and activities across all participants was 15% community inclusion (no accompanying staff reliance planned natural supports), 48% community participation (staff support in community places), 10% further education (certificate 1 level classes), and 27% at one of the sites.

Local community connections are central to Shepparton Access' success in enabling people with disabilities to participate in the communities of their choice. May, a staff member describes the planned way in which the CEO manages the presence of the service within its central Shepparton location.

Where I think our organisation may be a little bit different to others...we don't wear uniforms, we don't wear badges that identify us as Shep Access. She's [CEO] very anti that. When we are out in the community with our service users, it's not, they are the ones with the disability and you're the worker. It's all - we're all one. I think we - the way we access the community with our guys here is very much just how you and I would access it. I think it makes a big difference here, our position where we are in town. Makes a massive difference, because we're not driving buses everywhere and parking them in the disability park and loading them all out, loading them back in. We just walk down the street. They go from here, they go right up past the lake, back round, here, there and everywhere. (May, staff)

The Victorian state government funds the program, but like many other services, funding in the future when the NDIS is rolled out will be primarily from the individual packages of participants. The organisation is also funded by Skills Vic to run three Certificate 1 courses and an Initial Adult Literacy and Numeracy course. Whilst the primary focus of the service is community participation it also runs an older carers respite group, a family support group and provides individually brokered leisure activities and in-home personal support.

This case study draws on data gathered from semi-structured interviews with five program participants, seven Shepparton Access staff, including direct support workers and senior staff, and review of program documents and reports. Support workers were significant contributors to the interviews conducted with some program participants who had limited skills in verbal communication. Names have been changed to ensure confidentiality. Tables 1 and 2, in the appendix, summarise the characteristics and quality of life indicators for these five participants. Notably, their scores on part 1 of the Adaptive Behaviour Scale ranged from 140-275, where a score of 151 or below is indicative of a more severe level of intellectual disability.

Aims

The mission of Shepparton Access is also their motto; 'creating pathways into the community'. The program has a coherent design and seeks to create opportunities for individual participants to 'experience a sense of belonging which embraces people from

diverse backgrounds' (Shepparton Access Annual Report, 2016). The service has carefully defined its interpretations of community participation and inclusion; terms that are often used interchangeably elsewhere. The CEO describes community participation as being part of a process to achieving the longer-term goal of inclusion. From her perspective, being active and visible in the local area and in locally based non-segregated activities with support could lead to the gradual lessening of the need for that support to the point where the participant is engaged independently, accepted and included. Whilst a range of activities are offered at the Shepparton Access site, there is a strong emphasis on participants getting out as much as possible and becoming engaged and included in work, education and training programs, volunteering and leisure activities.

... when a person goes out in the community and interacts with the community with little or no support...then we have community inclusion...we also have another level of community inclusion, which we don't call complete inclusion, where clients might go out with staff support that might be ones or twos or threes. So, if they go out - like, if they go to the pool and there might be three or four people with a staff person, that's not complete inclusion. Even though they know the staff at the pool, they interact with the staff at the pool; they're still supervised by one of our staff, so that's a level of inclusion...So, to get to complete inclusion they have to be able to participate in activities with little or no support... And when we put our programs together we are able to identify the percentage of their week in a variety of things. So, whether they're involved in education, whether they're involved in virtually a segregated setting, which is back here, whether they're involved in partial inclusion or whether they're involved in inclusion. So, what we try to do is to build people up to more complete inclusion, so therefore that will allow us then to look at a work placement or enrolment in TAFE so we can transition them out. (Margaret, staff)

Kaitlin, a support worker describes community participation as being about;

...just getting out in the community...out of the building, rather than being cooped up here and doing whatever in-house. It's better for them to get out and be involved. It gives [the person being supported] independence...she might go out by herself eventually if she gets to know people.

All our staff, we've got a fantastic team, and they're very motivated to be in the community and very community-minded. ...the main goal is for us to be in the community, really accessing it, putting our footprint out there. (Eric, staff).

Community participation then in this program is perceived as a step towards the idea of ‘social inclusion’ and all activities are judged through this lens.

We mark ourselves very high, I know that, because other organisations would probably class going to a basketball stadium and hiring a court and it’s just them, inclusion. Well it is inclusion, don’t get me wrong, but we would like the part about doing it with other people in the community... well we believe here at Shep Access, that’s total inclusion...If I say community participation, that is actually participating in something in the community. (Eric, staff)

There are some participants who never attend the main building, instead are supported in the community setting in which their activities are taking place.

Community participation is something that takes place beyond the service walls.
(Jenny, staff)

The guys are engaged in the community...out amongst the local community. There’s just been a lot of benefits, like socially, confidence, just being out in the community.
(Eric, staff)

An important aim of the program is to alter local community perceptions about people with disabilities and their capacity to engage and to make meaningful contributions.
It’s important for Shep people to see our people contributing...as a normal person.
(Jeff, staff)

Ideally, we want to engage our service users into the community so they can be treated the same as everybody else. So that’s the ultimate goal. (Eric, staff)

Perceptions about the nature of the service were important too;

We get people out in the community...and it gets our name out there, which I think is really important – that we’re not a disability service that people come in and watch TV all day. (May, staff)

For example, the retail shop Eco Store, staffed by program participants with support from staff is important in both raising the profile of the service and in offering the opportunity for social interactions to occur. The shop is well known and patronised by a broad cross section of the Shepparton community.

Eco Store is well known. The shop’s really been helped by ads on TV...The amount of people that I hear now talk about, oh that shop, that’s connected to Shep Access.
(May, staff)

Program inputs

The main building is located on a main street in the Shepparton central business district and comprises offices and group activity spaces. The main building is leased while another site, located a few shops away, comprises a local produce store called Eco Store and a post-secondary Learning Centre which are owned by the service. The third site is a produce farm called Eco Park, based on the edge of the city's residential sprawl and leased at a minimal cost in partnership with a local primary school. The location of the main building is important and means that participants can use and move around the local shops without relying on public or service transport. This enables relationships to develop with workers who spend significant time in the district such as shop owners and assistants, and for participants to enjoy fleeting encounters with shoppers and others coming into town. Such informal recognition among people using town centres are an important aspect of life in regional cities. There is a strong sense that the location of Shepparton Access in a country town is an enabling factor that positively impacts on the opportunities participants have for community participation.

I think it is a sense of that belonging that you get from participating in the community, being there, and especially in a small town community...here you'll just say g'day to anyone, really. (Beverley, parent)

...regional areas seem to be a bit more open to listening to people, just more open than in a city. They're happy for a chat, that's an advantage we have. (Eric, staff)

The central location also enables managers and staff to develop and maintain rapport with local business owners, facilitating the creation of work or volunteer opportunities for participants.

Significant attention is paid to ensuring staff are able to support participants well, in the activities of their choice. Managers purposefully recruit staff with particular qualifications and skillsets. For example, qualified and experienced chefs are employed to support participants to cook food, personal trainers to support participants to improve physical fitness, qualified teachers to support participants in structured learning programs, and local community art directors to support participants to develop performing arts skills. Staff with demonstrated team-working skills are particularly sought after, based on the notion that they are more likely to work collaboratively with others to provide good support to participants. Regular staff meetings, supervision and training are important program inputs. An

organisational culture which encourages staff to work as a team is strongly promoted by the senior staff.

They need to be able to collaborate, be a part of a team. We have a very tight team here. (Margaret, staff)

Other inputs to the program are from partnerships and sponsorship arrangements with businesses and community organisations in the Shepparton district. The installation of information technology infrastructure in the recently established Learning Centre site was supported by two local service clubs and Australia Post. Links to the local community groups and businesses by the development of strong positive relationships by senior staff are important in creating opportunities for work experience, voluntary work and participation in mainstream activities.

Funding for the Department of Health and Human Services has been attached to each individual for some years, and will shift to funding through participants' NDIS packages when the transition occurs for this service. The service is also funded to deliver post school pre-vocational programs in literacy and numeracy through Skills Vic. The service developed a formula several years ago for calculating the support needs of individuals participating in group and individual activities. The costs of support can be calculated for 1 or multiple hours. This formula was incorporated in the Service User Information Program (SASU). Other costs included in the formula include fixed costs such as our rent, depreciation, internal travel in program etc.

The program has a total annual budget of approximately \$2.5m, and 19.8 effective full time staff. The management team comprises a full time CEO, Business Manager and Program Manager. In addition, there are two full program staff, a full time personal assistant to the CEO and 20 part time staff. Staff are paid under an organisation specific collective agreement (The Shepparton Access Disability Services Collective Agreement 2008). They have various qualifications including TAFE certificate 4 in Disability Services or Training and Assessment, Advanced Diploma in Disability Services, and Bachelor of Applied Science (Disability Services). There is a low rate of turnover among staff whose length of service ranges from 9 months to 15 years.

There are no waiting lists for the program, and most requests for support are accommodated. Detailed information about participants and pre-existing plans, medical needs, and consent issues are collected when a participant commences at the service. During

the intake process both participants and families are provided with an information kit and service agreement.

Program components

Individual and program level planning of activities

Staff work closely with each participant and their families and carers to find out their preferences and interests and plan a program based on these.

Obviously, each service user comes with different goals and aspirations, and how far they can [properly] access the community on an individual basis. And obviously, these get set with their planning as well, their goal setting and planning for what they want to gain out of the community as well, and we can assist and help them. (Eric, staff)

A high level of planning and organisation goes into creating opportunities for purposeful activity and engagement using individual plans as the foundation;

So, the plan ideally drives the roster to a degree, because if Joe Smith wants to go swimming we'll have a look at if there's availability at that time, is there a group already there, if he wants to go in to it. So, it all works hand in hand, the planning, and the roster. (Eric, staff)

They're [programs] not just there for no reason. Every program has a purpose even if just for enjoyment, recreation, but then it's not as sporadic as what you think. There's a lot of planning; that goes into all that...'this can lead into that', 'that fits in there'. (May, staff)

Activities which have community participation as their focus are structured in one of two ways, as described by Maria, a support worker;

All the activities are about participation and inclusion whether they're coming into us or whether we're going out to them.

Shepparton Access invites others from the local community 'in' to their programs and activities in a range of venues which include the 'Eco Store' retail shop in the centre of town and working with volunteers to grow produce at 'Eco Park'. Alternatively, opportunities are created for participants from Shepparton Access for 'going out' to engage in activities in others in places such as the pool, school, retirement village, as exhibitors in the Shepparton horticultural show and competitors in the Goulburn Valley Netball League. Activities in the community vary from just being there or present in a mainstream place but doing separate

activities with peers to being actively engaged with other community members. A staff member described the difference between people being present in the community doing activities in the same space but not together and therefore not 'included' with this example;

But if we're just accessing a room, at Arukna hub doing our craft program, we are participating in the community not really included. (Eric, staff)

One approach for example, has been to organise cooking classes in a local retirement village in which the participants are a mix of people with intellectual disabilities and retirement village residents. This example of proactively 'going out' to facilitate community participation is indicative of an approach which seeks to creatively engage with as many groups as possible in the local area.

The best part [of working at Shepparton Access] is just helping them and watching them progress. I run all kinds of gym programs and sports...eight of the nine activities I run are community-based...I'm always out of the building...we're always out, always in the community. And nine times out of ten, people will see our group and they'll know us. (Kaitlin, staff)

Tapping into the opportunities for participation already available in the Shepparton area and finding those of interest for participants was an ongoing process for the service and for family members;

... just getting out and being involved in, for example, say art classes or some sort of activity that interests you. Going to the local North Shep hub, or whatever they call it now. You know community centres? And being involved in activities through that...getting out and doing some voluntary work, that's probably going to be the next stage. I don't know maybe that's another way to be involved in the community. (Caroline, parent)

Creating work and volunteering opportunities through networking

The program offers a range of pre-vocational and certificate 1 courses through Shepparton Access' Learning Centre and these have a strong vocational training and life skills focus which a staff member describes as putting people in 'real-life scenarios' which attempt to replicate a process from start to finish;

...you need to wash it and then dry it and then put it away and then all these sort of things that, if you're skipping and - working as a team's good but, if you're skipping a few processes, you never actually get to see the whole picture. It's all about building

up confidence...we try and let [Kristina] be as independent as she can be...be active in the community. (Jenny, staff)

We think about where do you support and where you don't support. And you never want anyone to get hurt or anything like that but sometimes when they can't do something you've got to let them not be able to do it so they learn. (Maria, staff)

Skills development through participation in classes is designed to happen alongside work experience for participants who are ready and interested. The program facilitates a range of opportunities for participants to engage in unpaid supported work which reflect the interests and preferences of the participants. Placements are carefully selected and negotiated and ongoing support provided to ensure positive outcomes for participants.

What we do is go and work out what the job entails, dividing it down, working out who the supervisor is on the day...so we've actually been able to negotiate to do a day that suits us and her other activities. And so, we now have been up and we've spoken to one of the employees, probably the senior employee of the day, and we've done some work around her about how to instruct, that she needs simple instructions, she needs regular check-ups, only one or two step instructions. (Margaret, staff)

This staff member described a successful long-term work experience placement for Tim at a local secondary school.

...he's like a maintenance assistant. He has a couple of special designated jobs that he does. He gets to use the sweeper and does some of the paved areas and stuff...He gets to do that and empty some bins, he loves it. The feedback from his employer is that he knows his job and he's showing some initiative. (Eric, staff)

Work experience is described by this staff member in these terms;

...clients are going in and interacting with the community. (Eric, staff)

One of the goals of the work experience program is to develop opportunities for ongoing paid supported employment. This goal is described as being 'the ultimate'. Whilst some service users are already employed on a part time basis at Yooralla's Dual Ware site in the nearby town of Mooroopna, this is a segregated setting and Shepparton Access' goal is to develop opportunities for employment in local organisations and businesses which are not disability-specific.

Using and supporting natural supports

The way in which people are supported to participate is critically important. Rather than always providing direct support to participants in volunteer or work placements, staff work with other people in a setting to enable them to provide less formal support. As Margaret said about a work experience placement she had organised,

And we've done some work with that employee and now the employee supervises her. And we go up every now and again and have a cuppa and see how she's going.

Another staff member described the programs' 'natural support model';

We use a natural support model which is people participating in programs that other [people] in the community are participating in at the same time... You set up a work experience model... I'll be there one-on-one with the client for the first - everyone's different. It might be a month, it might be two weeks. It depends on the employment placement, the host, and also the client to make sure everyone's happy. When everyone's happy and they're comfortable, then we wean off support to allow independence. We've got guys out there doing work experience which are totally now basically just dropped off and picked up, so they're getting that natural support model which - the more natural support models we can actually within the community, works for us and also works for the service users because they feel so much more part of the community. (Eric, staff)

He went to relate an interesting anecdote about the way in which support was gradually removed in order to facilitate independent participation and reliance on natural supports. A number of Shepparton Access participants had gone regularly to the local pool for a swim, walking there from the service building. The women were accompanied over many weeks by a support worker. Gradually over time the support worker ceased doing some activities such as going into the changing rooms and then it was determined that the participants could go independently to the pool. This led to a surprising phone call from staff at the pool to the support worker at Shepparton Access when they noticed that the women were not being 'supervised';

The first day they were doing it independently, I had a phone call from Aqua Moves after I'd set it all up, and they said, where's your worker on the side of the pool? And I said, no I've discussed it, and I forget the person's name at the time, and they said, oh well what happens if they start to drown? And I said, well I would hope the

lifeguard saves them, like they would save everyone else. Oh, they said, that's a good point. (Eric, staff)

Outcomes

Shepparton Access' strong focus on building an element of community engagement into all their activities had led to some positive outcomes for individual participants.

Regular convivial encounters and sense of belonging to Shepparton community

Most program participants spent a proportion of their time engaged in a range of individual and group activities in the local community where they were known and interacted with community members. Support workers said for example,

But the attitude, everyone is really good towards them. (Kaitlin, staff)

The school is beside us, the kids were up wandering around and working on their garden beds. She went over and introduced herself, the kids all said hello to her, and the teacher spoke to her. Look the grin on her face couldn't have been any bigger when she came back. She said, "[Maria] the kids said my name," because they all said, "Afternoon [Louise]!" And the teacher. So, there's that community inclusion and there's that respect and everything like that. (Maria, staff)

Through regular contact as part of program activities, participants were also recognised and acknowledged in other settings by community members. One staff member commented that she had mostly observed positive interactions in the town of Shepparton between program participants and other community members;

...nine times out of ten they're happy to smile and say hello or whatever else...their attitudes towards them are always pretty positive. (Kaitlin, staff)

They go out and bowl and everyone knows everyone...they make friends. You don't want them to be sheltered and excluded from everything, so it's just good because they're always out and meeting new people. (Kaitlin, staff)

Staff described the positive outcomes Tim had gained from working at the local school;

He's not here for a free ride. He's got to work...over the time he's got to know what he needs to do...he shows initiative. I don't have to tell him. He just keeps going. The local community, they all know him too. (Jeff, staff)

All the kids say 'hi' to him at the school and they had a massive cake for his birthday. People know him around Shep. (Eric, staff)

Indeed, a number of interviewees commented that the Shepparton community had become accustomed to seeing people with intellectual disabilities regularly in the local facilities such as the pool and in the shops and cafes in the town. This regular contact and exposure was important in emphasising that people with intellectual disabilities belonged in community places. For Caroline, whose daughter is a program participant, the profile of the program in the local community had contributed to a sense of belonging and safety;

I think it is a sense of that belonging that you get from participating in the community, being there, and especially in a small town community, I guess, not that I've ever lived in a city. So, I don't - it's hard for me to comment on that...also I think it's the safety thing a little bit, too. I guess knowing that there are people there that will look out for Kristina, if I wasn't there. (Caroline, parent)

The notion that everyone in the community recognised and 'looked out for' Shepparton Access participants was echoed by other interviewees.

Friendships with peers

All of the participants interviewed described both long standing and newer friendships formed with other participants. Some also described developing friendships with co-workers whilst on work experience placements. One support worker described friendships formed between the person she supports and other participants who were fellow gym attendees. These were 'in house' and not pursued outside the gym but had been important in her enjoyment of the program and desire to continue attending.

They sort of make their in-house friendships as well. Like, I don't know if she was friends with them before the gym program, but I know that she is now since the program started. So, she's made at least about three or four friends just through that. (Kaitlin, staff)

Enjoyment, confidence and skill development

Louise, a participant talked about the enjoyment she gets from gardening at Eco Park describing with humour how dusty and dirty she is by the end of the day;

I come home and mum says what have you been doing? (Louise, participant)

She has grown in self-confidence since she first began in the program and is becoming more independent;

Mum's had an operation on her shoulder. I've been coping very well without her. (Louise, participant)

Another staff member described the feelings of independence, confidence and enjoyment the person she supports had gained out of her engagement with the Shepparton Access program;

...she has gained a lot of independence...it goes back to feeling important, that recognition...we all want to feel good and needed and cared for, that's human, that's natural. She feels included and knows people. She has built friends as well. Look it's just building her confidence and getting her to be able to do it and think that she can do it and feel valued and needed. And she's giggly, bubbly, she's very light-hearted, she loves a joke. (Maria, staff)

For Colin, another program participant, his interest in computers has been developed through classes at the Learning Centre and his one of the staff team is now exploring opportunities for him to undertake some vocationally focussed IT training through the local TAFE College.

Colin also works in the Eco Store with his support worker describing him as 'the most competent one' who both packs the fruit and vegetable boxes and also produces the templates for filling the boxes on the computer. Colin says that he enjoys the range of activities in which he's involved at Shepparton Access and feels 'welcome';

Yeah, I enjoy it. The people here, they're kind. (Colin, participant)

Whether or not they're just thinking oh, look at that cute little boy with Down's syndrome and he's doing something that's you know, rather than actually not seeing that at all and just seeing someone that's delivering a paper. You've got no idea but I think generally we get a pretty good go by most of the people that we - you know, community partnerships and stuff that I suppose treat the guys that we're with respect, do you know what I mean, and see the fun that they're having and want to be a part of that rather than feeling sorry for them. (Jeff, staff)

Vignette

The following vignette illustrates outcomes for one Shepparton Access participant:

Tim is a 38-year-old man who lives with his mother in a rural town. He works four days a week as a Maintenance Officer at a local private secondary school, where he supports the Maintenance Manager, Ross. Tim and Ross have officially worked together for 8 years, although prior to this Tim attended the school as a student, and helped Ross with the occasional job when class did not interest him. Tim and Ross reflected on their strong working relationship: Tim: "I like to be here with Ross." Ross: "We have our moments, don't we, Tim?" Tim: "You're Hutch, I'm Starsky, right?" Ross: "Starsky and Hutch."

Tim's work responsibilities include emptying bins and ensuring other maintenance processes are carried out, such as vacuuming, organising road safety equipment, and refuelling buses. A favourite part of the job is emptying the bins: "I just do bins, all that". The school made adjustments to the waste processing equipment so Tim could complete the job independently. Tim often reminds Ross about jobs that have been overlooked. Tim knows he is an important part of the team: "Ross needs me, he does." In between maintenance tasks, Tim makes hot drinks "black coffee" for colleagues including administrators, teachers and the school principal, and enjoys chatting with them on morning tea and lunch breaks. Tim is famous for his speeches at school events, such as birthday celebrations.

Tim makes the most of the time off work by kicking his boots off and putting his feet up: "I have a beer". He spends his time listening and playing music: "Just guitars, strumming," and regularly attends musical events with his mother in Melbourne. Tim and Ross also spend time together out of work hours. Over the years, they have got to know each other's family members very well.

Every few months, a support person from Shepparton Access calls Tim and Ross to talk about Tim's role in the maintenance team and to ask if they need any additional resources to ensure Tim is supported in his role. Ross is hoping to retire soon, and is working with other maintenance officers and the support person from the local disability service to ensure Tim can continue in his role once Ross retires.

Arts Project Australia - summary model of community participation

Theory of Change

Creating a space in which individuals with intellectual disabilities are supported to produce art will develop their sense of belonging to the arts community, and an identity as a working artist.

The primary conceptualisation of community participation is concerned with belonging and identity.

Place

Arts Project is a segregated program setting within a dedicated building close to a neighbourhood centre in inner urban Melbourne

Activities of interest

Arts Project offers program participants art activities which include making art, exhibiting and selling works of art and learning about art styles, techniques and history. It also offers artists visits and tours of other studios and galleries and opportunities to work in collaboration with external artists.

Social interactions

Participants have regular social interactions with others with intellectual disabilities in the studio and gallery at Arts Project. They had regular interactions with the staff and volunteers at Arts Project and with external artists and mentors, and intermittent interactions with workers in local businesses, especially the cafes in High St, Northcote, and others in the arts community through joint exhibitions, commissions and collaborations.

Outcomes

Participants develop strong identities as working artists and experience considerable enjoyment in practising as an artist at the same time as further developing their skills. They gain a sense of belonging to the artistic community. They have developed friendships with peers, and experience convivial encounters with peers, others in the arts community and shopkeepers in the local neighbourhood.

Logic model: Arts Project Australia

Theory of change: If we create a space in which individuals with intellectual disability are supported to produce art, then they will develop a sense of belonging to the arts community, and an identity as a working artist.

Inputs/ resources

Funding- Cwth, State (70%)
Fundraising
Misc. grants
Sponsorship
Donations
In-kind service provision
Facilities, equipment, resources
Staffing 10EFT
Supervision
Staff meetings
Training
Estimated NDIS costing \$24 per participant hour
Total budget \$1.7m
Typical attendance 2 or 3 days a week from 9.30am to 3.30pm
Total participants 135, 45 on any day

Program Components

Selection process
Artist studio and hand in glove support
Curation of exhibitions
Collaboration with external artists
Organising gallery visits and art appreciation sessions
Selling art works or supporting commissions

Outputs

Serious art practice and production of art
Sale of art, placement in exhibitions
Exposure of artistic community to talents of people with intellectual disability and collaborative opportunities

Outcomes

Strong identity and enjoyment of being an artist and artistic skill development
Sense of belonging to artistic community
Convivial encounters with peers, others in the arts community and shopkeepers in the local neighbourhood.
Friendships with peers.

Context: The mission of Arts Project is to advocate for the inclusion of people with an intellectual disability in the arts community and to provide a space within which people can work to produce pieces of art.

Detailed Case Study: Arts Project Australia, Northcote

Arts Project Australia has operated since 1974 in a number of different venues in the inner-city Melbourne suburb of Northcote. It is currently located in a former shoe factory within which there is a ground floor art gallery, stock room and offices and an art studio on the upper floor which runs the length of the building. A total of 135 artists, most with mild intellectual disabilities work in the studio two or three days a week between 9.30-3.30 Monday and Friday. At any one time there are likely to be 45 artists in the studio. Another 50 artists attend one of the two recreational programs that run for two hours on a Saturday. There is also a weekly small life drawing class from 4.30 to 6.30 on Tuesdays. The program tends to take school holidays but opens early in January meaning it operates for 43 weeks a year. Some of the artists have a long-standing relationship with the program having attended over many years. There is a waiting list for a place in the program.

Arts Project staff, themselves artists and called 'Staff Artists', work in the studio and guide the participants in the production of painting, drawing, ceramics, printmaking, 3D sculpture or digital media. There are also volunteers who work in the studio. Staff artists and volunteers do not offer instruction, but support individuals to develop their technique and personal style. All of the artists show their work in an annual gala show and others who have developed their art practice over many years may have a solo show in the downstairs gallery. Collaborations with artists outside Arts Project are facilitated by staff, as are relationships with other galleries and art dealers with an interest in selling or promoting the work of particular artists. The program is funded by the Commonwealth and State governments and some income from the sale and lease of art and merchandise, memberships and some one-off grants.

This case study draws on data gathered from semi-structured interviews with five program participants, six Arts Project staff, five parents or carers of participants and review of program documents and reports. The researchers spent 12 hours over several days in the studio observing the program and attended two gallery events. Names have been changed to ensure confidentiality. Tables 1 and 2, in the appendix, summarise the characteristics and quality of life indicators for these 5 participants. Notably, their scores on part 1 of the Adaptive Behaviour Scale ranged from 180-277, where a score of 151 or below is indicative of a more severe level of intellectual disability

Aims

The program has a coherent design. Its mission is to support artists with a disability to produce works of art, to promote their work and advocate for their inclusion in the arts community. This is clearly reflected in comments made by staff;

Well, our mission is to promote, support and advocate, and I think - or support's the first thing. Support artists with a disability, promote their work and advocate their inclusion, and that's the bottom line.... I guess because part of our mission is about advocating for inclusion, within contemporary art practice, so when I talk about participation it's within the contemporary art practice. (Katherine, staff)

The studio manager states the mission simply as;

For people with an intellectual disability to make art. (Stephen, staff)

Arts Project staff are also clear about what the program does not provide and in so doing identify its point of difference from other disability programs.

We're not trying to fix people, we're trying to supply a space where artists can work, so if you need support in other areas, you go somewhere else. But, we supply a space to do the art. (Fiona, staff)

...we're not here to do anything else, really, and that's a part of Arts Project's strong philosophy, really, as well. We're an art studio. If you want other things, we'll help you find them. And, some of the artists say, "I'd like to learn how to do cooking. Why can't we do that here?" and we go, "Well, because we're an art studio," and they go, "Oh, yeah." But if you want to do cooking, they do at Northern Support and we can help you go there. But, we're not going to do that here, and the artists are usually pretty good and I think that they understand. (Gabrielle, staff)

...because the organisation is about the artist having a serious arts practice. It's not just a leisure activity. (Lesley, staff)

...so, we don't do dance lessons, and we don't do cooking, and we don't - so from where we are, it's about helping artists develop relationships with artists that don't work here, other artists, external artists, curators and gallerists. (Katherine, staff)

The Executive Director of Arts Project sums up:

We're not a disability organisation, we're an arts organisation, where the artists happen to have a disability. That's how I prefer to look at it. So, we don't bang on about the disability, we bang on about the art.

Program inputs

Funding for the program is through State and Federal grants. Nineteen of the artists are funded by FAHCSIA and the remainder have individualised packages through DHHS. Arts Project is currently undertaking work to bring in new systems to manage the transition to NDIS funding packages for program participants. Additional income is generated through the sale and lease of artworks, the sale of merchandise and through one-off grants from Philanthropic Trusts. A number of volunteers provide labour in the studio and there are one-off in-kind contributions. For example, an architect developed the designs for the studio and gallery in the current premises pro bono. Artist mentors and guest exhibition curators also make in-kind contributions. The building is fully owned by the program. The overall per annum program budget is \$1.7m. It is estimated that the cost per participant hour is \$24.

Overall there is the equivalent of 10 full time staff. Four staff are full time, 16 are part time and three are casual. As well as Staff Artists, most of whom are part time, there is a management team of an Executive Director, Business Manager, Studio Manager and Gallery Manager and administration staff. All staff have at least a Bachelor degree and Staff Artists working with participants in the studio are required to have qualified with a Bachelor of Fine Arts or equivalent. The program has its own enterprise bargain agreement which is based on the SCHADS award which is used when necessary.

We have a few staff who do have some disability training, or background, but if you look at the position description, it's nice, but not required. So, that's the requirement, is that you have to have a fine arts degree, and if you come with disability training, that's nice. And, we try to avoid people with arts therapy background, even though we do have one staff member who does have arts therapy background, but she recognises the difference between what we do at Arts Project and what she's been trained to do, and she's very good at making sure she doesn't bring that with it. (Fiona, staff)

On average, staff have worked in the program for 4-5 years, with the longest serving member having been there for 12 years. The age range of staff is wide, between 25-55 years. Staff are strongly committed to their work, as one staff member explained.

I feel like the staff are all passionate and engaged in the work they do. They're all here for the right reasons. And the amount of Staff Artists that will go above and beyond in a kind of unpaid capacity while I try and manage that, because its, you know, you need to maintain a work/life balance, it tells me that they're interested just beyond coming here as a day job. All of the staff are here on a permanent part time

basis, so they're here from two to three days a week, but they all know that it's a commitment and it's not just paying their way through uni. It's not a café job, it's not working at the supermarket three days a week to make rent. (Stephen, staff)

Staff are regularly engaged in training which supports the way the organisation wishes them to work with the participants and develops their skills and knowledge.

...we do external workshops or when we get somebody else to come in and show us to do a few things, those really invaluable resources. So, an exchange of ideas or an exchange of knowledge from somebody else, it's just really to spice things up a bit. So, at the moment we're thinking of doing a workshop on sound, on creating sound effects, and that's something that I'm not an expert in, but we definitely need someone to come in and show us what is possible. So, those sorts of things are exciting, and they are very good resources. (Emma, staff)

Staff also participate in regular training on disability service standards, first aid and managing challenging behaviours. Regular staff meetings and daily 'studio debriefings' are also scheduled.

Program components

Selection process

An intake process is managed by the studio manager. The program is open to any person with an intellectual disability who is interested in art. There are two or three enquiries per week. If a participant requires support with activities of daily living such as eating lunch or using the toilet then that needs to be provided separately from their funding package as externally paid support. Those enquiring about the program are invited to come for a tour of the studio and gallery and talk with the studio manager about their interest. If there is a vacancy in the program then an interested applicant is invited to attend for a trial period.

So really, I just want to see that they want to make a commitment to being a studio artist here. And then we have an enrolment process, and then we'll give them, I guess a probationary period, which generally will just then turn into a prolonged enrolment in the studio. (Stephen, staff).

Artist studio and hand in glove support

Artists attend the studio between 1-5 days per week, with most attending for 3 days. There is no limit on the amount of time artists can be a part of the program, and one man has been

making art at Arts Project for 23 years. There is currently a waiting list which is managed by the studio manager. There are also two recreational arts classes that run on Saturdays.

Several of the staff noted that the approach of slowly introducing people into the program and carefully checking their interest in making art had led to few people being asked to leave the program;

There have been times when we've asked people to leave, but it's very, very rare and it's usually to do with - their behaviour indicates that they're not happy at Arts Project, and that's pretty much all. (Fiona, staff)

Staff work with artists to find out what kind of art they would like to make and there are people producing ceramics, paintings, drawings, crafts and digital works. Staff Artists with particular expertise work closely with artists wanting to explore or develop skills in that medium, for example, one of the Staff Artists has her own practice in digital art. Some of the artists work in a range of different mediums whilst others focus on just one. The ways in which the Staff Artists work with participants are a crucial part of the inputs to the Arts Project program. In combination with the purpose designed and well equipped physical space, they create a 'nurturing' environment, described here by one of the staff;

...the artists are seen as people that have their own distinct style and they are developing a strong arts practice of their own, alongside their peers, the mainstream artist peers in the wider community. So rather than it being like a classroom situation, where we are all doing the same thing today, it's about them having their own arts practice in an arts studio, and we are just facilitators who are supporting them. It's not about directing them so much. It's about being a nurturing environment for people who might have difficulty with certain things... (Lesley, Staff Artist)

Staff describe a particular way in which they work with the artists in the study which is reflective of this emphasis on art rather than disability knowledge and focus. Calling it a 'hand in glove' approach, staff do not touch the artists' work.

We expect the Staff Artists to engage with and support people as they are making art. Not to be hands on, interfering, but supporting and sometimes being available to share specialist knowledge...about materials, techniques... So, I think we recruited really well and just to see the personal relationships that develop, and they do get to develop because the artists want to be here for a long time. All of our studio staff have been here for a number of years now, so they're on that journey together. I tried not to say journey through this whole - and I just said it! (Stephen, staff)

The gallery manager describes the ways in which the staff work as ‘opening up the world’ of participants through collaboration, support and advocacy. When observing interactions in the studio and gallery spaces between the artists and the Staff Artists researchers noticed that they were positive, warm and often had an element of humour. Positive reinforcement about progress on pieces of art came from all of the staff and a gentle but direct approach was taken to manage any disruptive or anti-social behaviours in the studio. Art is produced in the studio by the person with an intellectual disability, no other person intervenes to ‘help’ to make the art and therefore they can legitimately claim it as their own. The studio is a work-like environment in which all are busily engaged in production and as workers. People attend on set days and at set times, there are tea breaks and lunch breaks, there are offices and managers, all of these are features of a workplace.

Exhibitions and collaborations

An annual gala show features exhibitions by all of the 120 program participants and there are also a number of other shows and solo exhibitions which feature some of the more experienced artists in the studio. A small number of the artists participate on a voluntary basis in a group called the ‘Northcote Penguins’ which extends explorations into art history and appreciation and involves members in talks, gallery visits and tours.

Selection for participation in these activities is not ‘tokenistic’. Whilst everyone makes art during their time at Arts Project, they may not be selected to exhibit their work or take part in other activities. This is in line with the organisation’s commitment to providing a place for individuals to produce art and to be included in the creative but commercially competitive arts economy.

I think it’s treating the people as adults in this community and not being tokenistic about what we do. Not everybody gets a poster for participating. We think that that’s part of being an artist, and you don’t always have success, and you don’t always get recognised, and sometimes you get pushed down and down and down again and again and again, and so long as we’re there to make sure that we support them through that process, it’s an important part of being an artist, I think. So, avoiding that tokenism that you can get in a lot of disability services... (Fiona, staff)

Collaborations with external artists and galleries are an important activity in the Arts Project program. The studio manager describes these activities as being of benefit both to the artists at Arts Project and the external artists:

A lot of the feedback we've had is it's a two-way learning process. So, the external contemporary artist will come in and either work in the studio amongst our guys, or they'll go to their studio, but either way, they'll let us know that it actually helped their own practice as well. They got some things from the way the artists they worked with worked and thought about things, that they are taking on to their own way of working. So, I think there's often a kind of cross-pollination there... (Stephen, staff)

Through its exhibitions and collaborations with external artists, Arts Project has developed a strong profile, nationally and internationally as a provider of supportive space in which people with intellectual disabilities can produce art. Arts Projects' reputation and connections particularly to 'Outsider Art', which both the Executive Director and studio manager described as growing in popularity, have helped its artists to benefit from the expanding market for this type of art.

So, we've held a symposium here about six years ago, we brought in a few international studio and artwork from those studios with some key speakers. We had the Outsider Art conference in 2014 partnered with Melbourne University, and again, that brought in a wider audience. I think just internationally, the field of Outsider Art, Art Brut has become much more popular as well, so I think a lot more people are seeking out the kind of work that's made by people with intellectual disabilities, or people who have been on the fringes of those kinds of things, intuitive art, all of that. So that profile's quite big at the moment, it's having a real - not resurgence, because I think it's never been as popular as it is now. (Stephen, staff)

At least three pieces of art from two Arts Project artists are included in the Museum of Everything exhibition of outsider art at MONA in Hobart which was held during 2017/2018.

Outcomes

Participation in the Arts Project program has produced a range of outcomes for the artists.

Development of strong positive identities as working artists.

The focus on the production of works of art and on the studio as a workplace for artists and Staff Artists contributes strongly to the development of strong positive identities. The unpressured way in which individuals are free to explore and develop their own skills and personal artistic style are also key to the sense that they are people with developing careers acting in purposeful and meaningful ways.

The business manager described conversations about identity with the parents of several artists;

I got to sit down with [artist] and his mum and dad, because Ian's a little bit difficult to understand his language, and it was just great. And, right at the end of the interview, I asked [Ian], "Are you an artist?" He says, "Yes, I think I am. Yes, I am. I'm an artist," which was really quite nice. And his parents told me when he's at home, his language about coming to Arts Project is, "I'm off to work. I have to go to work." (Fiona, staff)

I was talking to one of the mums. She came in here to do her planning meeting, so we had the NDIS ladies, all the Brotherhood ladies were coming in to do the meeting with [D], and I think she said something like, "Arts Project's really changed the way [D] sees herself," and that we're wonderful and we treat her really well, and all those things. (Fiona, staff)

I am an artist. People like my stuff. They buy my stuff. Mum likes it, it's a better place than other places I've been in the past. Now I am an artist. (John, artist)

It gives him a reason to get out of bed in the morning. (Laura, parent)

The notion that the artists are developing a 'career' is an important part of the idea that Arts Project is about developing and supporting working artists;

...once they get in and they start working towards a career - I mean an art career for any artist is a long, it's a lifetime commitment, and these are any other artists, and they recognise it as well. (Fiona, staff)

The Business Manager says that Arts Project works to develop an understanding

... that the career of an artist is by being recognised by your peers, and it's not just being recognised here at Arts Project, it's being recognised by your peers out in the community... And, you'd probably get maybe 25 per cent of the artists here that would really, truly understand that, and know that that's the process through which you become successful in the eyes of the arts world, I guess.

Through supporting and advocating for artists, Arts Project seeks to develop and affirm the participants' identity as working artists and to instil an understanding that art practice takes time, as does finding an audience, and potentially customers for pieces of art. Those who have sold or shown art shared feelings of great pride or have worked hard to finish a piece and the staff share in those feelings.

I just enjoy those small moments of success, just when someone has a little breakthrough, or when someone's spent a long time trying to accomplish a goal of theirs and they achieve that. (Stephen, staff)

...I get paid for what I'm good at...When someone buys it I know that someone loves it more than I do! (Stephen, artist)

I've been longer than most. My work is popular. I sold a few at the pop up we had [at the Sofitel] and everyone said they liked my [ceramic] ladies. The manager bought a painting. (John, artist)

I had a solo show at the front. I've been doing my art for years. (Elisabeth, artist)

The mother of one of the artists commented that Arts Project had, over a number of years 'mentored, supported and nourished' her daughter's sense of herself as an artist and that this had transformed her confidence and happiness.

A sense of belonging to an art community

Arts Project develops for participants a sense of belonging to an art community. The Executive Director is quite explicit in her articulation of the mission of the organisation that it is to 'include within' the arts community. Close relationships and collaborations occur in the segregated studio environment at Arts Project but also further afield through collaborations with external artists which occur within and outside the studio and in the local community. Exhibitions of artists' work at the Arts Project gallery and in other galleries in Australia and overseas contribute strongly to the artists' sense that they are part of a large and specific community.

Artists like Alan have their work in the National Gallery, people collect his work, he is acknowledged as an artist by other artists. (Katherine, staff)

A parent offered this comment;

...it's being able to be part of the wider community by her work being displayed in the exhibition centre or Fed [Federation] Square it sort of heightens the level of participation that normally she wouldn't be able to... (Kate, parent)

Art is the vehicle for building community for the artists;

So, it is very much – it's the studio that people come to, and make art, and that goes out into the community and people come in. (Emma, staff)

Convivial encounters and friendships

The ‘community culture’ described by one staff member is built on friendships and relationships with those who work in studio; artists and Staff Artists whose interactions took place mainly within the studio. Only one of the artists we interviewed described having social interactions with other Arts Project artists outside the time they spent at the studio or on breaks in the nearby Northcote shopping strip, but all spoke enthusiastically about friendships and positive interactions they had with others in the studio.

Relationships develop between staff and artists and between the artists which are supportive and positive.

I’ve got good friends here and we all love doing our art. They are very understanding of my problems. I feel comfortable... (Elisabeth, artist)

We are artists when we are here. I think my stuff is pretty good. Other people say good things about it people here. (Connor, artist)

Another artist commented;

I like being here and being around my friends. (Carol, artist)

Commenting on her son’s sense of belonging to an art community, Chris’s mother said;

He just fits into that art wanker world. (Laura, parent)

Connections to the local Northcote community have developed over the long period of time that the organisation has been based there. A number of the artists described a level of comfort and safety in that community and that it was a ‘friendly place’. The staff describe the connection and positive regard of the local community for the artists as being strongly grounded in their recognition of them as being part of Arts Project and as artists. The links to the local community were important and positive but the focus of Arts Project seemed most strongly to be about developing connections within the art community created at the studio and in the broader sense. Artists had developed a sense of belonging which had engendered a ‘sense of confidence’ about ‘moving about in the world’ (Emma, staff)

The studio manager commented that;

From our point of view it’s just trying to have the artists engage with the broader community, but in an unforced way.

Vignette

The following vignette illustrates outcomes for one artist participant:

Elisabeth is a 37-year-old artist who has been working in the Arts Project studio for 20 years. She is at Arts Project 4 days a week. Elisabeth lives with her mother and their much loved tabby cat about 15km from the studio. She travels alone there and back by tram and train. On the one day a week Elisabeth is not at Arts Project she works as a volunteer at a kindergarten where she does cleaning tasks and also plays with the children.

Initially Elisabeth found it difficult to feel comfortable at Arts Project because of her OCD. She began working with acrylics but found them 'too messy' so she experimented with a range of other media until she found other ways of making art which she really enjoyed. At the moment, she most enjoys drawing landscapes and working with ceramics. She has had a solo show at Arts Project and her work has been displayed in other exhibitions. Elisabeth has worked on a number of collaborations with other artists and says she is 'really happy' with her work. She has sold a number of pieces of her work and says that she finds it 'very exciting' but 'strange' that someone she has never met has bought her pieces.

Elisabeth said that the staff at Arts Project make her feel 'safe and comfortable' and that it 'feels good' to know they are always available for a chat. She also has three close friends in the studio and although she doesn't see them outside their time there she says that they are good to talk to and she enjoys eating lunch with them each day. Elisabeth contrasted the level of comfort and safety she feels at Arts Project with the way she sometimes feels on her journey to the studio on public transport. She says that she feels that people 'pick up' that she has an intellectual disability and are rude. This makes her 'get very upset'. Elisabeth also described the community places local to Arts Project as being 'friendly' and 'kind', saying that the café staff 'know all the artists' and are 'kind'.

Outside her working hours at the studio and kindergarten, Elisabeth enjoys spending time with her mother, her sister, nieces and her boyfriend and with some encouragement and support from a family friend has joined a women's public speaking group which meets monthly. Elisabeth says that the supportive staff at Arts Project and her friends and family have helped her to manage 'things that are very hard' and to be confident about trying new things and enjoying them.

The Ringwood Spiders - summary model of community participation

Theory of Change

Creating a formal structure that enables people with intellectual disabilities to train and play football will allow participants to develop friendships with peers and a sense of belonging to the broader group of sports people in the community.

The primary conceptualisation of community participation is about belonging and identity.

Place

The Spiders is a segregated football club which shares dressing rooms with a mainstream club and uses a community oval owned by the local council.

Activities of interest

The Spiders offers the opportunity to play in a football league for people with intellectual disabilities that is embedded in the mainstream AFL or to volunteer in the club. It also offers members opportunities to be involved in demonstration matches as part of AFL games or be coached by members of mainstream clubs, and participate in a range of social activities with other members and their families.

Social interactions

Members have regular social interactions with other members with intellectual disabilities and committee members who are parents of members. Many have friendships with other members or see them as mates. They also have interactions with guest coaches and members of other football clubs at joint events. They may also come into contact with others interested in sport or members of the public when they participate in events as part of AFL matches or social events organised by the club.

Outcomes

Members develop friendships with peers who are members of the club, and experience convivial or fleeting encounters with others involved in the club, and members of mainstream football clubs and the general public. They enjoy playing footy and gain a sense of belonging to the club and the wider community interested in footy and sport. Members develop confidence, social skills and have new experiences.

Logic model: Ringwood Spiders

Theory of change: If we create a formal structure that enables people with intellectual disabilities to train and play football then they will develop friendships with peers and a sense of belonging to the broader group of sports people in the community.

Inputs/ Resources

Volunteer committee of management
Grants
In-kind contributions
Sponsorships
Membership fees
Parent or other volunteers (coaching, catering, transport)
Equipment
Typical participation 2-3 hours a week after hours, variable across year.
Total 30 registered players
Total budget approx. \$18,000

Program Components

Joining and screening players
Registration and insurance
Organising regular training and guest coaching
Organising match fixtures and transport for away games
Managing behavior
Organising social events
Informal support through committee members

Outputs

Participation in footy training and an intellectual disability specific league competition.
Participation in a range of other footy and social activities.
Raising the profile and exposing AFL and football community to people with an intellectual disability and their capacity to participate in sport.

Outcomes

Convivial or fleeting encounters with members of mainstream football clubs and the general public.
Friendships with peers.
Development of sport and social skills
Enjoyment, satisfaction, confidence
Sense of belonging to club and broader football community.

Context: people with intellectual disabilities who have limited opportunities to engage in sporting and social activities as members of sporting clubs.

Detailed Case Study: The Ringwood Spiders – Member of the Football Integration Development Association

The Football Integration Development Association (FIDA) was founded in 1990 as a local initiative in the City of Boroondara. Since 2014 it has been part of the Australian Football League (AFL), overseen by a full time general manager. FIDA manages a football competition relevant to the skill level of people with intellectual disabilities, providing a way for this group to be involved in playing football when they cannot, for whatever reason, be included in their local club. The FIDA competition is:

adapted in a way that there is flexibility around the rules and the number of players on the field to ensure that players can get out there in the park (FIDA manager)

Seven hundred registered players are distributed across FIDA's four Melbourne divisions and 23 teams. They range from players who are unlikely to have 'had a kick for 6 years [and] just love putting the jumper on and running on the field ... [to a] handful of players who regularly turn out for North Sunshine' (FIDA manager).

FIDA aims to facilitate participation through helping players develop skills and confidence and encouraging community football clubs to socially include people with an intellectual disability. The FIDA clubs vary in terms of their professionalism and connection to mainstream clubs. One of the current goals of the association is to build stronger relationships with mainstream clubs as a way of creating more opportunities for social inclusion and shared events such as presentation nights. Summing up potential outcomes for people with intellectual disabilities from being part of FIDA, the FIDA manager said:

It obviously gives the physical health outcomes and [the opportunity to] just to go out and play footy in that team environment. They are the main reasons for it. And as well, from the family point of view as well... A bit of respite for the parents... From what I've understood from conversations with [previous FIDA manager], a lot of these guys make long-term friendships. [In these ways] abled sport and disability sport, they're the same.

The Ringwood Spiders Football Club (the Spiders) is part of FIDA, and notably part of the Ringwood Spiders All-Abilities Sports Club which includes a netball program and junior football development team. The Spiders has 30 registered players all of whom are males with mild to moderate intellectual disability living in outer Eastern Melbourne. Most are long term members of the club, with almost two thirds having been members for more than 4 years, and

40% for more than 7 years. Two members have been with the club for 20 years. Their ages range from 14 to 45 years old with a majority (21) aged between 20 and 34 years old. About two thirds of players (19) live in the family home with their parents. Eleven live independently with some support, and three live with a partner. Just over half of the players (16) have some sort of employment and four are still at school.

This case study of the Spiders draws on semi-structured interviews with four players; four committee members, two of whom are also parents of players interviewed; two other parents of players and the AFL FIDA manager. It also draws on an observation of a training session and a review of relevant documents. Names have been changed to ensure confidentiality. Tables 1 and 2, in the appendix, summarise the characteristics and quality of life indicators for these five participants. Notably, their scores on part 1 of the Adaptive Behaviour Scale ranged from 208-237, where a score of 151 or below is indicative of a more severe level of intellectual disability.

Aims

The Club has a dual focus on participation in community sport and social activities as ways of facilitating opportunities for people with intellectual disabilities to ‘interact, participate and build social skills and leadership within the community’ (mission statement). One committee member said that the club existed to help people with intellectual disabilities ‘who probably have difficulty being involved in anything’ to get involved in ‘something’. As the description of the club’s ethos on the website and comments from one of the committee members illustrate, the competitive aspect of playing is downplayed to highlight the value of skill development and formation of friendships:

Winning is great and always raises the spirits of the players, but it is not our main aim. Learning new skills – both physical and social – forming friendships and giving people an opportunity to be their best whatever level that may be and having fun; that's what's important at the Spiders. (website)

We don’t have ‘best goal’ or ‘best player’ [awards] or anything like that, we have more clubman type awards... like for those who attend training, who have the right attitude around the club... (Ian, committee member)

Underscoring the reduced emphasis on competition, a committee member said, ‘We’ve got guys who just like getting changed and running out on the footy field and don’t touch the ball... [as well as] those who are quite good sportsmen’. The Spiders aim to be inclusive of all people with intellectual disabilities who want to participate. As one committee member

said, 'you come, you want to play, you'll get a turn, you'll get a game.' Those who don't want to play in the competition are still welcome to train with the team or participate in other roles such as being part of the cheer squad, helping with scoring or running the water out to players on the field during matches.

The program of activities during the off season aims to keep the players and parents socially connected as well as offer information about a wide spectrum of issues. Committee members are also very involved in providing emotional and instrumental support to individual players and their families.

Another aim of the club articulated by one of the player's parents is to provide social opportunities for families of people with an intellectual disability; to help them meet others they can 'chat to' who are 'more understanding' than people who do not have children with a disability. Summing up the club's multiple aims a committee member said,

We've always tried to position ourselves to be more than just a footy club, so we try and introduce opportunities for the people that they wouldn't normally have. And try and teach them along the way whilst they're having a bit of fun. And importantly to try and develop more friendships, to try and make it a bit more of a family. (Ian, committee member)

Inputs

The Spiders is run by a volunteer committee of management and does not have any paid staff positions. One of its income streams is a grant from the Maroondah City Council, which for the last 4 years has been an annual amount of \$2,500 a year. The Council (in 2017) provides at a 50% reduced rate the use of Jubilee Park Oval for training and shared club facilities with a mainstream football team, the Ringwood Redbacks. The Spiders also receive sponsorship from local businesses such as LJ Hooker Real Estate, Printer Services and Bendigo Bank that is used for things such as travel or uniforms. The total budget is approximately \$18,000.

Participants pay a joining fee of \$15, and an annual fee of \$85, \$75 of which is the cost of registration and insurance through the AFL. This amount is much lower than the \$300-\$400 members of mainstream clubs tend to be charged. The FIDA manager thought that in the future if players had an individual NDIS package this may include costs of registration or other expenses associated with participation in the club.

The committee of management has both a governance and operational role. It is elected annually and has eight members who, at present, are all parents of players. The four committee members who were interviewed had been involved with the club for between 5

and 12 years. Their motivation was primarily to ensure their sons had high quality leisure opportunities and robust social networks. Committee members take responsibility for all operational aspects of the club, from record keeping to coaching, booking transport and organising social events. None had formal training in working with people with intellectual disabilities, drawing instead on their own family experiences of having a child and then young adult with intellectual disability.

Ad hoc assistance with transport or preparing food on match days is provided by parents of some of the players. Parents also provide volunteer support for the social activities organised by the club throughout the year. For example, participation in the annual Lilydale to Warburton rail trail bike ride where ‘a number of parents are involved at the front and at the end so we don’t lose anybody where other parents have gone ahead to prepare lunch.’ (Jonathan, committee member). Some, but not all parents, make modest financial contributions to the Club in lieu of their time. Some volunteer coaching is provided to the club by the Yarra Valley Old Grammarians Football Club as part of their leadership development program. AFL players from Collingwood and Hawthorn football teams have also provided a few training sessions for Spiders in the past.

New club members, or their parents, tend to find out about the club through various means, including online searches for local activities, disability service providers, articles in the local ‘Leader’ newspaper or presentations at schools or supported accommodation.

Program components

Joining

Prospective members are invited to meet committee members and players by joining in a training session. Before a member can start playing in games they must demonstrate an understanding of the rules of football (as played in FIDA), and a level of skill that means they do not pose a danger to themselves or others. Whether a new member is sufficiently skilled to play or might be better to take up another role in the club such as helping in the canteen or assisting with scoring is decided mutually between the member, coach and other committee members. As one committee member said, there are some players who go to training but don’t play in competition and a very few who are encouraged to look at options for involvement other than playing.

Pretty much what we do if someone’s interested is say, ‘come down, join in, and see if you like it’... We probably have around four or five guys who come down to training and won’t play competition and that’s fine. I would hope that there are no

real barriers to involvement. When it comes to playing, though, we have had one or two where we've said no to them playing competition because their disability was such that they don't have the awareness and...we assessed there would be risk of injury. (Ian, committee member)

The Club collects information relating to players' physical disabilities or medical needs and their preferred communication methods as well as age and contact information. Other personal information such as financial or family situation may be shared with committee members but is not formally recorded.

Organising training and matches

The club coach runs training sessions, pre-season (February to March) on Sunday mornings and during the season on Wednesday evenings for an hour between 6-7pm. There are 30 training sessions during the year with an average of 22 players attending. The FIDA football season begins in April and teams play 10 games in addition to finals. Games are usually played fortnightly on a Sunday morning with 15 players on each side and 15 minute quarters. Team transport is arranged for away games. We observed one of the training sessions.

At 5.30 there were four or five players who had come down to the Oval straight after work. They were interacting easily with each other as the football got kicked and hand passed amongst the group. Other players began arriving, some driven by parents, some on public transport and one who drove himself.

By 6pm there were 21 players and about half a dozen observers. One player who couldn't participate due to injury walked around the field giving pointers to other players through the session. Other observers were an ex-player who chatted to many of the players, the mother of the Spiders' longest running player who came to watch, even though her son had got there independently, and a few other parents who stayed inside the club room watching and talking amongst themselves.

The training session was jointly led by the Spiders coach and a member of the Yarra Valley Old Grammarians. The latter coach was very focused on giving training instructions, and was interrupted just a few times with requests for help with doing up shoelaces and similar. He put players through exactly those kinds of drills any football team would be asked to do. In one of the drills players were told to shout each time they handballed and if they didn't the whole team would have to do push-ups. Players yelled as aggressively as they could muster. Their skills varied considerably.

The club secretary, Chairman, and another committee member were also there. The secretary spent most of the session working out logistics for upcoming events, while the others watched from the sidelines.

Afterwards, in the changing rooms the secretary talked about upcoming events: the Appreciation Day lunch – which was going to involve the players having a meal together with the other team they were playing – and attendance at a recording of the Footy Show. Players were reminded to ask their parents as soon as they ‘got in the car’ or saw them to let the Club know if they could help or were coming to the lunch. (Observation)

Club members have also participated in demonstration games organised by FIDA that are hosted at the Etihad Stadium or MCG before or during half-time at AFL games.

Managing behaviour

Several committee members acknowledged that dealing with players’ behaviour could be difficult at times; in particular, fighting and swearing. One player a few years ago had been sufficiently violent that his club membership had to be revoked. Another challenge was behaviour off the field. In one incident, a player in a Spiders jersey was captured on the news hurling abuse at an AFL player on field. A committee member suggested there ‘were lots of learnings’ from this.

Organising social and other events

The club organises social activities for members and their families throughout the year. Those during the football season are generally football related. For example, a visit to a recording of The Footy Show, players having a meal together with the team they are playing, a beginning season celebratory dinner and end of season awards night.

Football season social activities also provide opportunities for advocacy and awareness raising around disability issues. For example, the Spiders website refers to an event from last year:

For the second year we hosted a luncheon to further promote our message about inclusion for all-abilities. It was a great success with many Redbacks supporters, local MPs and councillors in attendance. Following the luncheon, a combined Spiders Blacks and Reds side took to the field to play a combined Mazenod team in the 25-minute game prior to the Redbacks’ main game.

The club also organises social activities in the off season. These have included attending cricket matches, playing lawn bowls, tenpin bowling and mini golf and participation in community activities such as Clean up Australia days.

Both on and off-season activities are designed so that club members and families can participate, and normally attract about half of the players. The more popular events like ten pin bowling will attract more than two thirds of players. Ideas for social activities are generated and agreed upon by the committee and players.

The club also organises two or three information sessions a year for players and/or their family members. Topics have included eating well, financial scamming and the NDIS. The club has introduced to the team a players Assistance Card. The card conveys to others such as police officers or revenue protection officers the message that the cardholder may need help dealing with an interaction.

Informal emotional, social and practical support

Membership of the club offers players, particularly those living independently with little family support, a safety net of informal emotional, practical or material support. Various examples were given where committee members had stepped in to help sort out difficulties in finding housing, managing the cleanup of a back yard, dealing with the death of a parent, and organising a wedding. Indeed, several of those interviewed suggested that belonging to the club was like being part of a family. Players said, for example,

What I like about [the club] is that it supports all the players. Not just in the club, but in their personal lives, the club sort of tries their best to support them as well. (Andy, player)

[The club] helps people out; they look after people when they're down. (Cameron, player)

Benefits of membership extended to family members as well who drew attention to the mutual support they gained from meeting others with a family member with intellectual disability.

We've got a really good circle of people. You know, we'll just ring one another, 'Look, how about we all go out for dinner?' Yeah, so we'll do that. (Angela, parent)

One example of this mutual support was the joint house purchase by two families whose sons now live together in the shared house.

Raising the profile of people with intellectual disabilities in the wider sporting community.

Players from mainstream clubs and people from the general community are exposed to the Spiders team through demonstration matches, volunteer coaching and the shared use of facilities, although Spiders games were not usually attended by people outside the social circles of players.

It's a win for our guys because they've got people who play high level mainstream ball. And they're taking their time out to train people with a disability. And they win because now they're learning and seeing how people with a disability function. (Ian, committee member)

We've opened a lot of doors from both sides. Guys have got access to what's around and then councils and politicians are aware of what we're about and what these guys are going through. (Paul, committee member)

Outcomes

Friendships and social connections among the club members

Membership of the club enables members to feel part of a group of mates and for some people develop friendships with peers.

[My son] can catch up with those guys again on say, a Sunday... and on Wednesday night, and just yeah, catch up and say, 'What have you been doing this week?' (Jonathan, parent)

Over the years, we've had lots of parents come along with their kids and the kids have been loners and haven't had friends and to see the friendships develop and to get the feedback from the parents, this is just wonderful. They've had years and years of their son sitting at home playing play station, not getting out and doing things. And now they're out doing physical activities and they've developed some friendships. (Ian, committee member)

Examples were given of the longevity of some of these friendships and the extent to which they provided avenues for shared social activities beyond club organised events.

[The] club that allows them to have friends that they can talk to and enjoy, friends that will back them up on the field... [They] can go out and watch a movie with one or two friends. (Ian, committee member)

...a few of the guys are organising as many Spiders players [as possible] to go down and see the Redbacks play next Saturday... And the good thing is that it gets my son

out for the afternoon to hang around with his mates and have a kick and that's what they love to do. (Peta, parent)

Patrick, one of the players reported that he often 'does stuff outside of footy' with his teammates. He said 'Sometimes I go out, down to a pub. Have some drinks and have some tea'.

Not all friendships were close but as one parent said, her son had 'got mates' and having people to go out with meant that he had learned how to 'socialise in the mainstream'. Another parent talked about an ex player staying in touch with the club and continuing to attend games and social events.

I still see [ex-player] and he stopped playing around 4 or 5 years ago but – he's a life member – and he still goes to the games... And he still goes down to training. And he still helps out with things around the team when they're playing and that sort of thing. And he goes to the presentation night and any other function they have. And his mother goes with him. (Peta, parent)

Playing footy and belonging to a wider community interested in sport

Club members enjoyed the opportunity to play footy, as well as meet players from mainstream clubs and be part of a wider community interested in sport. One player said that the best part of being involved in the Spiders was that 'it just gives an opportunity to play footy. Because I'm not fast enough to play in, like, a mainstream team.' Another was proud that his skills had been recognised, saying that membership of the Spiders had,

Made me achieve medals and stuff. Like premiership medals and runner up medals and I won a rising star award in 2001. (Liam, player)

Another said, 'I just like coming out. Sunday, kicking the footy. That's what it's all about.' A parent talked about how it was exciting that her son could now play a sport that he knew all the rules of as he had been a devoted follower of the game for some time.

Having opportunities to play in front of large crowds at the Etihad Stadium or the MCG or be involved in other events gave members considerable enjoyment. For example, one mother said her son had been 'very happy' when he appeared on television when Collingwood players trained with the Spiders.

A sense of being involved in footy extended beyond participation in games or organised events. One parent explained, for example, how her son had gained a broader

interest in the sport which meant he watched football on television and he ‘has his footy picks and has taken it all on board and has a team [that he follows].’

Activities, such as volunteer coaching and joint events with mainstream sporting clubs, and the shared use of club facilities with the Ringwood Football club has brought Spiders members into contact with others with an interest in football and sport. For example, one parent said that whilst his son had not developed friendships with any volunteer coaches, he did have a sense of connection with them,

He knows their names and...he speaks to them and he listens to what they say. I wouldn't call it an actual friendship but it's an association. (Addison, parent)

Another parent described as ‘fabulous’ the annual dinner hosted by the Yarra Valley Old Grammarians and the Spiders.

Development of social skills and new experiences.

Members had developed skills beyond the technical ones required for playing footy. These included teamwork, playing by the rules, acceptance of not always being able to win, being organised, skills for handling particular social interactions as well as a greater sense of confidence. One parent said, for example, about her son's independence,

With having to play and that, he's usually pretty good with...putting the notes and stuff on the fridge and following through to check when they're playing, because they're only playing every second weekend. I think it has helped enormously. (Peta, parent)

One committee member thought that players learned about themselves, being part of a club and a team. Another suggested that the club helped to broaden the social experiences of members who generally lived fairly restricted lives. He said,

When we do these recreation activities sometimes we do things to try and challenge them a bit too...just give them opportunities. Because a lot of them live normal lives and a lot of them don't get to go out into the community to do a lot of things. (Dylan, parent)

Parents and players drew attention to changes in levels of confidence.

He's just able to be more open with people ... About 5 years ago, yeah, you'd hardly get any words out of him. (Addison, parent)

For sure. When I first started at this club I'd sort of hide myself away... I wouldn't go near the ball. (Andy, player)

I have no doubt that my son is far more confident because of the environment just with his communication because the peer group pressure isn't there. (Dylan, parent)

Two parents said that they believed the team environment had encouraged their sons to help other people. One reported that he knows his son 'gets in and helps out some of the [other] guys and things like that...Just helping them out on the field and, you know, whatever.' The other said that when his son identifies players who are struggling in training 'or couldn't comprehend, he would try to the best of his ability, and go over and help him'.

Vignette

The following vignette illustrates outcomes for one Spiders participant:

Liam is a 45-year old man who lives with his mother in Croydon, close to the home of his football club. He has worked full time for 10 years in a supported employment program. He is also a dedicated supporter of the Richmond Football Club. He and his mother frequently attend Richmond matches. Liam's love of football means that he is extremely happy that he gets to play the game regularly with the Spiders.

Liam is a founding member of the Spiders and has now played with them for 26 years and never missed a season. He is talking about retiring next year but he has been bestowed life member status and believes he will continue to be involved in the club in a variety of ways like 'running the water' out to the players. He will also continue going to the off-season social events like bike rides, barbeques and picnics, of which he is currently a regular attender.

Liam feels he really belongs at the Ringwood Spiders and strongly identifies himself as a football player and proud member of the club. He has celebrated his 21st birthdays and 40th birthdays at the club. A few of Liam's colleagues from work also play in the Spiders. The social aspect of playing is of equal importance to Liam as the sporting competition. For him, the best parts of being in the Spiders are 'having good friends and stuff and when we win games'. He has also enjoyed being recognised for his achievements; he has won various medals over time including a 'best new talent' award.

Liam's family believe that the club has helped him develop independence and confidence. They think the expectations of the club have also helped him to take on more responsibility for tasks away from footy. The cycle of wins and losses, Liam's mother says, has also helped him deal with disappointments in broader life.

Liam's mother has made many friends there. In turn, she has helped out other players and their families in the club who have struggled with various personal issues.

Cross Case Analysis - What can be learned from promising community participation programs?

This section of the report compares and contrasts the key dimensions of each of the five promising programs for which case studies were prepared, and explores the design and practice issues they highlight. It aims to draw out the commonalities and differences between programs in terms of primary group served, theories of change, program logic and activities, staff skills and outcomes. Capturing the program and practice wisdom embedded in promising programs, which is seldom made explicit, provides valuable insights for organisations to develop or refine community participation programs. Also for people with disabilities and their families to make choices about what aim they want to pursue and thus type of program they prefer.

Conceptualisations of community participation

The five programs were chosen as exemplars of program typology developed from the literature, and spanned the three primary aims of community participation programs: as building social relationships (Gig Buddies); as developing a sense of belonging and identity (Arts Project and Spiders), and; as creating opportunities for convivial encounters with community members (Melba and Shepparton Access)¹. Table 1 summarises the primary aim and strategy adopted by each program and the nature of each of the three ICF components.

Strategies

As anticipated, strategies reflected the way each program conceptualised the aim of community participation. For example, both Arts Project and Spiders aimed to support belonging and identity. The phenomena from which belonging and identity were derived differed; for Arts Project it was identity as an artist and belonging to the artistic community, and for Spiders it was identity as a footballer or sportsman and belonging to a community interested in sport. Specific strategies differed between these two programs but they had in common a focus on fostering skills and engagement in the activity from which identity was derived; art and sport. One might imagine other programs with a similar aim that focused on

¹ Our analysis used the framework developed from the literature, which did not always reflect the terms used by programs to describe their characteristics. Notably Melba and Shepparton Access did not use the language of convivial encounter, rather they saw what we have defined as convivial encounters as a mean to gain a sense of belonging to local community. This is an issue taken up later in the paper.

Table 1 Primary conceptualisation of community participation and nature of ICF domains of each program

	Gig Buddies	Melba	Shepparton	Arts Project	Spiders
Primary conceptualisation	Social relationships	Convivial encounter	Convivial encounter	Belonging and identity	Belonging and identity
Primary Strategy	Recruitment of buddies, and matching for shared likes and interests of person with intellectual disability with person without disability.	Creation of tailored mixture of daytime activities and engagement in specific tasks in collaboration with groups and organisations in the locality that maximise social interaction with others and reciprocity.	Creation of tailored mixture of daytime activities with an element of interaction with community members, also skill development, supported voluntary work with broader goal of paid work and greater independence.	Support to create, display and sell pieces of art.	Creation of opportunities to belong to an active football club with a distinct identity and associated social activities.
Activities	Interest-related activities in the context of matched relationships or as part of a bigger group organised by the program.	Skills training, sport, group activities such as cooking, food distribution with peers or others in locality, individual activities as part of social enterprises or micro businesses.	Skills training, sport, group activities such as cooking, food production with peers or others in locality, individual activities, as part of social enterprises, micro businesses or paid employment.	Create, display and sell pieces of art.	Training and playing football, social activities, social skills training.
Place	Mainstream community places.	Locality based. Mixture of segregated and mainstream community places.	Locality based. Mixture of segregated and mainstream community places.	Segregated and some mainstream community places.	Mainstream community places.
Social interaction	Fleeting and convivial encounters and friendships with matched volunteer, peers and others involved in the program and at mainstream venues.	Fleeting and convivial encounters with peers and others without disabilities in the local community.	Fleeting and convivial encounters with peers in the program, and people with and without disabilities in the local community. Friendships with peers.	Fleeting and convivial encounters with peers in the program, artists and the wider arts community. Friendships with peers.	Fleeting and convivial encounters with peers in the program, and people without disabilities such as committee members, volunteers, players family members and others interested in football. Friendships with peers.

performing arts, music or gardening. The primary aims of both Melba and Shepparton Access were to create opportunities for convivial encounters with people without intellectual disabilities. Each program used broadly similar strategies of creating opportunities for shared activities, engagement and interaction with people without intellectual disabilities. Each emphasised different types of activities. Melba, for example, focused particularly on activities that offered engagement in specific tasks or made a contribution to the wider community, and Shepparton Access on activities that gave participants visibility in the locality or led to volunteer or paid employment opportunities. In contrast, the primary strategy used by Gig Buddies was recruitment and matching of volunteers with participants, with the aim that sharing attendance at music or other events would lead to longer term and stronger social relationships, than those characteristic of convivial encounters.

ICF domains

Activities

Table 1 illustrates the diverse nature of the three ICF domains; activities, place and social interactions, across these programs. All programs either directly organised or facilitated participation a very wide range of activities. These ranged from skill development such as cooking or literacy, leisure activities such as swimming and football, social activities such as going out to music or sporting events, and vocational or work-related activities such as production of art work, micro enterprises, voluntary work or work experience. Even the programs that focused on a particular interest such as art or football, offered a range of associated activities. For example, as well as creation of art works, Arts Project offered participation in exhibitions and visits to galleries, and the Spiders, a range of social events as well as football training.

Many activities created by Melba and Shepparton Access were described as work, but encompassed differing work types and amounts of time. These included, volunteer work, work experience, work paid at competitive open rates, and supported employment paid at negotiated productivity based rates. Time fractions included, a few hours a week, longer regular part time hours and casual self-employment that took up variable periods in any week.

Places

Activities occurred in many different places, both mainstream and segregated. Mainstream places are open to others in the community, and included sports ovals, shops, businesses and

community centres. In some instances, these might be business places operated by a program such as Melba's Able Bakehouse or Shepparton Access' Eco Shop which sell goods to the general public. Segregated places included dedicated program buildings, such as the studio of Arts Project, or the main centre building of Melba. In most instances program buildings were located close to or as part of mainstream places such as a TAFE campus or central business district, and were easily accessible to non-program participants. For example, the Arts Project studio is regularly open to the general public through staging of exhibitions. In some instances, mainstream places were host to segregated activities. For example, Spiders participants played football in a segregated team as part of a league for people with intellectual disabilities on a mainstream oval. There were also examples of activities occurring in places segregated on the basis of age or frailty rather than disability, such as the class organised by one program in a residential aged care facility open to program participants and residents of the facility.

In all the programs, boundaries between mainstream and segregated places were crossed by participants, though the relative balance of time spent in each varied. Gig Buddies and Spiders only offered activities in mainstream places, and typically participants in Melba and Shepparton Access divided their time between segregated and mainstream places. Arts Project was the only program where participants spent most of their time in a segregated place. However even in this program, there were intermittent opportunities for participants to attend events in mainstream places and many participants went out to the local strip of shops for lunch or coffee. The diversity of places suggests the danger of assumptions that community participation only occurs in mainstream places, as this devalues programs such as Arts Project primarily situated in segregated places, and concerned with identity and belonging.

The five programs were located in different geographic places: outer urban localities (Melba; Spiders); a regional town (Shepparton Access); and inner urban areas (Arts Project and Gig Buddies). One of the questions considered later is whether location matters and if some program types are more suited to particular types of locations.

Social interactions

Despite the variety of activities and the places where they occurred, participants in all of the programs interacted socially, either with peers or people without intellectual disabilities, arising from sharing activities or interests. In four of the five programs, social interactions with people without intellectual disabilities resembled fleeting or longer convivial encounters

rather than lasting friendships. The relatively short life of Gig Buddies made it difficult to assess the long-term nature of the social relationships participants developed with volunteers, but the qualitative data suggests some of these had moved beyond convivial encounters to friendships. Participants in Arts Project, Shepparton Access and Spiders, identified particular friendships they had developed with peers in the program, although this was not articulated as an aim in program documents or by program staff. It is important to note that these friendships were specifically mentioned by participants or their family member, and not assumed to exist by program staff or parents simply because participants shared the same disability-related characteristics.

Relative importance of ICF domains

The relative importance and diversity of each ICF domain differed between programs, illustrating the potential breadth of choices to be made by people with intellectual disabilities when considering different types of programs. As the literature had suggested, activity featured as the central domain in programs aiming to develop belonging and identity (Arts Project and Spiders). In the other types of programs, social interaction was the more central component. Most commonly, program staff emphasised interaction between participants and people without intellectual disabilities in these programs but as indicated earlier, both participants and their families also pointed to the value of social relationships with peers.

Program participants

As Table 2 shows the support needs of typical participants differed across the programs. Participants in three of the five programs (Gig Buddies, Arts Project, Spiders), were predominantly people with lower support needs who were able to travel independently on public transport, and manage their own personal care. People with higher support needs were not specifically excluded but informants suggested the nature of these programs made it hard to include them. For example, Gig Buddies staff informants suggested it would be difficult for volunteers to form relationships with people with more severe intellectual disabilities, Spiders players had to demonstrate they understood the league rules and were not a danger to others, and Arts Project participants were required to bring support staff if they needed significant support with personal care.

Table 2. Key program dimensions

	Gig Buddies	Melba	Shepparton	Arts Project	Spiders
Support needs of typical participants	Low support needs.	Moderate to high support needs.	Low to high support needs.	Low to moderate support needs.	Low to moderate support needs.
Typical time occupied	2-3 hours a month after hours.	5 days a week from 9am-3pm.	5 days a week. 9am-3pm.	2-3 days a week 9.30am to 3.30pm.	2-3 hours a week after hours. Variable across the year.
Total participants	45 matched pairs and 190 unmatched volunteers and potential participants.	97 participants 75 full time, 22 part time.	98 participants approx. 95 per day, mainly full time 5 part time.	135 participants approx. 45 any one day plus 50 on Saturday.	30 registered players.
Staffing	2.5 EFT and unpaid interns.	35 EFT (23 casual, 59 part time, 12 full time).	19.8 EFT, mix full and part time.	10 EFT, mostly part time.	No paid staff – reliance on volunteers mainly family members.
Estimate program budget or individual cost	Estimated cost per participant 3 hours per month @\$57.71 per hour.	Not available.	\$2.5m	\$1.7m Estimated cost per participant hour \$24.	\$18,000
Notion of community	Shared interests - social, sporting and cultural.	Place - local - outer urban localities.	Place - local - regional town.	Shared interests - the Arts.	Shared interests –footy.

Only two programs included people with severe or profound intellectual disabilities (Melba and Shepparton Access). These were the ones that conceptualised community participation as creating opportunities for convivial encounter and which participants typically attended for 5 full days a week. This suggests people with severe and profound intellectual disabilities may have more limited choices of community participation programs, and raises the question of whether other types programs could be adapted to be more inclusive of this group, and if so how this might be done.

Long term attendance at programs was a characteristic of the more established ones, particularly the Spiders and Arts Project, where some participants had attended for more than 10 years. Only at Shepparton Access did informants raise the idea that participants might leave and progress to employment.

Program governance, size and scope

As Table 2 shows the programs varied in scale and size, in terms of budget, staff and participant numbers and hours of support offered. All except Spiders employed managerial, administrative and support staff who worked directly with participants. Most programs relied heavily on part time staff, and several also used volunteers or interns. Spiders was completely reliant on the voluntary labour of committee members, participants' parents and members of other football associations to manage and deliver the program.

All of the organisations offering these programs had boards or committees of management and organisational mission statements that conveyed a strong sense of commitment to inclusion of people with intellectual disabilities. The organisations had relatively flat structures that helped to convey a sense of equity between staff, and staff and participants. They were led by strong and charismatic leaders, who were close to the operational aspects of programs and whose knowledge of participants illustrated the principles of equity valued by organisations and absence of social distance between staff and participants.

Two of the programs, Melba and Gig Buddies, had formal mechanisms for consulting with and gaining feedback from program participants, and the data suggested that this occurred informally on at least one other program. The Melba ARROWs group is a longstanding part of the organisation, while the Gig Buddies *Soul Fly Band* is in its early stages. The challenges of supporting such participant consultative groups to help design and gain feedback on programs did not feature in the data. Participants' families were also

regarded as an important means of gaining insight into perspectives of participants, and all programs aimed to build relationships with family members of participants.

Most programs were one of a number delivered by an organisation. For example, as well as the Community Connections program, Melba Support Services offers supported accommodation, and Spiders is part of the Ringwood Spiders All-Abilities Sports Club which offers a netball program and junior football team. Shared administration, and cross subsidisation of programs within organisations made it difficult to accurately identify program budgets, and sometimes boundaries between different programs. For example, some of the Shepparton Access participants attended the pre-vocational certificate 1 training course the organisation was funded to deliver, but whether these classes were separate or integral to the community participation program was not fully clear.

The total number of participants in programs ranged from 30 in Spiders to over 200 in Gig Buddies. Four of the five programs had less than 100 participants. Detailed budget information was not available, but the estimates suggest that these are small scale programs with annual budgets varying from \$18,000 to \$2.5m. Primary sources of income were small local government or philanthropic grants, and state government disability support service funding. All the programs were in the process of rethinking budgets and calculating costs per participant hour in order to align their business models with the NDIS individualised funding model. Considerable uncertainty existed around future funding when the data collection was completed at the end of 2017.

The maximum hours of support offered a week to individual participants, and thus the proportion of time programs occupied in participants lives varied greatly, from 2-3 hours a month to 30 hours a week. The timing of support also varied between programs from predominantly school hours between 9am-3pm, to a few hours on evenings or weekends. Gig Buddies and Spiders operated after hours, and offered 2-3 hours a month and 2-3 hours a week respectively. Participants in these programs were also involved in other social programs and some had supported or open employment. Typically, participants attended Arts Project 2 or 3 days a week, and Melba and Shepparton Access 5 days a week.

Significantly, the two 'full time' programs had their own sites where activities occurred when participants were not out in mainstream places. These two programs were also the only ones that supported people with higher support needs. In some respects, these programs (Melba and Shepparton Access) resembled traditional day centres that in the past have had a respite as well as skills development and community participation roles in

people's lives. It was very clear however, that programmatically they were very different from a 'day centre' and had diverse and effective strategies that supported community participation and led to positive outcomes for participants. With a few exceptions, most participants in these two programs were involved in a mix of different activities, in different places and with different people. Interviewees talked about finding a balance between preferred and less preferred activities.

Program components

The key components and a logic model for each program were pieced together from documents and interviews, as most organisations did not have these clearly articulated in one place. Gig Buddies, which was also the most recently formed program has the clearest delineation of specific program activities.

Initial screening

All the programs had some form of screening process that involved staff meeting with prospective participants, and sometimes a family member as well, to discuss the program, understand more about the person and to reach a mutual decision about entry. Some programs had trial periods before final acceptance, and some had waiting lists. For example, Arts Project had little turnover of participants and a lengthy waiting period, and Gig Buddies had approximately 190 people accepted into the program but unmatched to a volunteer, meaning they could only participate in group activities.

Individual and program level planning

All the programs were person centred, and gave significant attention to knowing each individual and their social connections well, and using this knowledge to develop individual support plans. Melba and Shepparton Access had more formalised individualised planning processes than the other programs, and included an annual plan review for all participants. They had developed their own planning formats, which at Melba was based on the 21 domains of the Personal Outcome Measure system (Council of Quality Leadership).

Table 3. Key program components and staff practices

	Gig Buddies	Melba	Shepparton	Arts Project	Spiders
Key program components and practices	Person Centred Screening Matching Supporting pairs Organising events Negotiating sponsors	Person Centred Individual and program planning Creating individual and group activities that maximise social interactions in locality, individual preferences, valued roles and making a contribution <ul style="list-style-type: none"> • with other community groups on their own site • with peers or individually in community places • on program site Plan engagement in micro tasks Flexibility on the day Collaboration with businesses, community groups and facilities Use and support for natural supporters Adapting environments for people with severe cognitive impairment	Person Centred Individual and program planning Creating individual and group activities that maximise being in the community, skill development and employment opportunities <ul style="list-style-type: none"> • with community members coming into program sites • with peers or individually going out to mainstream places • on program site Use and support of natural supports Skill development classes Collaboration with businesses, community groups and facilities	Person Centred Screening Studio and gallery Hand in glove support Exhibitions Collaborations Visits to galleries Raising profile	Person Centred Screening Training and guest coaching. Match fixtures and transport Managing behavior Organising social events Informal support

For some programs, more than others knowledge of the place in which the person lived and potential opportunities it might afford was important. For example, as participants and volunteers in Gig Buddies were drawn from all over Sydney, knowing this geography was important for matching, and at Melba and Shepparton Access, knowing localities where participants lived and business and community leaders was important in identifying and negotiating opportunities for convivial encounters.

Despite the formality of annual reviews, individual planning at Melba and Shepparton Access was described as a continuous process, as staff developed greater knowledge about participants' preferences and talents as they tried new activities. For these programs too, individual and program level planning was iterative, flexible and dynamic as individual preferences changed and new opportunities were developed. Individuals were not simply slotted into an existing program level plan or a rigid menu of pre-defined activities, rather the overall program plans were built from individual plans. A similar approach was also used by Arts Project which developed program level external collaborations with professional artists or staged exhibitions from their knowledge about individual participants.

Program strategies

Melba and Shepparton Access had similar strategies for creating activities that provided opportunities for convivial encounters with people without disabilities. The approach in both programs was creative and characterised by collaboration and negotiation with key personnel of community groups, public facilities, businesses and other organisations. These programs consistently looked beyond what was visibly on offer in their communities for ways of creating activities tailored to the people they supported. Strategies included;

- Seeking out already established group activities in mainstream places that participants could join either individually or as a small group. For example, joining an already established yoga or art class in a community centre.
- Finding public facilities that offered activities open to all comers. For example, public sessions at a swimming pool.
- Creating an activity in a mainstream place for an individual. For example, volunteering in a kindergarten, or supported work in a school.
- Creating group activities that used or visited mainstream places and involved collaboration with other groups in the community. For example, a cooking class in an older person's home, a fruit collection and delivery service to local schools.

- Inviting others into program spaces by creating social enterprises that produced and sold products or services to customers, or supported micro enterprises where individuals created or sold products to others. For example, the Able Bakehouse and Ecoshop.

Some activities, particularly skills classes, that were offered at program sites did not offer opportunities for encounters with people without intellectual disabilities, as they were attended only by participants.

Both Melba and Shepparton Access used task analysis to break activities down into discrete parts, ensuring that participants were engaged in at least some parts of an activity rather than being bystanders. When a participant was involved in an activity that took place within another group, organisation or business, program staff provided advice to relevant personnel about supporting their inclusion. In this way, the competence of ‘natural supporters’ to interact with and support the inclusion of people with intellectual disabilities was developed. In some instances, program staff gradually changed their role from negotiating activities or providing support to the participant or natural supporters to one of intermittent monitoring to ensure continuing success.

This approach to supporting natural supporters within community groups, classes or volunteer work places reflected the concept of ‘active mentoring’ shown to be an effective strategy to support participation of people with intellectual disabilities in groups (Craig & Bigby, 2015; Stancliffe, Bigby, Balandin, Wilson & Craig, 2015; Bigby, Wilson, Stancliffe, Balandin, Craig & Gambin, 2014) and the concept of co-worker support, effective in supported employment settings (Story, 2013). When active mentoring is used, the study by Bigby et al. (2014) demonstrated the importance of regular monitoring of participation and the natural support occurring within groups, and the intermittent necessity for more intensive support from program staff to take account of changes both to group dynamic or membership and individuals’ circumstances. The simplistic notion that once a person has been introduced and established as a participant in a community group or as a volunteer, community participation support can be withdrawn fails to take account of changes to groups over time, or indeed the time limited nature of some groups, particularly classes in community settings - as one class finishes, program staff are negotiating inclusion in another.

Strategies used by the other three case study programs were more closely tied to a focal activity. For example, a weekly training session for Spiders players, the organisation of demonstration games or a pre-season dinner; individual support for art work for participants

in Arts Project, and organisation of exhibitions, matching, volunteer support and organisation of group-based activities in Gig Buddies.

Practice skills

Arts Project was the only program that documented the qualifications, skills and practice approach expected from staff. All Staff Artists in this program were required to have a degree in fine arts, and take a ‘hand in glove’ approach whereby participants were supported to create their own artistic work rather than Staff Artists sharing in its creation. The possession of qualifications or skills in specific focal activities, such as footy coaching, cooking, or exercise science were valued by the Spiders, Melba and Shepparton Access programs which often employed specialists for small time fractions to run specific activities.

However, program managers most commonly talked about the personal attributes they expected in staff, such as respect for people with disabilities, teamwork or community connections rather than more specific practice skills associated with aspects of the program or supporting people with disabilities to be engaged. The strong tendency to downplay practice and support skills or disability related knowledge suggests that program managers valued personal attributes over skills, reflecting the notion that skills can be taught but attitudes cannot.

If practice skills for supporting individuals with intellectual disabilities to participate in communities are to be taught however, they need to be identified and accorded value by programs and the disability support organisations that manage them. From our data, particularly observations and interviews, it was evident that staff drew on a range of practice skills. These included:

- Task Analysis - breaking activities into smaller parts to aid learning or participation (Thompson & DeSpain, 2016);
- Active Support - providing just the right amount of support for a person to successfully complete a task or engage in an activity or social relationship (Mansell & Beadle-Brown, 2012);
- Active Mentoring – supporting a person to participate in a group through training and resourcing community group members (Stancliffe et al., 2015);
- Support for Decision Making - supporting a person to express their preference and respecting these, through knowing the person well and involving the network of others who may know the person from differing perspectives,

which may also involve knowing a person sufficiently well to interpret their preferences from their responses to experiences (Douglas, Bigby, Knox, Browning 2015);

- Person Centred Planning – preparing with a person and others who know them well an individualised plan that includes goals and means to achieve them (Robertson, et al., 2007);
- Positive Behaviour Support – use of applied behavioural or functional analysis to understand the function of behaviour for the individual, and design of support or intervention targeted at the individual or their social context to enhance their quality of life (Ockenden, Ashman & Beadle-Brown, 2014);
- Enabling Risk - a process of supporting a person to exercise choice and control and take actions important to them while being protected from harm (Bigby & Douglas, 2017) and;
- Communication skills - adjusting communication to take account of a person's cognitive capacity and receptive or expressive language (Balandin, 2007).

Our analysis suggests staff also used skills more usually associated with community development or social work, such as community analysis, networking, negotiation, and advocacy (Ife, 2013; Bigby & Frawley, 2010). However, few program documents or staff made reference to these types of skills sets required by staff, or named them. The understatement of skills required for practice in four of the five programs has potentially negative implications, as it fails to articulate a key program component, potentially important to scaling up programs, and undervaluing staff skills required has the potential to under cost the staff component of effective programs.

Differences in language and notions of community

The language and conceptualisations of community and community participation differed across the five programs. For example, Shepparton Access used the term community participation in a very specific way, seeing it as the initial step to full inclusion, which in turn this program defined as participating in a shared activity in a community place with other community members without direct support from program staff. The term work used by Melba and Shepparton Access referred to breadth of work-like experiences, which meant that for example, a participant who might work for several hours one day a week for no pay was described as having a job.

Community is a notoriously difficult concept to pin down (Bryson & Mowbray, 2005), so it was not surprising programs understood it differently: Spiders and Arts Project equated community to shared interest or talent (footy or art); Gig Buddies also understood community as shared interest but one which may be more diffuse and less focused than Spiders or Arts Project, such as fans or audiences who attended social, cultural and sporting events; Melba and Shepparton Access had place based understandings, seeing community as people tied together through living in a particular locality or town. The different conceptualisations of community were most evident in theory of change, which for four of the five programs was framed in terms of creating sense of belonging to community (see Table. 4).

Table 4. Theory of change as set out by each program.

Program	Theory of change
Gig Buddies	Matching people with intellectual disabilities with volunteers with similar interests will provide opportunities for friendship, expanding their social networks and participation in activities and choices about their social lives.
Melba	Supporting individuals with intellectual disabilities to engage in activities of their own choosing in the local community will mean they live more interesting and fulfilling lives and develop a greater sense of belonging to that community.
Shepparton	Creating opportunities for individuals with intellectual disabilities to participate in a range of activities in a variety of highly visible settings will mean they experience a sense of belonging to a community which embraces people from diverse backgrounds.
Arts Project	Creating a space in which individuals with intellectual disabilities are supported to produce art will develop their sense of belonging to the arts community, and an identity as a working artist.
Spiders	Creating a formal structure that enables individuals with intellectual disabilities to train and play football will allow participants to develop friendships with peers and a sense of belonging to the broader group of sports people in the community.

Diversity of community participation programs is important for consumer choice, but the absence of a shared or common language for work-like activities, program aims and meaning of community used makes it difficult for people with intellectual disabilities and their families to compare and contrast programs, or clearly understand primary aims and the type of support they offer. By superimposing a common language, and typology of aims for community participation programs on the language used by each program, our analysis was able to meaningfully compare similarities and differences between them.

Value of shared language and program typology

The value of shared language and a typology of programs is illustrated in considering whether some types of programs are only suited to particular places. At first glance, a comparison of the programs suggests that the three which did not understand community as place (Gig Buddies, Arts Project and Spiders) could be scaled up and delivered in any location, with the exception perhaps of isolated and small rural places. Participants in these programs did not necessarily live in the same locality as each other or where the program was based, and many travelled across multiple suburbs and localities to participate in the activities offered by these programs. The constraining factors for these programs in isolated or small rural places may be access to transport, a sufficient number of participants to form a footy team, those interested in art to develop a studio, or a sufficient number and variety of gigs to cater for different tastes.

Two programs, Melba and Shepparton Access, however, appeared to be more closely tied to particular types of place. They were located in similar places, outer urban localities and a regional town and its outlying districts. These were places where local people gained a sense of local community identity. Participants in these programs lived in the place where the program was located, and informants suggested that participating in the program increased recognition and acknowledgement of participants as community members outside program hours. Pararelling this, the programs' own language and theories of change articulated an aim of developing a sense of belonging to the local community where they operated. Framing the programs in this way suggests they will only be effective where there is a sense of local community identity.

A somewhat different perspective emerged, however, from our analysis when the typology developed from the literature was applied to describe these programs. In this typology, the primary program aim was to enable convivial encounters in mainstream places with people without disabilities rather than develop a sense of belonging to a local community. As already explained, program strategies were planning with each individual and identification or creation of opportunities for participants to be involved in activities in community groups, facilities, social enterprises, volunteer or paid work. A key underpinning strategy was developing knowledge of opportunities for shared activities with people without disabilities that might be available, making connections with groups or leaders of other organisations or businesses, and negotiating opportunities for individuals or small groups of participants. Describing the program aims and strategies in this way, a little differently from

the way the programs described themselves, it is more conceivable that this type of program could be successful in urban areas where community as locality or place is not strong, people often do not have a have a sense of identity associated with place, and fewer organisations and groups are locality based. Indeed, the anonymity of cities, and withering of local communities as places for identity and social connection was the genesis for early studies of encounters as a means of social inclusion (Iveson & Fincher, 2007).

Cities offer similar if not more opportunities than regional towns or outer urban locales for working with groups, organisations and commercial businesses to create opportunities for learning, leisure, social and vocational activities that can act as catalysts for convivial encounters. A similar skill set around analysing potential activities already offered by groups and organisations and negotiating new or individualised ones would be required, with the key differences ones of scale, a wider geographic area and more diverse interest groups that would be in focus.

This analysis suggests community participation programs aiming to enable convivial encounters are likely to be successful across a range of different places, and are not necessarily tied to places where locality based communities exist. It does suggest the potential limitations of describing programs in terms of belonging to local communities, which may be an idealised image rather than reality in urban areas, and the importance of developing shared language and typology of community participation programs.

Creating conditions that facilitate community participation – role of local government and mainstream groups

The primary focus of the study was the role of specialist disability services in designing and implementing programs to deliver individualised support for community participation. This was predicated on the fact that many people with intellectual disabilities, particularly those more severe impairments, need support to reach the places or participate in the activities where relationships are likely to develop or convivial encounters occur, no matter how accessible or welcoming they are. Implicit if not explicit however, in these case studies are a myriad of partnerships and collaboration between disability services and other community organisations and groups. Successful community participation relies not only on individual support, but also on the inclusionary potential of public places, groups, and ordinary community members.

In planning with each individual, disability services relied on the existence of a rich tapestry of community groups, classes, and organisations and the activities they offered. Most

commonly disability service organisations worked with members and leaders of community groups to create and sustain opportunities for individuals with intellectual disability to participate in an activity as part of the group. There were many examples of the openness of groups and willingness of their members to learning about how best to involve this particular individual in their group.

Disability services also relied on the accessibility of public or semi-public facilities, such as swimming pools, sports facilities, or TAFE colleges that either hosted community groups or offered additional sets of activities people with intellectual disabilities might participate in. It was apparent that local governments were important catalysts for the development of public facilities as well as community groups, through financial or in kind support. For example, FIDA had been an initiative of the City of Boroondora, and the City of Maroondah built and maintained the playing field the Ringwood Spiders used for weekly practice.

Earlier research on convivial encounters suggests that some community members have had little exposure to people with intellectual disabilities and feel ill prepared to interact with people with intellectual disabilities. They feel they do not know for example, the appropriate way to respond to a person who may communicate differently, who looks different or is accompanied by a support worker (Bigby & Wiesel, 2018). The disability services in these case studies played a role in increasing the visibility of people with intellectual disabilities and educating ordinary people to feel comfortable and confident in interactions. This type of role could also be played by local authorities through offering training to all community groups about including people with intellectual disabilities or findings ways to encourage local groups to be inclusive. An initial strategy might be an audit of groups in each local authority area to establish how many have members with intellectual disabilities, and the confidence of groups in being inclusive.

The case studies suggest that community participation is reliant on creating and sustaining community groups and facilities that are not only physically accessible but whose staff and other patrons are welcoming and open to the inclusion of all comers. They also reflect the literature that suggests some types of places are more conducive to convivial encounters than others. These are, for example, places of membership or community facilities where structured opportunities exist for people to engage in shared purposeful activities on a regular basis such as choirs, art groups and community gardens (Fincher & Iveson 2008). Similar features, including places where there are opportunities for personal interaction, shared activities and endorsement of authorities are identified in contact theory (Pettigrew &

Tropp, 2006) and earlier research about the successful inclusion and active participation of people with intellectual disabilities in community groups (Craig & Bigby, 2017). Bredewold and her colleagues in the Netherlands (2016), suggest the significance of built in boundaries, and clear rules and roles for social interactions that do not require reflexivity or negotiation in designing places to facilitate convivial encounters between people with intellectual disabilities and strangers. In their study for example, an odd job centre, a farm and a community garden were more successful places for convivial encounters than a community restaurant which had less well defined and more open-ended expectations about social interactions.

Our findings and the literature suggest the significance of local or state governments in continuing to provide the infrastructure that underpins the existence of community facilitates and groups that play such a significant role in community participation. Success of specialist individualised programs depend on the availability of public or semi-public spaces that are designed with an eye to being conducive for convivial encounters (Fincher & Iveson, 2008) and inclusive of people with intellectual disability. Inclusivity as we have demonstrated is achieved through design and partnerships with specialist disability services that involves pro-active effort and adjustment to make them accessible in all respects and welcoming for people with intellectual disabilities.

Outcome domains

Table 5 shows that despite differences in size, time occupied, and main participant group, our analysis suggested that, at conceptual level, these community participation programs had very similar outcomes both for individuals and society. At the individual level, outcomes common to all programs were enjoyment, convivial and fleeting encounters with people without disability, and for most, friendships with peers, confidence and skill development and a sense of belonging either to a community of interest or locality. These outcomes went beyond those articulated in program documents. In particular friendships developed with peers, an outcome of Shepparton Access, Spiders and Arts Project, and the inherent value of convivial encounters with people without intellectual disability rather than a means to something else such as belonging to a local community were not explicitly mentioned in these documents.

At the broader social level, programs are likely to have had an indirect impact on attitudes toward people with intellectual disabilities. Programs did this by bringing ordinary members of the public into contact with people with intellectual disabilities under the types

of conditions contact theory suggests foster breaking down of prejudicial attitudes. These conditions are ones that,

(a) allow opportunities for a meaningful level of communication that is personal in nature, frequent, and of reasonable duration; (b) promote equal status; (c) foster cooperation in working toward shared goals; and (d) take place within an environment where there is authority support (Allport, 1954; Novak & Rogan, 2010; Pettigrew & Tropp, 2006). (Craig & Bigby, 2015, p.13)

Examples of these conditions in programs were, for example, in Gig Buddies, the recruitment and matching of volunteers with shared interests and who attended events as equals with their matched person with intellectual disabilities; in Spiders, the recruitment of volunteer coaches for the team who shared interests with team members in footy skills and the game and; in Arts Project, the development of collaborations between individual program participants and professional artists. In some instances, programs brought members of the public into more fleeting and less personal contact with members of the public, such as the demonstration footy matches the Spiders team members played in. Contact theory suggests this type of contact is less conducive to breaking down prejudice but informants suggested it may be effective in drawing attention to capabilities of people with intellectual disabilities. Some programs also had a direct beneficial impact on members of the public who came into direct contact with them. For example, the local schools benefitted from the fruit distribution undertaken by some Melba participants, and some of the Gig Buddy volunteers felt they benefitted from participating in the program.

Table 5. Program outputs and outcomes

	Gig Buddies	Melba	Shepparton	Arts Project	Spiders
Outputs	<p>Shared activity and social interaction in mainstream venues with volunteer.</p> <p>Participation in social events and social interactions with other program participants and the general public in mainstream venues.</p>	<p>Social interaction and participation in a mix of preferred, group and individual activities and less preferred ones.</p> <p>Contribution to community.</p> <p>Modelling and exposing locality to people with severe and profound intellectual disability participating.</p> <p>Social enterprises.</p>	<p>Social interactions and participation in a mix of individual and group activities in local community.</p> <p>Certificate 1 courses.</p> <p>Social enterprises.</p> <p>Work experience and paid work.</p> <p>Exposing local community to people with intellectual disabilities.</p>	<p>Serious art practice and production of art for exhibition and sale.</p> <p>Exposure of artistic community to talents of people with intellectual disabilities and collaborative opportunities.</p>	<p>Participation in footy training, and specific league competition.</p> <p>Participation in range of other footy and social activities.</p> <p>Raise profile of people with intellectual disabilities in sports community.</p>
Outcomes	<p>Friendships with people without intellectual disabilities.</p> <p>Convivial and fleeting encounters with people with and without intellectual disabilities.</p> <p>Enjoyment.</p> <p>Skill and confidence development.</p>	<p>Convivial and fleeting encounters with people in the locality.</p> <p>Enjoyment.</p> <p>Sense of belonging and contributing to the locality.</p>	<p>Friendships with peers.</p> <p>Convivial and fleeting encounters with people in locality.</p> <p>Enjoyment.</p> <p>Confidence and skill development.</p> <p>Sense of belonging to locality.</p>	<p>Friendships with peers.</p> <p>Convivial and fleeting encounters with peers and people without intellectual disability.</p> <p>Identity as artist.</p> <p>Enjoyment.</p> <p>Artistic skill development.</p> <p>Sense of belonging to artistic community.</p>	<p>Friendship with peers.</p> <p>Convivial and fleeting encounters with people without disability.</p> <p>Enjoyment, satisfaction, confidence.</p> <p>Skill development.</p> <p>Sense of belonging to footy club.</p>

We did not identify in the literature review, any common indicators of success for community participation programs. Given differing program aims and individual interests, success should be measured against each individuals' personal goals. It is therefore difficult to compare outcomes across programs with differing contexts, client groups and scale of offering to individual participants (ranging for example from a few hours a month to 5 days a week), other than using methods such as goal attainment scaling. Our analysis of programs has helped to demonstrate the futility of measuring outcomes in terms of outputs such as hours of support provided, and the importance of individually referenced indicators of success such as goal achievement or change to quality of life dimensions of social inclusion or interpersonal relationships, and indirect outcome measures of changes to community attitudes or social capital. The challenge now is to develop robust and efficient methods for measuring outcomes, that do not rely solely on self-report which is particularly problematic for people with more severe intellectual disabilities.

Individualised programs or individual support

These programs help to illustrate the possibilities opened up for individuals when support for community participation is planned and delivered individually but connected to resources developed as part of a broader program or staff team. Only the tip of the iceberg was visible in these community participation programs – the moments when people with intellectual disabilities were attending a social event with a volunteer, playing football in a team, selling a piece of art at an exhibition, conversing with other members of a cooking class at the senior citizens centre or serving a customer with home-made biscuits. Our analysis exposed the hidden and multi-faceted work of enabling community participation, the work behind the scenes that is most commonly conceptualised as being at a 'program' or 'team' level rather than individual support work. It has demonstrated the planning, thought and skill that has to be brought together to create opportunities for activities, convivial encounters, and friendships. This behind the scenes work is both collective, concerned with a group of individuals, and at the same time individualised and tailored to each participant, it then combines with individual support in the moment as necessary.

Enabling community participation is much more than one to one support to a person with intellectual disability to go out into the community or participate in one-off activities. As we have demonstrated these programs did things such as creating opportunities for interaction, creating new activities, ensuring regularity of attendance at an activity so that fleeting encounters evolved into convivial ones or meant people were recognised, trained or

supported natural supporters to feel comfortable interacting with people with intellectual disabilities, analysed and broke down parts of activities to enable people with severe and profound intellectual disabilities to be engaged, and negotiated connections with other groups and organisations. Behind the scenes programs or teams of staff provided the ingredients or resources for enabling community participation, that were then mixed and matched to each individual together with in the moment support if necessary. Without these ingredients, developed and combined by skilled managers and support staff, it is unlikely the positive individual outcomes identified in all five of these programs would have occurred. According to some research in group homes (Clement & Bigby, 2010; Clement & Bigby, 2009) and anecdotally it seems there is a tendency to equate support for community participation with one to one outings with a support worker, which unless anchored to a program with a broader intent and resourced, is unlikely to lead to any of the outcomes, other than fleeting encounters, identified in the five programs in this study.

Conclusions

These case studies have demonstrated the applicability of the typology of approaches to supporting community participation developed from the literature in the first part of this study (Bigby et al., 2017). By analysing these five well regarded or promising programs, the study has identified the nature of the ICF domains in each program and the differing emphasis accorded to each by different program types. The detailed exploration of each programs' program logic has provided a detailed understanding of the design of each, and made explicit some of the embedded program and practice wisdom. In some ways the case studies are blueprints that could be used to develop or refine programs that aim to support community participation for people with intellectual disabilities.

The cross case analysis illustrates the value of a typology of approaches to supporting community participation, and a common language in this arena. The differing assumptions about the nature of community integral to these programs has been exposed, and use of the typology allowed a move away from using 'community', an often vague and misinterpreted concept, in the definition of program aims. In particular by framing one type of program as supporting convivial encounters, rather than support for belonging to 'the community' the overarching similarities, aims and strategies of programs such as Melba and Shepparton become clearer. Convivial encounters may be a new term to many people but it is unlikely to have the multiple interpretations associated with community. Using the typology, and avoiding the use of 'community' in program aims has also opened a way for thinking about

how programs aiming to support convivial encounters could be replicated in urban places where there is no local community to which people might aspire to belong. Finding and evaluating examples of programs that aim to support convivial encounters in urban locations will be important to test the proposition that such programs can effectively operate in urban as well as outer urban and regional places. Further thinking is also required about the way 'work' is used by programs supporting community participation, as currently this is used to refer to a multitude of different activities, both paid and unpaid. This is important both in developing new programs and giving clear messages to people with intellectual disabilities and their families about potential activities that do not muddle community participation with employment.

The case studies have also illustrated the limited choices of program type that may be available to people with more severe intellectual disabilities. Although very small, in our sample only one type of program included this group of people. Notably, Gig Buddies, the most recent and perceived as most innovative program primarily served people with milder intellectual disabilities who could travel independently. This suggests a need for programs aiming to build relationships or belonging and identity to consider what changes to design might be required to include people with higher support needs. Also, that new funding for innovation or demonstration pilots should be directed towards programs that are inclusive of people with more severe intellectual disabilities to ensure this group has choices comparable to other groups.

The case studies also suggest the potential difficulties of replicating any of these programs in rural or remote areas, where there are likely to be limited potential groups and organisations with which opportunities for shared activities can be negotiated (for convivial encounter programs) or too narrow range of events available (for relationship programs such as Gig Buddies) or insufficient numbers to create a critical mass of people with a particular focal interest (for identity and belonging programs such as Spiders or Arts Project). This suggests further exploration is required to identify and analyse the type of support for community participation that is effective in rural and remote places.

The balance of time between mainstream and segregated places varied, associated with individual participant characteristics and preferences, and type of program. Some outcomes were similar across different types of programs, and participants, and their family members, were very satisfied with the programs they attended. The similarity of outcomes and level of satisfaction suggest that type of place may not be an important factor influencing

outcomes. This should warn against potentially stereotypical views derived from social role valorisation that are blind to the potential advantages of using segregated places for some time, for some types of programs supporting community participation. In particular the Arts Project case study has demonstrated that developing skills and identity through specialist support in a segregated place can act as a catalyst for belonging to wider groups or communities based on interest, or a springboard for use and enjoyment of mainstream places such as galleries or museums, which hold the potential for convivial encounters with others who use these places.

Several issues are raised that require further consideration by three interconnected findings from the analysis: the variation of participants' time occupied by support for community participation programs; that activities in 'full time' programs may not always be participants' most preferred option, and; in the full time programs some activities more closely resemble skill development classes rather than support for community participation. It may be that the 'full time' nature of programs means that for part of the time they also offer support that is different from and thus not support for community participation, particularly for people with more severe intellectual disabilities. This group cannot safely be left alone, and for various reasons, including capacity of family carers or staffing and funding of accommodation support services, may have to leave their home during the day (Bigby et al., 2001). This is a longstanding issue that juxtaposes rights and resources, which new funding mechanisms may tackle. It is important, however, not to confound design of effective community participation programs for people with more severe intellectual disabilities by muddling together different purposes of support. Differentiating between support for community participation and simply 'care' to ensure safety, respite for unpaid carers, or fill gaps in accommodation support poses a challenge in thinking about community participation for the NDIA and new individualised funding packages.

All of the programs were relatively small in scale, especially compared to some of the larger disability service provider organisations created from recent amalgamations. The relatively flat structures, absence of social distance between all staff and participants and the close connections of organisational leaders with participants are likely to be associated with the small scale of programs and the organisations that delivered them. It may be that small scale is a pre-requisite for effective support for community participation programs. However there is insufficient evidence from this study to reach this conclusion, although this was also a feature of most of the programs identified in the review of the literature. This suggests that

further exploration is required to test this proposition by either locating and evaluating larger scale community participation programs or establishing a larger scale demonstration program.

Despite being framed as ‘programs’ the case studies show that person centred support was delivered, underpinned by individual planning processes that required staff to know each participant well. Families of participants were included in planning and for many participants, families were partners in negotiating the type of activities they preferred and support they needed. Importantly too, a significant proportion of total staff time was spent behind the scenes, establishing the infrastructure to create opportunities for convivial encounters and engagement, or ensuring the competence of natural supporters. These tasks require consideration, staff time and skills and cannot be left to chance. As the case studies demonstrate, direct support in the moment is only a small fraction of the overall work associated with supporting community participation in these programs. This must be recognised, and embedded in funding rates, together with recognition of the centrality of staff knowledge about individual participants, and importance of individual planning processes. So too, the ongoing need for community participation should be recognised, given for example, the continuous dynamic of community groups and individual circumstances. The type of support and its intensity may fluctuate over time but it is important for people with intellectual disabilities to retain connections to program staff who can identify quickly when things are going wrong or negotiate a new activity to replace the one just finishing.

Several programs had mechanisms for seeking collective participant input in the design of the program and feedback about its delivery. Such mechanisms enable participants to exercise additional influence over the program than is available to them as individual consumers. As the case studies demonstrate, participant participation in program governance, design and quality assurance has not yet become standard or expected practice. Raising expectations in this regard is one way of furthering choice and control by people with intellectual disabilities over the support they receive and fostering their participation in civil society, in keeping with the current rights based agenda.

This detailed review has enabled an initial mapping of the range of skills staff used in these programs, which span community development, established evidence-based disability support worker practice such as Active Support, and various newer approaches for which evidence is emerging, such as Active Mentoring, Risk Enablement and Support for Decision Making. Further mapping of skills and competencies of staff is required as well as bringing

together these various approaches into a coherent practice framework. Recruiting staff with preferred attitudinal attributes and training them to be competent practitioners with the types of skills identified as necessary will be a major challenge for disability support organisations as the demand for support for community participation grows with additional funding available from the NDIS.

Data from program participants and their family members suggested a range of positive outcomes from the case study programs which were fairly similar. Peer friendships were an outcome of several programs, which was not however, a program aim or acknowledged in program documentation. Such friendships are important, especially given the growing body of research suggesting the loneliness of people with intellectual disabilities and long held knowledge about their desire for friendships (Petroutsou, Hassiotis & Afia, 2018; Emerson, Davies & Spencer & Malam, 2005). It should be acknowledged that support for community participation programs other than those that specifically aim to build relationships, can support the development of peer friendships.

The knowledge developed from this study can inform future design of programs to support community participation and the typology will be useful in finding a common language for people with disabilities and their families, the NDIA and disability support organisations to talk about these programs. It can also inform individual NDIS planners, and broader decisions by the NDIA about types of effective support for community participation. Setting out the common characteristics and differences between promising community participation programs will also be useful to people with intellectual disabilities and their families in making decisions about planning and purchase of services. There is significant room for further development of this material into more accessible guides to thinking about support for community participation for people with intellectual disabilities, their families, NDIA planners and local areas coordinators.

Recommendations

- These findings reinforce the diversity of experiences that might be described as instances of community participation and the attendant dangers of vague or ill defined approaches to support. Planning and funding for community participation should be closely attuned to identifiable types of participation, include a clearly articulated and evidence based logic for the type of support provided.
- Support for community participation can be typically represented as either:

- Social relationships - the development of social relationships between adults with or without intellectual disability. Interventions aims to develop social relationships prioritise social interactions, and matching with volunteers or support to meet people with similar interests.
- Convivial encounters - support for social interactions that are neither free mingling in public places nor based on long term relationships, where there is a shared identity or activity with others and a sense of pleasantness or warmth. Interventions to support convivial encounters prioritise place (mainstream community groups or community organisations) and activities (based on individual interest) and pleasant social interactions in for example, community groups, where a person is known and recognised.
- Belonging –activities and places where subjective feelings of a sense of attachment and belonging to close and more distant others develop. Interventions to support a sense of belonging prioritise participation in activities with the potential to lead to a new social identity and valued role as for example an artist, in a mix of segregated and mainstream places.
- Expected outcomes of community participation should be defined for each individual and measures should include some or all of the following and be tailored to reflect the primary goal of the individual;
 - personal development such as skills, self-esteem or confidence;
 - increased social networks, including peer relationships;
 - subjective experiences such as enjoyment or happiness.
- The benefits of peer relationships for people with intellectual disabilities should not be underestimated and are often an unnoticed outcome of community participation programs.
- Community has multiple meanings, and can be based on place, locality, ideology or interest. A community of peers which is based on choice, common interest or talent is a legitimate form of community participation that should not be devalued and may also facilitate inclusion other communities that include people with and without disabilities.

- Visible direct one to one support is likely to be a small fraction of the work of supporting a person with intellectual disability to participate. Individual person centred support for community participation can be delivered by identifiable programs which are likely to enable better client outcomes ensuring support is developmental rather than simply paid companionship. Programs facilitate behind the scenes support, that involves key elements such as developing opportunities for community participation, recruiting volunteers, supporting natural supporters in groups or organisations, sharing of practice wisdom about community places and training and supervising staff.
- Supporting community participation requires skilled staff who are competent in a range of community development skills, such as analysis of community groups and community mapping, as well as disability support practice such as Active Support, Active Mentoring, Risk Enablement and Support for Decision Making.
- Particular attention should be given to developing interventions or programs that support community participation of people with more severe and profound intellectual disabilities, as some of the new innovative programs exclude this group.
- Further exploration is necessary of interventions or programs to support community participation for people with intellectual disabilities in rural or remote areas where small populations may be too small to support the three types identified in this study.
- Support for community participation should be distinguished from support for every day care, respite or support that compensates for gap in support in a person's accommodation.
- The success of strategies to support community participation of people with intellectual disabilities depends on partnerships and collaboration between specialist disability services and the broader community, including the availability, design, accessibility and inclusiveness of community groups, mainstream and the general population. Potential strategies and roles of local government authorities in designing places conducive to convivial encounters, facilitating inclusivity of community groups and public places in respect of people with intellectual disabilities requires further exploration.

Commentary on Policy Implications

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Increasing the social and community participation of people with disability is an unambiguous policy goal and a priority topic for current disability reforms including the National Disability Strategy and the National Disability Insurance Scheme (NDIS). The NDIS Act (2013) includes a number of objectives that give rise to this goal, namely provision of supports that maximise community inclusion and building community awareness of issues that facilitate greater community inclusion.

Despite the legislative basis and strong policy intent for supporting people with disability to achieve social and community participation, people with intellectual and developmental disabilities continue to experience high rates of social isolation (Bigby, 2008; Forrester-Jones et al., 2006; Milner & Kelly, 2009; Robertson et al., 2001). This highlights that despite deinstitutionalisation and increased ‘community presence’ of people with disability, progress to advance community participation has been slow (Wiesel & Bigby, 2016).

The literature review for this study illustrates the continuing conceptual ambiguity about community participation and the paucity of research about effective programs or interventions to support it (Bigby et al., 2018). These remain obstacles to achievement of better outcomes.

Research on community participation is not unique in this respect. An Audit of Disability Research in Australia in 2014, and the 2018 update, found that the disability research base is not ‘fit for purpose’ for the reform agenda (Llewellyn, 2014, 2018). Australia lacks a well-coordinated and coherent disability research agenda with critical mass and a sustainable funding base. The implications of not having well - articulated lines of inquiry about ‘what works’ when it comes to community participation are a considerable impediment to better policy and practice (i.e. innovation), and ultimately for better outcomes for the many NDIS participants who need effective community participation support. The best available estimates indicate that people with cognitive impairment constitute 38% of participants entering the scheme to date (NDIA, 2018). This is the sum of percentages in the categories of intellectual disability, acquired brain injury, developmental delay and global developmental delay, as there is no category for cognitive impairment. As a service type, ‘core - social and

civic support' is reflected in 19.7% of the total annualised committed support, making it consistently one of the most commonly funded supports. By comparison, employment and education support make up around 2.5% of the total volume of support for NDIS participants.

Relatedly, the absence of reliable national data on outcomes of funding to support community participation is hampering the spread and sustainability of good practice. We must look to other international jurisdictions to see how good data, effectively shared, can support innovation diffusion by illustrating the differential outcomes of people with intellectual disabilities compared to the whole population, the extent of a postcode lottery, and in relation to the interface between the provision of specialist disability services and other services, environments and citizenship outcomes. Two examples from the US are worth highlighting.

Americans with Disabilities Act Participatory Action Research Consortium (ADA-PARC)

The [ADA-PARC website](#) has a collection of public data sets that shed light on the status of people with disabilities in local communities as well as national, state, county, and city levels. Data describes the demographics of the population, and the status of disability in an area in three domains, community living, community participation and work and economics. Access to equitable community participation opportunities is a civil right for citizens with disabilities within the Americans with Disabilities Act. The indicators focus on community features and policies that support people with disabilities to go out and participate in the community. These include; information about access to private, public and alternative transportation systems, access to local community resources and buildings, such as libraries, police stations, grocery stores, restaurants, parks and schools, and information on "liveability" of the community, including indicators such as access to health care and insurance, affordable and integrated housing, education, and other neighbourhood features such as crime and poverty rates.

US National Core Indicators

[National Core Indicators](#) (NCI) is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the program, which began in 1997, is to support NASDDDS member agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks.”

Models of support

Good evidence informed policy should guide service providers toward promising models of care and support, and NDIS participants, their families and carers toward informed choices about effective supports. For adults with cognitive impairments in Australia, organisational strategies to support community participation have traditionally focused on provision of day services most of which have been centred based. Day services emerged in the 1950s to provide respite for families and address the lack of options and pathways for adults to participate in community life. Commonly delivered by specialist disability service providers, the nature of day program activities varies as does the setting in which the activities take place (Bigby, 2005). Coupled with increased funding of disability services under the NDIS and options for NDIS participants to exercise greater choice, there is growing awareness of alternatives to traditional day services. More recently, models such as micro-boards and non-specialist disability or ‘mainstream’ providers such as activity and leisure centres are offering alternative approaches to planning, co-ordination and provision of support for community participation. These developments require scrutiny and evaluation to determine whether they support people to be in more inclusive environments or lead to more empowering outcomes, including employment. The case studies in this project illustrate, for example, effective collaborations between specialists in disability support and this type of mainstream provider. Such collaborations ensure planned support for participation and increase the skill base of natural supporters in mainstream places. They shift the emphasis to resourcing ‘natural supporters’ to develop strategies and skills necessary to support participation by a person with cognitive disability and avoid reliance on a visible (paid) direct supporter, which often inhibits social interactions in mainstream places. The case studies illustrate the potential for person centred supports for community participation to occur as part of programs that facilitate genuine participation through behind the scenes activities such as recruiting and training volunteers, creating opportunities for participation in mainstream places and resourcing natural supporters.

A distinctive feature of this project is the in-depth case studies of good practice by five organisations. The collaboration of academic and sector stakeholders has advantages to other forms of research. Input from key stakeholders has guided thinking about how community participation is defined. This helped to enhance conceptual clarity, support working toward a common set of goals, and importantly, facilitate agreed criteria for evaluating community participation approaches. Similarly, the research outputs associated

with this project are intended for a range of stakeholders. In particular the detailed case studies offer worked examples to encourage service providers to develop service offerings that reflect the best available evidence. The case studies demonstrate the value of analytical tools such as ‘theory of change’ or program logic models as a way of communicating to staff, clients and families how support activities are intentionally linked to desirable outcomes.

The need for greater emphasis on the measurement and demonstration of outcomes emerged as a further implication for policy and practice. Research by NDS (2012) demonstrated that there is considerable interest amongst service providers to use validated, or at least promising outcome measurement instruments that assist service providers to measure and demonstrate outcomes in a range of service settings. Recent developments in NDIS pricing policy indicate that future payment for results/outcomes achieved will feature more prominently in NDIS payment structures (McKinsey, 2018). To achieve this, in addition to validated tools, the capabilities and capacity of service providers to use them to measure and demonstrate outcomes need to be developed. There is an equally strong case for simple and easy to use outcome measurement tools which could be trialled across a number of services to test their applicability to different types of community participation and to people with intellectual disabilities. Some tools developed in the Australian context are beginning to show some promise for simple outcome measurement (Koritsas, Hagiliassis, & Cuzzillo, 2017).

How community participation is funded and priced is a complex consideration, particularly in the context of the portable, individualised funding environment which is the hallmark of the NDIS. As the case studies vividly demonstrate, effective support for community participation can be achieved in a variety of ways. Each of the five case study organisations demonstrates a ‘theory of change’ with similarities but also important differences. Other variations exist in respect of:

- How paid supports are blended with volunteer time? Use of volunteers has its own cost structures relating to how an organisation attracts, maintains and develops and deploys this important, and hard to replace, form of social capital.
- Whether services and supports are tied to a capital base, such as day services or other community infrastructure? This highlights issues about how shared utilisation of this type of fixed assets is distributed or charged across individual budgets? What is the ‘right’ price / cost and what degree of cross-subsidisation is occurring, potentially

obfuscating the total and marginal costs for the preservation and maintenance of those assets for others who may need to use them occasionally or episodically in the future?

In relation to these complex questions the case studies demonstrate that innovative practice is diverse and outpacing current NDIS pricing policy, but also potentially restrained by it. Current NDIS pricing does not remunerate or reward service providers for the demonstrable difference they make, rather it operates with a fixed national tariff with loadings for place and point of service based on geographical location, time of day or week (linked to labour costs as per modern award terms and conditions), client complexity and staff to client ratios.

There are a range of potential responses to the complexities associated with funding services and supports intended to achieve an individual mix of personal development, increased social networks and positive subjective feelings. One response is to be neutral about inputs, activities, outputs, place, and to focus exclusively on individual outcomes against goals. This ‘input neutral’ approach, though conceptually attractive, evades the harsh market realities of needing to ensure that enough service providers remain viable to offer community participation services in any given area where needed, thereby making choice and control a reality. There is much discussion of ‘thin markets’ and the risk of choice being diminished for all because of insufficient numbers of people in any given area who do not have ‘enough’ community participation in their NDIS plans to encourage service providers to offer a service. There is also emerging evidence that NDIS pricing for one-to-one community supports are insufficient and that one consequence of this could be a perpetuation of group-based community supports which may not always be the option of choice. NDS research (2018) on service providers’ strategic intent to supply community participation found that 30 per cent of community participation providers and 50 per cent of centre-based providers are planning to cease, shrink or not grow their services under NDIS prices. Community access supports are central to the NDIS’s goal of improving social participation for people with disability. The case for rigorous independent benchmarking for pricing policy that supports diverse local service ecosystems to enable real choice is a clear implication and is made stronger by this evidence.

A further implication for policy is the question of purpose. What is community participation for? Is community participation an end in itself or a facilitator of other goals, such as the development of social skills that make self-advocacy, or employment more likely? The conspicuous absence of a national policy framework for social and community

participation and its relation to other service types, especially employment, is directly implicated here. The broader policy imperative is clear and unambiguous - increasing the employment participation of people with disability and carers is fundamental to the financial sustainability of the NDIS. In its 2011 report on 'Disability Care and Support', the Productivity Commission anticipated that the then-proposed NDIS would generate substantial economic benefits and that a key source of these benefits would be "increased economic and social participation for people with disabilities and their informal carers" (Productivity Commission, 2011, p.iv). Research by NDS estimated the economic benefits from the NDIS would be a GDP gain of up to \$23bn per year (at full scheme in 2019, in 2015 dollars) (Long, 2015). This was against a background of Australia's low performance in disability employment compared with most other developed countries. Research indicated that, in 2010, Australia ranked 21st out of 29 OECD nations in terms of employment rates of people with disability (OECD 2010). Statistics show the labour force participation rate for people with disability (aged 15–64 years) in 2012 was close to 30 percentage points lower than other Australians (ABS, 2013). The gap remains persistent. The reasons for Australia languishing near the bottom of the OECD league table in relation to the employment of people with disability are many and varied and beyond the scope of this work. Areas of focus remain school to work transition, transport options, and ensuring that community participation, especially in the form of day services, are not presented as a default option for adults with cognitive impairment.

At the time of writing, the proportion of employment support in NDIS participants plans remains disturbingly low. In the third quarterly report of 2017-18, only about 2.5% of the total committed support was for employment (NDIA 2018). In the pilot of the NDIA Outcomes Framework (2015) only 13% of respondents indicated that the NDIS had helped with employment, the lowest of any domain. This needs to change quickly if the social and economic gains from the NDIS are to be realised. NDIA planners and Local Area Co-ordinators need to consider employment as an option for a much larger proportion of NDIS participants and emphasise a 'work first' approach. The outgoing inaugural Chairman of the NDIA, Bruce Bonyhady, admitted that the quality of plans is one of several challenges facing the NDIA in implementing the NDIS. In a letter to then Federal Minister, Christian Porter, he stated: "The First Plan process, together with the requirement to complete almost as many new plans during the current six months as throughout the entire trial phase of three years, has led to some plan quality issues" (Bonyhady, 2016). The poor quality of plans continues to

require substantial—and unfunded— intervention by providers and consumer advocates to assist NDIA participants to ensure plans better reflect their needs and broader policy objectives.

Community participation is a pathway to work but it is also important to recognise that many people use community participation because they do not work or cannot obtain enough work or cannot get to work. The reasons why aspirations to employment are not more prevalent in NDIS plans may include; that employment is not a strongly expressed preference of NDIS participants or their families or others involved in planning their support; poor quality planning that reflects expediency, a lack of imagination, or a real bias toward social as compared to economic participation.

There is an urgent need for research on how goal development and choices about services and supports thought to be relevant to the achievement of goals are being supported in the NDIS planning process. We need to ‘get inside’ the NDIS decision making and planning processes. Understanding the factors informing NDIS participants’ expressed preferences for social participation, economic participation, and their trade-offs between goal-oriented activities and preferences for different forms of support are all highly relevant to systemic improvements to NDIS planning. The direct benefits of research of this kind would be to enhance consumer, provider, and carer education, and better information, linkages and capacity building strategies, especially local area co-ordination. There are multiple influences on the expressed preferences of NDIS participants.

What is the continued relevance of programs? Many commentators have heralded the development of the NDIS, with its greater emphasis on individualised packages of supports, as ‘the end of programs’. Reasons for this are the supposed inflexibility and lack of person-centeredness of programs. There is clear evidence from the case studies presented here that funded activities have features of programs and that these features have resulted in demonstrable positive outcomes. What all the case studies have in common is the provision of an evidence-based structure or ‘scaffolding’ for individually tailored responses that assist in personal goal attainment. The findings here illustrate that individual interventions and ‘micro practices’ such as person centred active support can co-exist within the context of a well-designed ‘program’ with a clear program logic or theory of change that serves individuals that share common characteristics. The heuristic of components and outcomes of community participation presented here (see Figure 1, p 33) is an attempt to represent and capture both the diversity (matters of emphasis) and the similarities (the common thread) of

the ‘thinking in action’ or praxis that are represented in the literature and demonstrated by the case study organisations.

Returning to one of the original aims of this research, it remains imperative that there is conceptual clarity about what we mean by community participation. Government funders, primarily the NDIA, need to be clear about what will be funded and why, on what basis, with what social result, for which beneficiaries? Service providers need to design interventions, programs and services that align to these intentions, with equal clarity about means and ends, if they are to be held accountable. Most importantly, people with disability, their families and carers need certainty about the parameters of choice, and what is available.

An extended study of the kind reported here would enrol a wider set of services to evolve their service offerings – customising promising organisational models within the context of NDIS funding / pricing to determine whether and under what circumstances the delivery of models that reflect the best available evidence are achievable, or not. It would collect evidence on the direct experience of consumers and practitioners seeking to implement models and help to identify champions for facilitating organisational and system wide change. As noted above, it would trial and refine simple and easy to use outcome measurement tools across a number of services to test their applicability to different types of community participation and in particular to people with intellectual disabilities. In short, applied research of this kind would more fully validate the models and enhance sustainability of community participation outcomes.

A national conversation...?

The implications raised here can only be properly addressed by new forms of policy development and stakeholder engagement that are undertaken in a manner consistent with the principles that underpin reform. These include a renewed commitment to the ‘nothing about us without us’ maxim but re-invigorated with greater emphasis on co-design and co-production which involves, “*deliberately engaging users of the system, delivers of services and other experts to actively understand, explore and ultimately change a system together*” (NDS, 2016).

Finally, this research, has developed a typology of community participation, provided blue prints of promising programs, identified practice skills and strategies for supporting participation and surfaced the work of orchestrating participation that does not occur as part of one-to-one direct support hours. It provides the starting point to initiate an urgent national

conversation about community participation. It should be guided by the following lines of inquiry:

- What do we mean by community participation, what is it for, and how should it interact with other services and supports, especially employment, transport and accommodation, to optimise the social and economic participation of adults with cognitive impairments?
- What do we know, not know, and still need to know about effective models of community participation?
- How should effective models of community participation be funded so that service providers are encouraged to adopt them and are increasingly rewarded for the demonstrable difference they make?
- What are the barriers and enablers to the spread and sustainability of good practice and to innovation?
- What is the continued relevance of programmatic approaches to community participation?
- How do we retain the best features of programs and re-invigorate them with more personalised approaches?

Summary of implications for policy, research and practice

There is a need for further **research on the effectiveness of models of community participation**, as part of a coherent national disability research agenda to ensure that the optimum interaction between community participation and other forms of supports, especially accommodation and employment, are investigated. The collaboration of academic and sector stakeholders has highlighted the advantages of the approach to this research. A further implication is that consideration be given to how people with disability, the service providers they choose, and other stakeholders are engaged in meaningful research about them and that effectively mobilises new knowledge to sector stakeholders.

There is an urgent need to **build the capabilities of service providers to measure and demonstrate outcomes** using validated tools. This anticipates the direction of NDIS pricing policy which looks likely to place greater emphasis on payment for successful achievement of outcomes or social results. To avoid the emergence of thin markets and to

promote choice, there is a need for independent costing and pricing, (i.e. benchmarking) to better understand the real costs of effective service and business models.

The absence of a **national policy framework for community and social participation** is an impediment to progress. It remains imperative that there is **conceptual clarity about what we mean by community participation**. Government funders, primarily the NDIA need to be clear about what will be funded and why, on what basis, with what social result, for which beneficiaries.

There is an urgent need for **research on how goal development and choices about services and supports** thought to be relevant to the achievement of goals are being supported in the NDIS planning process. We need to better understanding the factors informing NDIS participants expressed preferences for social and or economic participation. There is a conspicuous absence of **reliable national data about outcomes** being achieved for adults with a cognitive impairment.

A **national conversation** intended to answer key questions about what community participation is for, how leading-edge practice should be funded, what barriers and enablers to the spread and sustainability of good practice exist, and the continued relevance of programs of supports are all relevant questions that should feature in an inclusive conversation about the future of community participation.

References

- ADA-PARC. *Community & Work Disparities, A Program of the ADA Participatory Action Research Consortium*. Retrieved May 1, 2018, from http://centerondisability.org/ada_parc/community_participation/index.php
- Australian Bureau of Statistics (2013). *Disability, ageing and carers, Australia: Summary of Findings, 2012 (No. 4430.0)*. Table 9. Canberra: ABS.
- Bigby, C. (2005). Comparative program options for aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disability*, 2(2), 75–85.
- Bigby, C. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability*, 33(2), 148–157.
- Bigby, C., Anderson, S., & Cameron, N. (2018). Identifying conceptualisations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual and Developmental Disabilities*, 31(2), 165-180. doi: 10.1111/jar.12390/full.
- Bigby, C., & Wiesel, I. (2015). Mediating community participation: Practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disabilities. *Journal of Applied Research in Intellectual disabilities*, 28(4), 307–318.
- Bigby, C., Wilson, N., Stancliffe, R., Balandin, S., Craig, D., & Gambin, N. (2014). An effective program design to support older workers with intellectual disability participate individually in community groups. *Journal of Policy and Practice in Intellectual Disability*, 11(2), 117-127. doi: 10.1111/jppi.12080.
- Bigby, C., Fyffe, C., Balandin, S., Gordon, M., McCubbery, J.(2001) *Day support services options for older adults with a disability*. National Disability Administrators Group, Melbourne
- Bonyhady, B (2016). Letter from Mr Bruce Bonyhady, Chair NDIA to Minister for Social Services Hon. Christian Porter. Retrieved May 1, 2018, from

<http://www.everyaustraliancounts.com.au/wp-content/uploads/Letter-by-Bruce-Bonyhady-to-Christian-Porter.pdf>

- Bryson, L., & Mowbray, M. (2005). More spray on solution: community, social capital and evidence based policy. *Australian Journal of Social Issues*, 40(1), 91-106.
- Clegg, J., & Bigby, C. (2017). Debates about dedifferentiation: twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group. *Research and Practice in Intellectual and Developmental Disabilities*, 4(1), 80-97. doi: 10.1080/23297018.2017.1309987.
- Clement, T., & Bigby, C. (2009). Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual disability. *Journal of Applied Research in Intellectual Disability*, 22, 264-275. doi: 10.1111/j.1468-3148.2008.00458.x.
- Clement, T. & Bigby, C. (2010). *Group homes for people with intellectual disabilities: Encouraging inclusion and participation*. London: Jessica Kingsley.
- Clifford-Simplican, S., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, 38, 18-29. doi: [10.1016/j.ridd.2014.10.008](https://doi.org/10.1016/j.ridd.2014.10.008).
- Craig, D., & Bigby, C. (2015). "She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disabilities in community groups. *Journal of Intellectual and Developmental Disability*, 40, 12-25. doi: [10.3109/13668250.2014.977235](https://doi.org/10.3109/13668250.2014.977235).
- Douglas, J., Bigby, C., Knox, L., & Browning, M. (2015). Factors that underpin the delivery of effective decision-making support for people with cognitive disability. *Research and Practice in Intellectual and Developmental Disabilities*, 2, 37-44. doi: [10.1080/23297018.2015.1036769](https://doi.org/10.1080/23297018.2015.1036769).
- Emerson, E. Malam, S., Davies, I., & Spencer, K. (2005). *Adults with Learning Difficulties in England 2003/4*, Lancaster: Lancaster University.
- Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Hallam, A., Knapp, M., & Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from

- long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, 19(4), 285–295.
- Harlan-Simmons, J.E., Holtz, P., Todd, J., & Mooney, M.F. (2001). Building Social Relationships Through Valued Roles: Three Older Adults and the Community Membership Project, *Mental Retardation*, 39(3), 171–180.
- Koritsas, S., Hagiliassis, N., Cuzzillo, C. (2017). The Outcomes and Impact Scale – Revised. The psychometric properties of a scale assessing the impact of service provision. *Journal of Intellectual Disability Research*, 61(5), 450- 460.
- Llewellyn, G. (2014). Report of *audit of disability research in Australia*. Centre for Disability Policy and Research. Retrieved May 1, 2018, from https://www.adhc.nsw.gov.au/_data/assets/file/0013/300091/1a-Audit-of-Disability-Research-in-Australia.pdf
- Llewellyn, G. (2017). *Audit of disability research in Australia, update report 2017*. Centre for Disability Policy and Research. Retrieved June 20, 2018, from <http://nla.gov.au/nla.obj-640802934>
- Long, B. (2015). *An Estimate of the Economic Effects of the Implementation of the National Disability Insurance Scheme*. Centre for Applied Disability Research, National Disability Services, Canberra. Retrieved May 1, 2018, from [https://www.cadr.org.au/images/Publications_Files/ndis_economic_benefits%20main%20\(1\).pdf](https://www.cadr.org.au/images/Publications_Files/ndis_economic_benefits%20main%20(1).pdf)
- Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.
- McKinsey & Company (2018). *Independent Pricing Review*. National Disability Insurance Agency. Retrieved February 1, 2018, from <https://www.ndis.gov.au/medias/documents/ipr-final-report-mckinsey/20180213-IPR-FinalReport.pdf>
- Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24(1), 47–62.
- National Core Indicators (NCI). Retrieved May 1, 2018, from <https://www.nationalcoreindicators.org>

- National Disability Insurance Agency. (2015). *National Disability Insurance Scheme Outcomes framework pilot study: summary report*. Retrieved May 1, 2018, from <https://www.ndis.gov.au/html/sites/default/files/outcomes-framework.pdf>
- National Disability Insurance Agency. (2017). *COAG Disability Reform Council Quarterly Report*. Retrieved from National Disability Insurance Agency: <https://ndis.gov.au/medias/documents/h91/hbc/8805559468062/Report-to-the-COAG-Disability-Reform-Council-for-Q1-of-Y5.pdf>
- National Disability Insurance Agency. (2018). National Public Dashboard. Retrieved May 1, 2018, from <https://www.ndis.gov.au/medias/documents/dashboard-national-march-18-pdf/dashboard-national-march-18-pdf.pdf>
- National Disability Services (2012). *Measuring Outcomes for People with Disability*, Canberra.
- National Disability Services. (2018). *A snapshot of community participation and centre-based supports*, Canberra. Retrieved May 1, 2018, from <https://www.nds.org.au/news/media-releases/survey-on-community-participation-and-centre-based-supports-raises-questions-about-growth>
- National Disability Services. (2016). *Community Participation in Action: A Resource Guide for Disability Service Providers*, Canberra. Retrieved May 1, 2018, from https://www.nds.org.au/images/resources/resource-files/CII_Community_Participation_in_Action_Guide_2016.pdf
- Ockenden, J., Ashman, B., & Beadle-Brown, J. (2014). *Active Support – Fundamental to Positive Behaviour Support*. *Research and Practice in Intellectual and Developmental Disabilities*, 1(2), 98-107. doi: [10.1080/23297018.2014.961528](https://doi.org/10.1080/23297018.2014.961528).
- OECD. (2010). *Sickness, Disability and Work: A synthesis of findings across OECD Countries*, OECD Publishing, Paris, <https://doi.org/10.1787/9789264088856-en>
- Petroutsou, A., Hassiotis, A., & Afia, A. (2018). Loneliness in people with intellectual and developmental disorders across the lifespan: A systematic review of prevalence and interventions. *Journal of Applied Research in Intellectual Disabilities*, doi: [10.1111/jar.12432](https://doi.org/10.1111/jar.12432).

- Productivity Commission. (2011). *Disability Care and Support*, Report no. 54, Canberra.
Retrieved May 1, 2018, from <https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-overview-booklet.pdf>
- Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, 39(3), 201–214.
- Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., & Joyce, T. (2007). Person-Centred Planning: Factors Associated with Successful Outcomes for People with Intellectual Disabilities. *Journal of Intellectual Disability Research*, 51(3), 232-43. doi:10.1111/j.1365-2788.2006.00864.x
- Stancliffe, R., Bigby, C., Balandin, S., Wilson, N., & Craig, D. (2015). Transition to retirement and participation in inclusive community groups using active mentoring: An outcomes evaluation with a matched comparison group. *Journal of Intellectual Disability Research*, 59(8), 703-718. doi: 10.1111/jir.12174
- Stickley, T., Crosbie, B., & Hui, A. (2012). The Stage Life: Promoting the inclusion of young people through participatory arts. *British Journal of Learning Disabilities*, 40(4), 251–258.
- Storey K. (2003). A review of research on natural support interventions in the workplace for people with disabilities. *International Journal of Rehabilitation Research*, 26, 79–84. doi: 10.1097/01.mrr.0000070757.63544.c8
- Thompson, J., & DeSpain, S. (2016). Community support needs. In N. Singh (Ed.), *Handbook of evidence-based practices in intellectual and developmental disabilities* (pp 137-168). Switzerland: Springer.
- Wiesel, I., & Bigby, C. (2016). Mainstream, inclusionary and convivial places: Locating encounter between people with and without intellectual disability. *Geographic Review*, 106(2), 201–214. doi: 10.1111/j.1931-0846.2015.12153.x

Appendix 1 Details of case study participants

Table A1. Characteristics of sample for each group

		Arts Project	Gig Buddies	Shep Access	Melba	Spiders
	<i>N/n</i>	5	4	5	5	4
Age (years)	M	38	36	27	36	28
	Range	30 – 50	21 – 69	19 – 38	26 – 48	22 – 34
Male		<i>n</i> = 2	<i>n</i> = 2	<i>n</i> = 2	<i>n</i> = 1	<i>n</i> = 4
Part 1 ABS score	M	249	226	219	170	219
	Range	180 – 277	173 – 289	140 – 275	60 – 265	208 – 237
Total score on the ABC	M	7	14	14	21	6
	Range	0 – 19	3 – 34	1 – 40	15 – 27	4 – 9
Socially impaired		<i>n</i> = 1	<i>n</i> = 2	<i>n</i> = 2	<i>n</i> = 3	<i>n</i> = 0
Physical impairment		<i>n</i> = 1	<i>n</i> = 0	<i>n</i> = 1	<i>n</i> = 3	<i>n</i> = 0
Epilepsy		<i>n</i> = 1	<i>n</i> = 1	<i>n</i> = 1	<i>n</i> = 2	<i>n</i> = 0
Mental health problems		<i>n</i> = 1	<i>n</i> = 0	<i>n</i> = 2	<i>n</i> = 1	<i>n</i> = 0
Visual impairment		<i>n</i> = 0	<i>n</i> = 0	<i>n</i> = 2	<i>n</i> = 0	<i>n</i> = 0
Autism		<i>n</i> = 1	<i>n</i> = 1	<i>n</i> = 0	<i>n</i> = 2	<i>n</i> = 2
Primary form of communication						
– Verbal		<i>n</i> = 5	<i>n</i> = 4	<i>n</i> = 5	<i>n</i> = 3	<i>n</i> = 4
– Gestures		<i>n</i> = 1	<i>n</i> = 2	<i>n</i> = 2	<i>n</i> = 4	<i>n</i> = 3
– Body Movement		<i>n</i> = 0	<i>n</i> = 1	<i>n</i> = 1	<i>n</i> = 3	<i>n</i> = 0
– Facial Expression		<i>n</i> = 0	<i>n</i> = 2	<i>n</i> = 2	<i>n</i> = 4	<i>n</i> = 0
First language is English		<i>n</i> = 5	<i>n</i> = 4	<i>n</i> = 5	<i>n</i> = 5	<i>n</i> = 4

Table A2. Comparison of indicators of quality of life outcomes for each group

		Arts Project	Gig Buddies	Shep Access	Melba	Spiders
	<i>N/n</i>	5	4	5	5	4
Score on the Index of Participation in Daily Life	M	65	55	54	36	62
	Range	46 – 92	25 – 92	39 – 69	12 – 62	54 – 80
Score on the Index of Community involvement	M	36	55	60	57	64
	Range	25 – 63	46 – 63	56 – 63	40 – 68	56 – 73
Score on the Choice Making Scale	M	75	82	45 ¹	50	75
	Range	61 – 94	62 – 97	40 – 50 ¹	39 – 64	67 – 79
Regular family contact		<i>n</i> = 5	<i>n</i> = 4	<i>n</i> = 5	<i>n</i> = 5	<i>n</i> = 4
Contact with friends		<i>n</i> = 4	<i>n</i> = 4	<i>n</i> = 5	<i>n</i> = 5	<i>n</i> = 4
Have an advocate		<i>n</i> = 5	<i>n</i> = 3	<i>n</i> = 1	<i>n</i> = 5	<i>n</i> = 1
Advocate - Family Member		<i>n</i> = 5	<i>n</i> = 3	<i>n</i> = 1	<i>n</i> = 5	<i>n</i> = 1
Any type of work (paid or unpaid)		<i>n</i> = 2	<i>n</i> = 2	<i>n</i> = 4	<i>n</i> = 2	<i>n</i> = 2
Attended some form of day programme		<i>n</i> = 5	<i>n</i> = 2	<i>n</i> = 4	<i>n</i> = 5	<i>n</i> = 0
Accesses a social club		<i>n</i> = 1	<i>n</i> = 1	<i>n</i> = 2	<i>n</i> = 0	<i>n</i> = 0

¹ Only two of the five participants from this group answered this question

Table A3. Comparison of Mean Social Capital score for each group compared to supported living and Marillac/Neighbourhood Connections

	Supported Living study	Marillac/ Neighbourhood Connections	Arts Project	Gig Buddies	Shep Access	Melba	Spiders
<i>N/n</i>	<i>31</i>	<i>15</i>	<i>5</i>	<i>3¹</i>	<i>5</i>	<i>5</i>	<i>4</i>
Overall Social Capital Score (max score = 124)	76	82	54	70	74	72	82
– Participation in local community (max score = 28)	12	11	10	14	15	13	17
– Neighbourhood Connections (max score = 20)	14	13	9	9	11	13	12
– Family & Friend Connections (max score = 12)	7	9	7	8	8	8	9
– Proactivity in a social context (max score = 20)	15	17	7	8	11	11	12
– Feelings of trust and safety (max score = 20)	10	14	11	15	13	13	15
– Tolerance of diversity (max score = 8)	6	4	3	5	4	6	6
– Value of Life (max score = 8)	6	7	5	5	6	7	7

¹ Only three of the four participants from this group answered this question

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