Supporting Community Participation

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Community participation is a difficult concept to pin down. It takes many forms—going out with friends to an exhibition, the cinema or for lunch; playing sport; volunteering in a charity shop or coaching the local football team; attending a cooking class at a neighbourhood house; being a member of a walking club; or simply regularly going to the local swimming pool. It means being engaged in an activity and most likely some form of social interaction with others be they strangers, peers, friends or people who recognise you as another club member or participant. Community participation is the type of thing that is often taken for granted as part of everyday life. What it looks like depends on an individual's preferences, available resources and opportunities in their environment. Despite its everyday nature, community participation is a key objective of disability policy. This is illustrated in the objectives of the Australian National Disability Insurance Scheme Act (2013) which include:

- to support the independence and social and economic participation of people with disability;

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- to promote the provision of high-quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community; and
- to raise community awareness of the issues that affect the social and economic participation of people with disability and facilitate greater community inclusion of people with disability.

Support for community participation is also central to Australia's National Disability Strategy 2021–2031. Policy Priority 3 of the Strategy states that:

> People with disability should be supported to live more accessible and connected lives within their communities, including being able to fully participate in social, recreational, sporting, religious and cultural life. (p. 11)

Policy wording is often inexact, using words such as *community* and *social*, or *inclusion* and *participation* interchangeably. Disability services sometimes using terms such as *accessing the community* which distances community participation from everyday life. How many people without disabilities refer to going to a yoga class for example as 'community access'? Since the 1980s, significant government funding has been invested in supporting community participation; indeed, with the advent of the NDIS in Australia, more than 72% of adults with disabilities and 76% of those with intellectual disability who are NDIS participants were funded to realise goals for community participation in their plans (NDIA, 2022, p. 184).

The first part of this chapter explores the reasons why community participation is such an important part of disability policy and expenditure. It describes the low levels of community participation among people with intellectual disabilities, identifies the obstacles in their way and explains its significance to a good quality of life. The chapter then examines different ways of conceptualising community participation, the role of service providers and synthesises evidence about effective programs and practice into a practice framework to inform action. The final section considers strategies beyond individuals for maximising social participation of people with intellectual disabilities in their communities of choice.

Why Support for Community Participation Is Important

People with intellectual disabilities are considerably disadvantaged in terms of community participation compared to some other disability groups and the general population. Therefore, this chapter concentrates on people whose primary disability is an intellectual one, although some of the strategies discussed apply to other groups such as people with psychosocial disabilities.

People with intellectual disabilities have been framed as being 'present rather than participating' in communities and as 'living in a distinct social space' made up of family, people with disabilities and paid staff (Clement & Bigby, 2010). Evidence shows they are more likely to be lonely, socially isolated, disconnected from their locality and dissatisfied with neighbours or local community. They are less likely to be members of community groups, to go out, see friends or be engaged in activities or social interactions when they do go out (AIHW, 2022). One of the reasons for this is that people with intellectual disabilities experience many of the circumstances that limit or obstruct participation—they are likely to have smaller social networks, fewer friends and are often reliant on paid staff for support. They are more likely to have a low income, experience difficulties with transport and getting to and from places and have an increased likelihood of experiencing unwelcoming attitudes and discrimination from others. All of these factors mean that people with intellectual disabilities are likely to require support to select and participate in communities of their choice; there is also a need for broader social change to address the attitudinal and structural obstacles to their participation.

The following first-hand accounts from research exploring community participation illustrate the breadth of experiences it encompasses, and the enjoyment that goes with it (Bigby, et al. 2018a).

> Talking about the gig buddy program she is part of Sue said "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." Another participant Mel said, "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."

Talking about the Arts program she attends several days a week, Elizabeth said, "I've got good friends here and we all love doing our art. They are very understanding of my problems. I feel comfortable." John who also goes to the program said, "I am an artist. People like my stuff. They buy my stuff … it's a better place than other places I've been in the past. Now I am an artist."

Talking about the football club he belongs to, a member said, "I just like coming out. Sunday, kicking the footy. That's what it's all about."

Research suggests that some staff in disability services think it is unrealistic to expect people with more severe intellectual disabilities to participate in communities and at best they may be able to be present in communities (Clement & Bigby, 2010). This research shows, for example, that often people living in group homes are taken out *into the community* in groups or alone with a staff member without real purpose, do not interact with anyone but staff and are not engaged in any activities. As one support worker said about community participation, 'It's pretty hard with our ones, they can't talk, the more able bodied can participate' (Bigby et al., 2009, p. 363). One way of changing such attitudes and practices is to demonstrate that everyone can participate with the right support, no matter how severe their disability. This is illustrated in the following excerpts that describe participation by people with severe disabilities who don't use language.

James, a support worker, described the experience of a person he supported where "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 … he's got his SES kind of jacket on which is one of those fluoro outfits … 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." (Bigby, et al. 2018a)

Trudi, a support worker, talked with Chloe about her weekly participation at a local swimming pool: "you meet 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. She went on to say that Chloe had another gentleman that she sees there, Robin, who she has 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." (Bigby, et al. 2018a)

Experiences of community participation contribute to having a good quality of life. Despite its different forms, when people are participating in the way they choose they are likely to experience increased self-esteem, confidence, wider social networks, improved skills and better health. As community participation often means that others outside their immediate service are involved in a person's life or see them regularly, it can also act as a safeguard against abuse or exploitation.

Understanding Community Participation

In the 1970s normalisation was the dominant ideology in disability services. It meant community participation was often understood as participating in valued social activities, having firm relationships with people without disabilities and using mainstream or non-segregated places that were open to everyone. Since then, dogmatic certainty about the types of activities, people and places that should constitute community participation has disappeared. It has become clear that mainstream places are not always welcoming. Indeed, recent research shows that choices by people with intellectual disabilities about where to go are often based on factors other than whether a place is mainstream, and instead include familiarity, the quality or type of activities on offer or existing relationships with the people there (Wiesel et al., 2022).

An overarching definition of community participation is the "performance of people in actual activities in social life domains through interaction with others in the context in which they live" (Verdonschot et al., 2009). This way of seeing community participation is derived from the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) framework. It suggests that community participation has three essential elements: *activities*, *social interactions* and *place*. That is, doing something, somewhere, that involves interaction with others. This definition is not prescriptive about the types of activities, people or places that constitute community participation but rather recognises that every person has their own preferences about the type of community participation they enjoy or want to experience. Individual choice is important, recognising that:

- friendships or shared activities with peers with disabilities rather than people without disabilities may be preferred sometimes by some people;

- community has diverse meanings and is not necessarily a neighbour-hood or locality but may be a group of people with shared interests such as hikers or with shared identities such as the lesbian, gay, bisexual, transgender and intersexed communities;
- subjective feelings such as belonging or conviviality are important to some people; and
- relationships other than friendships, such as being recognised by other participants as a regular member of a yoga class, can lead to positive social interactions (Bigby & Wiesel, 2019).

Although the nature of community participation is diverse, having a shared language to talk about it and an understanding of its essential elements is important to delivering effective support. Shared language and understanding of community participation helps support workers and service providers to articulate their aims: what type of support they should provide a person, and how to design programs that draw on effective strategies or skills. Shared language and understanding also helps people with intellectual disabilities and those who support them—such as families or support coordinators—to be effective consumers by knowing what options are available to choose from and the type of support or community participation they prefer. Finally, shared understandings of community participation are important to ensuring accountability for government funds, enabling the development of criteria about the nature and quality of what is purchased, and the outcomes achieved for individuals.

Supporting Community Participation

The very nature of intellectual disability means that people are likely to require support with making decisions about the type of community participation they prefer, exploring options, negotiating access, getting to places, participating in activities and interacting with others and their environment when they get there. The type, timing and longevity of support needed depend on each individual and their circumstances. Others in the community without intellectual disabilities are also likely to require support to be welcoming, to communicate with and to understand how to include a person with intellectual disability in their group or facility. These other community members are often referred to as natural supporters (Bigby & Anderson, 2021).

Traditionally, support for community participation was provided through offsite activities offered by day centres, day programs, leisure programs or by staff in the case of those living in group homes. Although some programs offered tailored opportunities and support to individuals, the type and quality of support varied (Bigby, 2005). Too often in day programs support for community participation was muddled together with ensuring a person had somewhere to go during the day if they were unsafe to be at home alone.

In Australia, and internationally, much has changed as a result of the shift to individualised funding: some day programs have closed, and others have reinvented themselves as community hubs offering individualised support for participation. Others have created social enterprises that provide opportunities for volunteer work or interactions with community members. Innovative programs have taken new approaches such as recruiting and training volunteers or bringing together peers with common interests, and attention has been given to making mainstream facilities and programs more inclusive.

In Australia, with the establishment of the NDIS, more choice is now available to people with intellectual disabilities to support community participation. As well as using service providers, there are options for people or their families to employ their own workers to support community participation. Effective support for community participation however is much more than the *frontstage* or visible, direct one-to-one support; it requires supporters to have skills, knowledge and time to do the *backstage* or behind-the-scenes work. As the next sections explain, community participation is more than going out into the *community* with a support worker acting as a paid companion. Much depends on where people go, how regularly and accessing the quality of support needed to be engaged in an activity or social interactions when they get there. This is the *backstage* work to support community participation and, if it is done well, over time natural supporters may replace some, or all, of the role support workers play.

PROGRAM DESIGN AND PRACTICE FOR SUPPORTING COMMUNITY PARTICIPATION

For some people, families or other allies may plan and oversee the backstage work that facilitates community participation. They may also supervise the frontstage work by hiring and monitoring the work of supporter workers and ensuring support workers are skilled. Most people however will rely on programs delivered by service providers to do both backstage and frontstage work. This section describes the design of different types of community participation programs that research suggests are effective and lead to good quality of life outcomes for the people they support. Describing different types of programs helps to illustrate the backstage, often invisible, work of supporting community participation. Programs provide the infrastructure that enables individuals to make choices and receive effective individualised support; very few remain that operate on the type of group mentality of the past where people were offered a limited menu of choices and most things happened in groups necessitated by funding rather than participant choice.

The design of programs and the interventions or strategies to support community participation can be quite different, as they emphasise different aspects of participation (Bigby, et al. 2018 b). Knowing the different aspects of community participation that programs might emphasise helps a person to think more about what they want from participation and to choose what type of program they prefer. It also helps to guide the type of support a worker provides. The following examples help illustrate the different aspects of community participation that programs emphasise and types of programs this leads to.

Emphasising Social Relationships

Having social relationships with others who are not paid workers increases opportunities for a person to interact socially and participate in a range of activities and community groups. If a program emphasises relationships, then strategies focus on developing new social relationships by matching a person with a volunteer or helping a person find places or activities where they might meet others with similar interests. For example, in the earlier excerpt, the gig buddy program assisted Sue to build a friendship with a volunteer and have someone to go to gigs with.

Programs that Build Social Relationships

These types of programs aim to match participants with volunteers who have similar interests to their own, providing opportunities for shared activities and friendship. Staff work at getting to know participants, learning about things such as their interests, personality, where they live, age and skills by talking to them and those who know them well. Such information is important in matching them with a volunteer who they get on with and who lives in a similar locality. Programs promote their aims and recruit volunteers through various forms of advertising and websites that act as clearing houses for those seeking to volunteer. Before volunteers are accepted into a program, they are usually vetted by requiring, for example, a NDIS screening and police check, or providing referees and having an interview with staff. Once accepted volunteers receive some form of training. This might include briefing about the program, the expectations of volunteers such as the number of hours they spend with their matched participant each month, the code of conduct and background information about disability policies and safeguarding requirements. Training might also include tips about beginning relationships, communication and managing common issues identified as arising in programs, such as the difference between friendship and support work.

Once training is completed staff discuss the match with both the volunteer and the participant and introduce them, often facilitating their first meeting. The matched pair are left to organise future meetings around mutually chosen activities. These may be going to sports events, concerts, cinemas, restaurants or sharing time together with others in their network in private homes. Program staff remain available to mentor either volunteers or participants should problems or queries arise. Some programs organise activities for small groups such as dinner or going to a gig, to offer opportunities for participants who are waiting for a match, as well as matched pairs. They may use newsletters to keep people in touch with the program and share information about upcoming events or discounts that may have been negotiated. For more detailed information see descriptions of a Gig Buddy Program (Bigby, et al. 2018a) and a Leisure Buddy program (Fyffe & Raskin, 2015). Volunteer programs such as these primarily include people with relatively low support needs often excluding people with more severe disabilities. As one staff member from a Gig Buddy program said:

> 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. (Bigby, et al. 2018a, p. 61)

The balance of participants to volunteers in programs is often uneven meaning people may wait for a long time; and in large cities distances between where people live can make matches difficult. The point where people become friends, rather than participants and volunteers, is ill-defined which may raise issues around safeguarding if backup support from the program ceases.

Some befriending programs may be less formal and more inclusive of people with more severe intellectual disabilities. Their focus may be on staff nurturing a potential friendship a staff member might have identified or supporting a person to find and participate in activities where they are likely to meet someone who over time may become a friend (Amado, 2014).

Emphasising Pleasant Social Interactions or Convivial Encounters

Sharing an activity or identity with others in places such as libraries, community groups or volunteer organisations leads to pleasant social interactions which if they happen regularly mean a person becomes recognised and known by others. Although valued for themselves, over time convivial encounters may become firmer relationships or friendships. If a program emphasises convivial encounters strategies focus on finding community groups or public facilities which provide opportunities to share an activity and interact with other people. For example, in the earlier excerpt, going regularly to the local swimming pool meant Chloe was recognised and greeted by other regular swimmers who smiled at her and over time learned her name.

Programs that Create and Support Opportunities for Convivial Encounters

These types of programs aim to create and support opportunities for a person to regularly share activities with others and engage in friendly or convivial social interactions. Convivial encounters take place in

community groups or classes, public facilities such as libraries or commercial places such as leisure centres. They involve interaction between people with and without intellectual disabilities and, though friendly, are not friendships as there is no expected contact outside the context in which the encounter occurs unless two people serendipitously see each other.

Programs may be called community options, community access or volunteering and are offered as part of day programs, community hubs or retirement programs for people with intellectual disabilities. Programs usually serve 20 or more participants. However, what they offer each person is individualised although the person may not always participate in activities on their own. To illustrate this, Table 4.1 summarises different examples of convivial encounters and strategies for creating them. As Table 4.1 shows, plans need to be made at the program level to create opportunities that are tailored either to an individual or small group of participants. As with programs that assist in building relationships programs, staff also plan with each individual to understand their skills, support needs and interests.

Once activities such as those in Table 4.1 are identified or created, staff begin a process of matching and introducing the participant. This requires staff knowledge of the person from the planning process and knowledge about community groups, places and task analysis. For example, staff need to understand whether the place or group will be a good match for the person by understanding its culture and rituals, whether it is likely to be welcoming, and how confident others in the group are in communicating or being around a person with an intellectual disability. In terms of activities, inquiries need to be made. For example, are activities shared with other members, is there a common purpose, how might these be broken down into discrete tasks to facilitate engagement, what support might the person need to participate and who might provide this? This stage often requires negotiation with leaders of groups to gain entry and to assuage the reluctance that often comes with uncertainty and unfamiliarity with people with intellectual disabilities. The introductory period might involve staff providing some training or orientation to a group leader or members about the person's support needs. For example, members of a senior citizens group could be invited to be trained to mentor a new member with intellectual disability to ensure the new member knows the procedures for checking in, that someone says hello to them when they arrive and invites them to join one of the activities. Support from other members as natural supporters is much more likely to foster friendly social interaction than if

Table 4.1 Examples of convivial encounters and strategies to create them (adapted from Bigby & Anderson, 2021)

Identifying an opportunity for an individual and negotiating with a public institution or commercial enterprise

A young woman volunteers weekly in a local school replacing books on the shelves in the library. After a few weeks she is known by name by the teachers and many of the children in the school, who drop into the library to say hi to her.

Establishing a community service to a public institution and breaking down of process into discrete activities for a small group of people

A small group of people prepare fruit that has been discarded by a retailer and distribute it to each class in a school once a week. They cut up the fruit in the school kitchen and are welcomed by name by staff and pupils when they bring it to classrooms for the afternoon break.

Establishing a social enterprise and breaking down processes into discrete activities for a small group or individual

A young man regularly goes to collect jars purchased from a wholesaler to be filled with produce and sold in the organization's shop. He travels with a support worker and is recognized by the staff member at the wholesalers who is responsible for the order who asks him about his week and chats about work.

Identifying an opportunity for a group volunteer activity and negotiating with a commercial or public provider

Two people regularly volunteer with a local organization to deliver meals on wheels for older people. They take it in turns to get out of the van and bring meals to recipients' doors who recognize and thank them.

Identifying an opportunity for paid activity and negotiating with a commercial enterprise

Two people have a regular round delivering advertising material to letterboxes. They are recognized and greeted by people in the local area who are home during the day.

Identifying a suitable public facility or commercial place for an individual's preferred activity

One young woman goes swimming weekly in the local pool with a support worker. She has become friendly with an older man who goes at the same time each week and she often holds his hand and walks up and down the pool side with him.

Identifying an existing group for a preferred activity in a public facility, negotiating with facility staff

Two women go to a weekly water aerobics class at a local swimming pool, and over time gradually become more confident to attend without support from staff. After a while, they are recognized by people who sell tickets and greeted by other members of the class.

Creating a regular group or one-off activity for people with disabilities that is open to community members and people with intellectual disabilities in disability-specific, other specialist or mainstream spaces

A group of people who have been growing tomatoes invite community members to come to a chutney making day at the organization's shop. Some community members greet the people they recognize from the farm produce shop where they sell tomatoes once a week.

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a person is accompanied by a support worker unfamiliar with the group and its culture. Training natural supporters was referred to as *Active Mentoring* in one program, as it drew on skills derived from Active Support and trained natural supporters in identifying moments of potential for engagement of the person, offering and respecting a person's choices and providing the right type and amount of assistance to ensure their successful completion of tasks.

Regularity is important in this type of program to help ensure the person gains confidence or skills in participating and becomes recognised and known by others. Once a person is included and comfortable attending regularly, program staff may only need to monitor how things are going and be ready to step in if something changes such as their mentor leaving, a class going into recess or an activity being rescheduled.

Programs that support convivial encounters can include people with higher support needs who will also require support to travel to and from a place. Program staff may also need to liaise with accommodation staff or families to ensure the activity is built into a person's regular routines. Further descriptions of programs that support convivial encounters are found in Bigby and Anderson (2021), (Craig & Bigby, 2015) and Stancliffe et al. (2013).

Emphasising a Sense of Identity and Belonging

Participating in some types of activities that happen in particular places creates new identities for people such as artists, craftspeople, singers or athletes and opens up membership of groups to which a person develops a sense of belonging. Belonging to a group creates opportunities for social interactions with peers as well as people without disability who have similar interests. If a program emphasises identity and belonging then strategies will focus on finding places where a person can further develop their talents, identity or share common interests with others. For example, in the earlier excerpts gaining an identity as an artist gave Elizabeth and John a sense of belonging and brought them into contact with other artists at exhibitions or events.

Programs to Support Identity and Belonging

These types of programs aim to create a sense of identity or belonging to a specific group or community of interest which in turn facilitates not only

convivial encounters with immediate members of the group but with others beyond it who share a common identity or interest. Identities may be based on a person's creativity or talents (such as art, drama, singing or sport), or their status (for example as a self-advocate or peer). For instance, being a member of a football league for people with intellectual disabilities develops skills, brings people into touch with a regular group of peers and coaches interested in football and provides opportunities to be part of exhibition matches at bigger football events. Being a member of a self-advocacy group brings a person into touch regularly with other members and may provide opportunities to be part of other groups, such as advisory boards or delegations, to participate in conferences or to conduct training programs where a person might meet others with similar interests who belong to the wider community of people interested in disability rights.

Fostering a common sense of identity is the focus of programs that aim to further belonging. Some of the work of staff in these types of programs is organisational. For example, a program that supports people to participate in a drama group will need to manage the group's rehearsals and schedule performances. Some programs may need staff to have specialist skills in teaching, coaching or supporting the core activity. For example, an arts project employs artists as staff who use a technique called the 'hand in glove approach' to support the artist participants with intellectual disabilities. There may also be a process of recruiting participants to ensure they are a good fit for the program and understand what it offers as well as planning with them around their involvement and commitment.

Programs based on belonging or identity may only include people with intellectual disabilities as participants, such as Arts Project (Anderson & Bigby, 2021) or may include people with and without intellectual disability such as Tutti Arts described by Darragh et al. (2016). However, they always include activities that bring participants into contact with people without intellectual disabilities through, for example, exhibitions, performances or other types of events.

Practice Framework for Community Participation Programs

Despite the diversity of community participation, many have similar principles, processes and require staff to have a common set of skills, which can be brought together into a practice framework. This serves as a skeleton,

setting out what must be considered when thinking about a program rather than a set of procedures or instructions. The framework proposed here includes principles that should inform all aspects of programs, processes that need to be incorporated into them and the skills that are necessary for successful implementation. This type of practice framework is useful for organisational leaders or managers to reflect on the design of new programs or those already on offer and the skills of the staff they employ; for support workers in understanding the processes they should undertake and the skills they need; and for people with intellectual disabilities and their families in thinking about choice and the quality of programs or in designing their own program. A framework may also be useful to regulators and funders in identifying components that comprise effective programs. The following sections describe the principles, processes and skills and knowledge central to a practice framework for community participation programs.

Principles

- *Reflecting individual preferences and support needs.* There is no ideal form of community participation. Programs support individuals to make choices about the places and activities and the people they prefer to interact with. Support is tailored to individual needs and the context in which a person lives.
- *Acknowledging the importance of engagement.* Programs support individuals to be engaged in activities and social interactions rather than simply to be present in community places.
- *Recognising the need for frontstage and backstage support.* Work behind the scenes (backstage)—planning, exploring possibilities, creating opportunities, negotiating, recruiting or preparing natural supporters or volunteers and monitoring—which precedes moments of participation determines success and is as important as direct (frontstage) support.
- *Collaborating with natural supporters.* Inviting others in a community context to collaborate to support inclusion. Working with natural supporters to develop their skills and confidence to support a person's participation can be more effective than relying on paid supporters, increases opportunities for social interaction and inclusion in

a group's culture, and may be more sustainable and reduce reliance on paid support over time.

- *Working in teams and being reflective*. Design and implementation of programs requires a mix of staff skills and relies on teamwork and reflective supervision to improve quality and develop staff skills.

Processes

- *Knowing the person and planning*. Person-centred planning with the person (and with their consent others who know them well) is undertaken for staff to get to know the person and establish their goals and preferences. Part of the planning process should include risk assessment and enablement strategies.
- *Exploring possibilities*. Options aligned with individual preferences and characteristics are explored. This might involve scanning communities of interest, identifying potential groups or places and analysing their culture or other characteristics, recruiting volunteers or even creating new groups or activities. It is important to understanding that regularity of participation and continuity of other participants are facilitators of engagement and social interactions.
- *Negotiating*. Matching a person to a group, negotiating their entry with leaders, sharing information if appropriate with leaders and other participants and offering training and support to natural supporters to enable inclusion. It may be necessary to build the activity into the person's schedule and coordinate with others involved in their support.
- *Supporting and maintaining*. Supporting the person to attend, and participate in the moment if necessary, monitoring their engagement over time and providing additional support if needed as the context or personal circumstances change.

Skills and Knowledge

- *Person-centred planning* skills including communication, listening, mapping networks and supporting decision-making.
- *Community development* skills and knowledge for backstage work include understanding different types of communities and their assets, networking, analysing and negotiating.

- *Micro support skills* for front stage work include evidence informed person-centred practices such as Active Support (see Chap. 7), Enabling Risk (Bigby et al. 2018, b) and Supported Decision Making (see Chap. 11).

Maximising Benefits of Community Participation Programs

Individualised funding, like that available through the NDIS, means that people with disabilities are likely to lead more varied lives than in the past when they might have attended a day program five days a week. The chances are they participate in a range of community activities, perhaps supported by several different programs. A challenge however, particularly in working with people with more severe intellectual disability, is *coordinating* aspects of a person's life and their various support providers. Coordination is important to avoid participation being disrupted by failures to respect the significance of being on time for participating in classes or groups, to support travel to places or preparedness to go out and to avoid conflicting demands on a person's time. Further, maintenance of a routine can be important for some people. As well as coordination to maximise regular participation, a further challenge is joining up fragmented insights about a person and sharing new knowledge about their preferences, interests or social connections derived from observing their experiences. This knowledge can be used by others to inform their support or contribute to future goals and planning. For example, if support workers in a group home know a person has a growing friendship with someone at a community class they might facilitate further social contact, or shared activities out of class hours with that person.

The individualised programs of the type described in this chapter help in furthering possibilities of interaction between people with and without disabilities and allaying stereotypical attitudes and uncertainty about including people with disabilities in everyday activities or places. In parallel, more systemic approaches to change are necessary to remove structural obstacles to community participation. There are dangers, however, that community-wide systemic change initiatives tackle highly visible obstacles such as physical or sensory access and neglect those that are less visible and more relevant to people with intellectual disabilities. These include, for example, issues of communication access where staff are

unskilled in adjusting their modes of communication or where signage and information relies on people having literacy skills. Other examples of structural obstacles include:

- failures to recognise or adjust the pace or nature of classes or activities offered by community centres;
- unreliability or inaccessibility of public transport systems;
- a limited supply of accessible taxis; and
- poor designs of digital information, such as automated ticketing and phone enquiry systems that require complex problem-solving and literacy skills and do not have the option of talking to a person to assist with the process.

Despite the best intentions about accessibility, public facilities seldom adjust their practice sufficiently to enable participation of people with intellectual disabilities without support. Some research is also beginning to suggest that individualised funding may hold an inherent danger that, rather than developing their own expertise or bearing the costs of adjustment, mainstream programs or public facilities rely on individualised support to facilitate participation by people with intellectual disabilities (Wiesel et al., 2022). It takes skills and experience to apply a social model lens and identify the structural obstacles that particularly affect this group or recognise they can be remedied by systems change rather than just more individual support. Staff skilled in community participation programs are well placed to collaborate with other services and systems to identify the need for systemic changes and to remove obstacles through staff training, changing practices or adjusting infrastructure. Indeed, as well as individualised support, the role of such programs may extend to broader initiatives to develop greater accessibility of public infrastructure for people with intellectual disabilities and advocacy for systemic change.

Take Home Messages

- Support for community participation must be tailored to each individual and their interests.
- Community participation takes many different forms as does provision of support for participation, so it is important to be clear about what is expected to be achieved for the individuals you support.

- Engagement, including social interactions, are the hallmarks of community participation; simply being in a place or in a group are not the same as participating.
- Quality individualised support is likely to be delivered through well-designed programs and by skilled workers accountable to practice leaders.
- Behind the scenes or backstage work is important and may mean direct support in the moment from a paid worker becomes unnecessary or can be provided by other community members.

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