Evidence review of interventions for social, community and civic participation for people on the autism spectrum, or with intellectual or psychosocial disabilities: A summary report

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Research and Evaluation Branch

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The Research and Evaluation Branch is responsible for ensuring that NDIA policies, guidance, practices and priorities are informed by trustworthy and robust evidence so decisions can be based on an understanding of what works, what doesn't and what the benefits are to participants and the Agency. Our research is based on a collaborative approach in which we engage with participants and other key stakeholders to address scheme priorities. Our collaborative approach helps us to develop tailored approaches to the translation of the research. This includes developing resources for participants and providers to engage with best practice, as well as for partners in the community and other government departments to understand and apply evidence into their practices.

This document

This report covers the review of research on interventions for enhancing participation, for adults (≥18 years of age) on the autism spectrum or who have intellectual disability or psychosocial disability.

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Further information?

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Glossary

Autism Spectrum Disorder is a developmental condition that includes: persistent deficits in social communication and interaction across multiple contexts; restricted, repetitive patterns of behaviour, interests, or activities; with disturbances that cause clinically significant impairments (APA, 2013).

Civic refers to engagement of citizens in civic and political life of the state (Marshall 1965; Wilenski, 1986; Wolfe, 2002; as cited in Frawley & Bigby, 2011).

Community is "a group of people that interact and support each other, and are bounded by shared experiences or characteristics, a sense of belonging, and often by their physical proximity" (p.195, Cobigo, Martin, & Mcheimech, 2016). In relation to people with disabilities, community is sometimes expressed as an opposite of segregated or service settings, but it can also refer to self-authored segregated spaces (Milner & Kelly, 2009).

Intellectual Disability originates before the age of 18 and is defined by significant limitations in intellectual functioning (e.g., with an IQ<70) and adaptive behaviour in everyday social and practical skills (Schalock et al., 2007).

Person Centred Planning is an umbrella term with five key features: (1) the person is the focus; (2) family, friends or others from a circicle of support may be partner in the process; (3) plans capture what is important to the person, their capacity, and their support needs; (4) the plan generates actions focused on life and not just services or resources needed or available; and (5) the plan involves ongoing learning, listening and opportunities (Ratti et al., 2016).

Psychosocial disability is the term used to describe disabilities arising from mental health issues. Psychosocial disabilities are considered to be "multi-axial" and can comprise psychological, social, and occupational impacts of psychiatric, psychological, or developmental disorders, with an emphasis on the social consequences as opposed to the nature and severity of psychiatric impairments (NMHCCF, 2011).

Social capital is defined as the resources that one can access through their social connections.

Social prescribing is a primary care health service in the United Kingdom that links patients with non-medical needs to supports that are provided by the community and voluntary sector in order to help improve their health and wellbeing (Pescheny, Randhawa, & Pappas, 2020).

Background

Social, Community and Civic participation has important benefits for people with disabilities, their family and carers and the broader community. People with strong social connections and a sense of belonging in the community have better wellbeing, lower support needs, and increased opportunities to participate in study, volunteering or paid employment. The broader community also benefits when community settings are more accessible, and people can interact with others from diverse backgrounds.

A key objective of the National Disability Insurance Scheme (NDIS) is to support the independence and social and economic participation of people with disability. The scheme aims to support people with disability to have levels of social and community participation that are closer to the participation rates of people without disabilities.

How is participation defined?

Participation requires a broader view than presence in social or community settings, and should include the processes of feeling and being included, integrated and belonging in those places. Social and community participation, inclusion and integration is defined by:

- the activities people are participating in,
- the place where those activities are happening,
- the social relationships involved (e.g., who people are interacting with), and
- how participation makes people feel.

For example, participation has been defined as *"the process of engaging in self-identified activities within the community context that are meaningful and influence the community context and the individual."* (Bathje, 2016).

Why we did this research

Approximately two-thirds of NDIS participants are on the autism spectrum, have an intellectual disability, and/or have psychosocial disability. People with these disabilities often have difficulty with social, community and civic participation due to differences in their social skills, cognitive functioning, and access to social support or spending money. Moreover, the community is not always accessible or welcoming to people with disabilities.

We did this research to learn about which interventions and supports improve social and community participation outcomes in these target populations.

The research presented in this report is part of a larger research program that also included a mixed methods research study that explored the barriers and enablers to community participation through interviews with participants, and focus groups and an online survey with NDIS frontline staff.

What did the research involve?

A total of 522 studies that were described in 57 systematic reviews were included in the review of interventions for supporting or improving social and community participation. The full research report is here.

What did we find?

Three main types of interventions were found to help people to increase the social and community participation:

1. Interventions focused on identifying and linking people with participation opportunities,
2. Getting involved with participation activities
3. Building capacity to participate socially and in the community

What interventions and supports increase participation?

Many different types of supports were found that can help people to increase their social and community participation if they are on the autism spectrum or have an intellectual or psychosocial disability.

While the social model and interactional models of disability highlight the importance of barriers and facilitators outside of the individual's control (e.g., physical or social environment, and institutional practices, laws, legislation, and policies, human rights), nearly all interventions focused on the individual with disability (e.g., building their capacity, or linking them with activities).

Based on the three categories of interventions, the following types of approaches, supports and activities are usually effective at increasing participation:

1. Interventions that help people to **identify and connect with participation opportunities** and that provide support to enable them to participate in chosen activities, including:
    - person centred planning
    - social prescribing to identify and link people with social or participation groups or activities
    - befriending to link a person with a disability with a volunteer who has similar interests

    - peer support or mentoring to build networks of people with similar disabilities or experiences

2. Interventions that were a **participation opportunity**, included:
    - Community groups (e.g., Men's shed or craft group)
    - Art, drama and music groups
    - Farm, ecotherapy, gardening and horticulture programs
    - Physical activity or outdoor nature-based activities or camps

3. Some people may benefit from interventions that help them to **build skills and their ability** to participate socially and in the community, including:
    - Group-based social skill training for people with intellectual or psychosocial disability
    - Social skills training to learn specific communication skills for people on the autism spectrum
    - Social skills training in vocational settings to develop social skills for interactions and friendships at work
    - Relationship, family planning, abuse prevention, and parenting skills and knowledge training to build healthy relationships with others
    - Digital literacy training (e.g., to use email) and travel training (e.g., to use a bus network) to help people to connect with others and to move about the community
    - Helping people with intellectual disability create a "Life Story" to share their life experiences, and the types of activities that they enjoy doing

The only **civic participation** activity that was found was volunteering in the community. There were no studies that looked at other types of civic participation (e.g., voting, advocacy/activism, committees/leadership club/organisational membership, political engagement). For people with psychosocial disability, volunteering could increase social inclusion, social ties, and opportunities for social engagement, but it could also put them at risk of experiencing prejudice or stigma in the community, and strain from over-commitment.

No interventions were found for **changing the physical or social environment** (e.g., quiet spaces at festivals) to improve social and community participation for people on the autism spectrum, or with intellectual or psychosocial disabilities.

What next?

The NDIA is using this research to develop guides for participants and staff to understand what supports might help them to improve their social and community participation. For example, how participants can have a conversation about social participation, or activities or supports are effective.

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