



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 social relationships (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

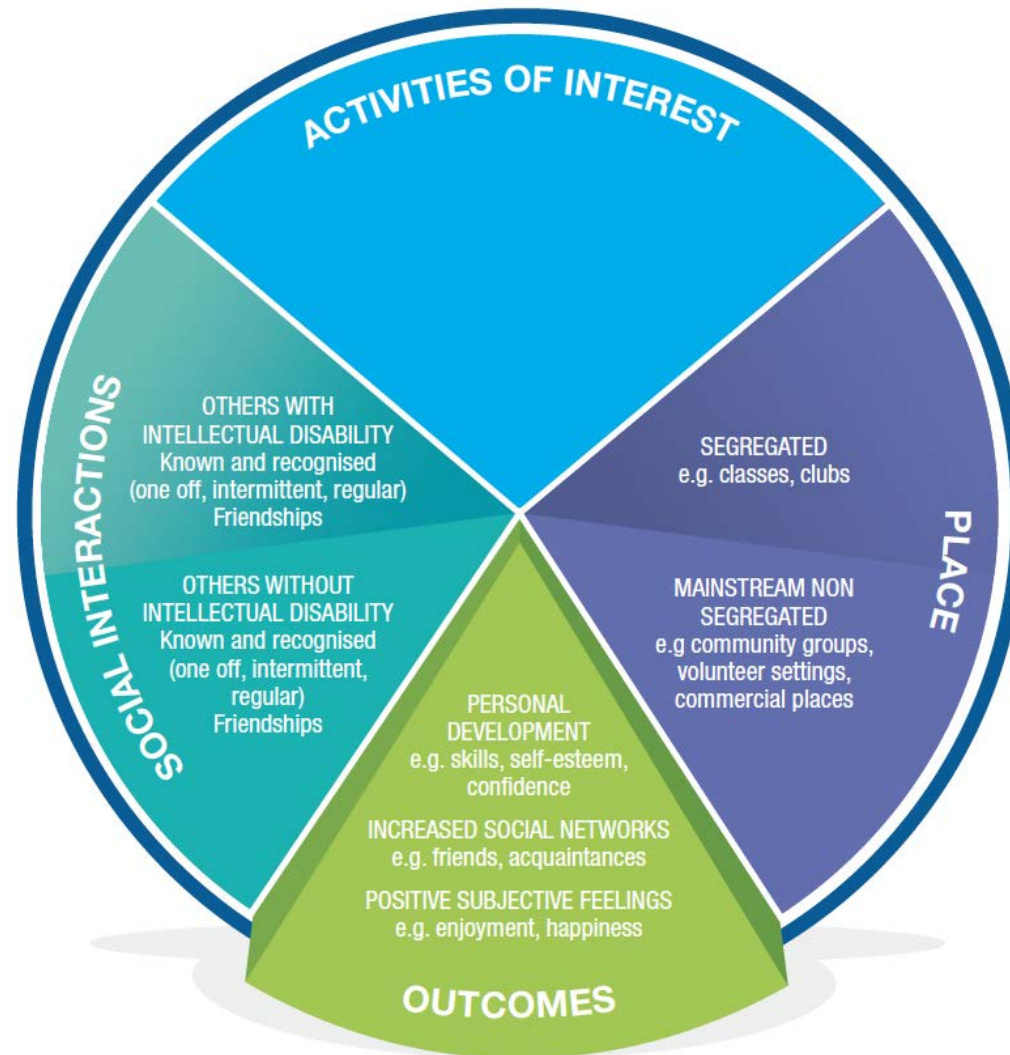
- Places where people with intellectual disability share an identity based on their skills, talents, interests - Transformative process “towards a sense of attachment and belonging to proximate and distant others” (Hall, 2013,p259) (e.g. Darragh et al., 2015 Tutti Arts)
- Logic - belonging important - 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



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	<p>Creating tailored mix activities and engagement in specific tasks</p> <p>Collaborating with groups in the locality</p> <p>Maximising social interaction and reciprocity</p>	<p>Creating tailored mixture of daytime activities</p> <p>Involve interacting with community members, skill development, supported work</p> <p>Goal greater independence</p>	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



Participants and operational

	Gig Buddies	Arts Project	Melba	Shepparton	Spiders
Main participants	Low support needs	Low to moderate support needs	High support needs	Low to high support needs	Low to moderate support needs
Time occupied	2-3 hours a month After hours	2-3 days a week	3- 5 a week	5 a week	2-3 hours a week
Size	45 matched pairs 190 unmatched	135 participants	97 participants	98 participants	30 players
Staff	2.5 EFT	10 EFT mostly part time.	35 EFT	19.8 EFT	No paid staff
Overall budget	Approx \$63,000 plus overheads	\$1.7m		\$2.5m	Approx. \$18,000

Different language – different concepts

- No common language – e.g. Distinction between community participation and community inclusion
- Different notions of community

Gig Buddies	Arts Project	Melba	Shepparton	Spiders
Shared interests - social, sporting and cultural	Shared interests - the Arts	Place - local - outer urban localities.	Place - local - regional town	Shared interests -footy

Gig Buddies community quite diffuse – anyone really without a disability

Two programs conceptualised as focused on convivial encounters –framed their aims as about belonging to local communities.

Interchangeability - Are particular program designs suited to particular places?

Might appear so

- Melba and Shepparton - place based understanding of community
- Both in defined localities - outer urban or regional town
- Participants also lived in these localities (participants in other programs – not local)
- Had dedicated program spaces
- Organisations conceptualised as community belonging rather than encounters
- Similar strategies
 - Individual and program level planning – knowledge person and locality
 - Collaboration with local groups, organisations and businesses to create opportunities for shared activities, work, volunteering, contribution, social interaction with people without disability
 - Use of micro and social enterprises
 - Reliance on negotiation and connections
- Community as place / locality less applicable in cities

On the other hand design features are transferable

If reframe aim

- From belonging to local community to creating convivial encounters around shared interests and identity with people without intellectual disability or community as shared interests
- Cities offer similar opportunities to collaborate with groups, organisations and businesses to create learning, leisure, social or vocational activities that act as catalyst for social encounter
- Similar skill set just a wider geographic horizon and more diversity of groups

Interchangeability - Are particular program designs suited to people with particular support needs?

- 3 of 5 programs only included people with relatively low support needs - able to travel independently and manage own personal care needs
- People with higher support needs not excluded but suggested as difficult to include
- These were the programs that occupied less time
- Programs included people with severe intellectual disability reinvented creative versions of traditional day programs
- Raises questions about how to ensure multiple options exist for this group



Under identification of key strategies

Gig Buddies	Arts Project	Melba	Shepparton	Spiders
Person Centred Screening Matching Supporting pairs Organising events Negotiating sponsors	Person Centred Screening Studio and gallery Hand in glove support Exhibitions Collaborations Visits to galleries Raising profile	Person Centred Individual and program planning Maximise interactions in locality, preferences, making a contribution Create individual and group activities <ul style="list-style-type: none">▪ With others on own site or in community places▪ With peers in community places or on site Micro task engagement Flexible Collaborate others Adapting environments	Person Centred Individual and program planning Mix of on and off site activities Create individual or group activities – <ul style="list-style-type: none">▪ Others coming into sites▪ Going out to mainstream places as a group or with other community members Use of natural supports Skills development with goals of independence. Collaborate with others	Person Centred Screening Training and guest coaching. Match fixtures and transport Managing behavior Organising social events Informal support

Practice skills - understated

Exception of Arts Project - 'Hand in glove approach to support'

Educational qualifications in art at bachelor level – rather than disability support

Other programs

- Valued specialist vocational /professional skills - chefs, footy coaching, exercise science etc.
- Personal qualities and values – team work, connections
- Reflect skills can be taught attitudes hard to change

If skills can be taught need to be identified – these were implicit rather than explicit

We identified

- Task Analysis, Active Support, Active Mentoring, Support for Decision Making, Person Centred Planning, Positive Behaviour Support, Enabling Risk, and tailoring communication to people with intellectual disability.
- Community analysis, networking, negotiation, advocacy, and event management.
- Potentially negative implications undervaluing skills and failure to articulate for recruitment, scaling up, costing.



Outcomes Individual and Broader Exposure and Modelling

Gig Buddies	Arts Project	Melba	Shepparton	Spiders
Friendships with people without intellectual disability	Friendships with peers		Friendships with peers	Friendships with peers
Convivial and fleeting encounters people with and without intellectual disability	Convivial and fleeting encounters with peers, people without intellectual disability	Convivial and fleeting encounters with people in the locality	Convivial and fleeting encounters with people in locality	Convivial and fleeting encounters with people without disability
Enjoyment	Enjoyment Identity as artist	Enjoyment	Enjoyment	Enjoyment satisfaction, Confidence
Skill and confidence development	Artistic skill development Sense of belonging to artistic community	Sense of belonging and contributing to the locality	Confidence and skill development Sense of belonging to locality	Skill development Sense of belonging to footy club



Individualised and Programmatic – Not either or But both

Only the tip of the iceberg visible

- Moments of engagement - social event with a volunteer, playing football, selling art, conversing with other members of a cooking class or serving a customer with biscuits.
- Exposed the multi-faceted work of enabling community participation ‘the program’
- Demonstrated planning, thought and skill that programs bring together
 - collective and concerned with the group of individuals
 - at the same time individualised and tailored
- Demonstrated programs do things such as
 - as create opportunities for interaction,
 - create new activities – social enterprises
 - ensure the regularity of attendance that turns fleeting encounters into convivial ones
 - support to natural supports
 - task analysis to ensure engagement
- Programs provide ingredients of enabling that can be mixed and matched to an individual.
- Without this people with intellectual disability remain visitors or have paid companions and be dangerously dependent on the broader community ‘inviting’ people in to shared spaces or activities.



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

Questions

- Work in progress
- Can small scale programs such as these be scaled up and replicated?
- Are there benefits to establishing demonstration programs?
- Are there benefits to sharing program logic and detailed case studies?
- Can strategies and skills be more clearly codified and built into training?
- Collecting further evidence advantages of taking a programmatic approach to supporting community participation?
- What happens if we don't – paid companionship?
- Community participation programs and community capacity building how closely aligned are they?

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Thank you

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