

Living with Disability RESEARCH CENTRE Supporting inclusion of people with cognitive disability



Effective Programs to Support Community Participation

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In collaboration with NDS and our Voice

Community participation – Enduring policy aim

to support people with disability to live "as valued and participating members of the community"

(1986 Disability Services Act)

'full and effective participation in the community'

(UNCPRD, 2006)

"support the independence and social and economic participation of people with disability"

(NDIS, 2013)

Absence of consistent conceptual frameworks used in research

(Verdonschot et al. 2009; Simplican et al. 2015; Overmars-Marx et al. 2014; Cobigo, et al. 2012)

Ambiguous Concept – Terminological Forest

- Interchangeable words
 - Inclusion, integration, participation
- Spray on words and prefixes 'social' 'community'
 - The community,
 - A community,
 - My community
- Based on
 - Place, Interests, Politics, Identity, Ethnicity
- Expansive or narrow
 - Multiple or single life domains leisure, work, domestic
 - Different arenas social political, economic

Why is conceptual clarity important?

For People with Disability

- Understand what might be on offer
- Parameters of choice

For Service Providers

- Intended purpose, or outcomes of program
- Design and delivery of support/interventions
- Accountability delivering what intended

For Governments and funding bodies

- Targeting, costing and decision making
- Enable accountability

For researchers

- Measure and evaluate success
- What interventions work for whom

Overarching Aims

- Develop a typology of community participation programs.
- Investigate, compare and contrast features of promising Australian programs.
- Implications for design and funding

Three parts

- Scoping review of literature*
- Case studies of promising programs in Vic and NSW*
- Cross case study analysis

Scoping review (Bigby et al., 2017)

- Interventions to facilitate community participation
- Empirical, published, peer reviewed papers 2000- 2015
- 17 papers 13 discrete studies

Analysis

- Aims -different conceptualisations of community participation
- Strategies to achieve aims
- Mapped ICF components activities, place and interactions

Overview of findings

- Small scale research, qualitative, little robust evidence re outcomes, effectiveness, program logic, costs.
- Claims not backed by evidence "qualitatively the services in the study lived up to their reputation as being a good thing" (Heslop, 2005, p.33)
- Diversity of experiences framed as community participation
- Similar outcomes claimed irrespective of model
 - personal development, skills, self-esteem or confidence, increased social networks, subjective experiences of enjoyment or happiness.
- 3 broad program approaches

Community participation as social relationships (4)

Aim

Building social relationships between people with and without disabilities — and between people with disabilities (e.g. Heslop (2005), befriending)

Logic – more relationships lead to engagement in activities

Strategies

- Matching volunteers to seek friendship
- Creating connections to places of common interest
- Teaching social relationship skills to people with disabilities
- Privileges some types of relationships unpaid, people without disabilities, reciprocal
- Limited data re durability or quality of new relationships
- Value on interaction –little emphasis on place and activities

Community participation as convivial encounters (4)

Aim

Creating opportunities for fleeting, intermittent, episodic convivial encounters (e.g. Active mentoring Bigby et al., 2015)

Logic - encounters important & may lead to lasting relationships

Strategies

- Facilitating participation in community groups volunteering being in regular places
- Distinguished by place
 - Public non segregated or community organisations where there are others without disability
- Equal value to diverse combinations of place, interaction and activities incorporates an experiential element of conviviality or pleasantness.
- Most robust evidence Potential for scaling up

Community participation as belonging & identity (6)

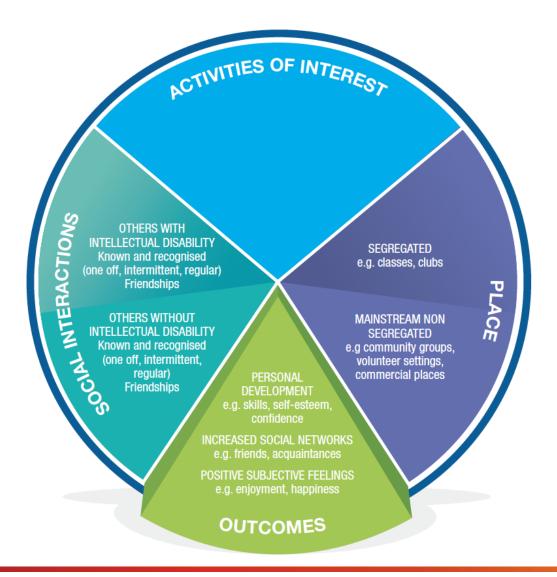
Aims

- Places where people with intellectual disability share an identity based on their skills, talents, interests Transformative process "towards a sense of attachment and belonging to proximate and distant others" (Hall, 2013,p259) (e.g. Darragh et al., 2015 Tutti Arts)
- Logic belonging important identity provides a catalyst for relationships with others in the mainstream – avenue for shared activities

Strategy

- Segregated groups, drama, sports or self-advocacy
- Connections to mainstream groups with similar interests
- Positive outcome re increased skill and confidence
- Little evidence of flow on effects re social interactions or status
- Emphasis on activity

From an ICF perspective choosing or designing community participation 3 core elements combined & emphasised differently





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Community participation as a sense of belonging and identity – a case study of Arts Project Australia, Northcote, Victoria

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Case Studies of Promising Community Participation Programs

Selection

- One of each of the three program approaches
- Mix of locations inner and outer urban and regional
- Reputation for quality and effectiveness —advice from reference and consumer groups and past research

Methods

- Interviews participants, staff, family members
- Open ended observations
- Document review
- Participant level data socio-demographics

Analysis

- Structured content re program logic –aims, inputs, program activities, outputs, outcomes
- Thematic re perspectives on quality and experiences
- 5000 word descriptions and 1 page summaries

Conceptualizations and Strategy

	Gig Buddies	Arts Project	Melba	Shepparton	Spiders
Concept	Social relationships	Belonging and identity	Convivial encounter	Convivial encounter	Belonging and identity
Primary Strategy	Recruiting buddies Matching for shared interests	Support to create, display and sell art	Creating tailored mix activities and engagement in specific tasks Collaborating with groups in the locality Maximising social interaction and reciprocity	Creating tailored mixture of daytime activities Involve interacting with community members, skill development, supported work Goal greater independence	Playing in football league and associated social activities

ICF Components

	Gig Buddies	Arts Project	Melba	Shepparton	Spiders
Activities	Interest in context of matched relationships or part of a program groups	Create, display and sell pieces of art	Skills training Group activities (cooking, food distribution) With peers or others Individual activities Part of social enterprises or micro businesses.	Skills training Group activities with peers or others in locality Individual activities, Part of social enterprises, micro businesses or paid employment	Training and playing football, social activities, social skills training
Place	Mainstream community places	Segregated and some community places	Locality Mixture of segregated and community places	Locality Mixture of some segregated and community places	Segregated activities in community places
Social	Fleeting and convivial encounters with matched volunteer, peers and others at mainstream venues. Friendships with volunteers	Fleeting and convivial encounters with peers in the program, artists and the wider arts community. Friendships with peers.	Fleeting and convivial encounters with peers and others without disability in the local community.	Fleeting and convivial encounters with peers in the program, and people with and without disability in the local community Friendships with peers	Fleeting and convivial encounters with peers, and people without disabilities such as committee members, volunteers, players family members and others interested in football. Friendships with peers

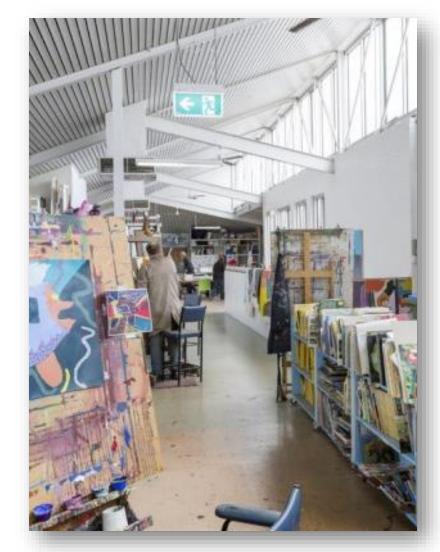


Credit: Miles Howard-Wilks (2016) Rockpools with sharks eggs. Arts Project Australia.

Case study: Arts Project Australia

"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." (Gabrielle, staff)

An overview of the program.



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

- Funding: Commonwealth Government, State Government
- Fundraising
- Grants
- Sponsorship
- Donations
- In-kind contributions
- Facilities, equipment
- Staffing 10 EFT Qualifications in fine arts
- Organisation; management, supervision, staff meetings, recruitment, training.

ARTS
PROJECT
AUSTRALIA

Program Activities

- 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



Key points about activities at Arts Project Australia

- Participation is voluntary
- The way in which support is provided is particular to the organisation and differs from other art programs. A 'hand in glove' approach. Staff never touch the works being created by participants.
- Avoiding 'tokenism':

"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 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)



- Serious art practice and production of art
- Sale of art, placement in exhibitions at Arts Project's own or other galleries
- Exposure of artistic community to the talents of people with intellectual disability and collaborative opportunities



Outcomes: Strong identity and enjoyment of being an artist and artistic skill development

Being an artist

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 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) Outcome

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

Putting in the work to become an artist and have a career

...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)

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)

Outcomes: Exhibiting and selling works of art

... I get paid for what I'm good at. (Connor, artist)

When someone buys it I know that someone loves it more than I do! (Connor, 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)

Outcomes: Sense of belonging to the artistic community



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)

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

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

I know art people very well since I come here. I'm an artist as well. (Carol, artist)

Convivial encounters with peers, others in the arts community and shopkeepers in the local neighbourhood



Belonging in the local community

The people in the coffee shop and other shops are friendly towards me. I get my lunch sometimes and they smile at me, maybe hello sometimes. (Carol, artist)

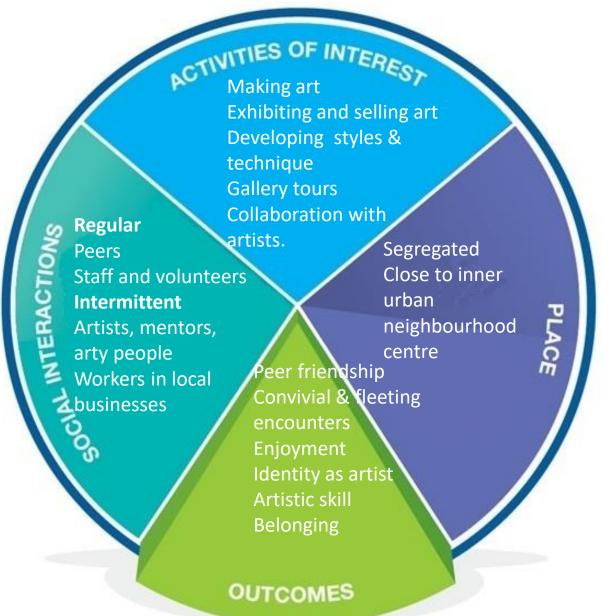
It's safe around here. Arts Project is nearby, [Stephen] is always there in the office to talk to. The shops are nice. I bring my lunch but I can go up there to the café. Quite friendly people. (Elisabeth, artist)

Friendships with peers

I think I might meet my next girlfriend here, the people are quite friendly. I've got the same ones I chat to every day. They're good mates of mine the other artists upstairs [in the studio]. (Connor, artist)

I've got good friends here and we all love doing out art. (Elisabeth, artist)

What does community participation look like in this case example?



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.

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