Self Advocacy and Social Inclusion – Learnings from the Speaking up over the years project.

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Outline

• Aims of the projected– scope and approach
• Key characteristics of Self Advocacy groups - UK and Australia
• Outcomes for self advocates and wider influence of self advocacy
• What has supported self advocacy
• What can go wrong - pitfalls to watch out for
• Things to think about
Overview of research

• Generated by interests of self advocate and academics in strengthening self advocacy

• What is the significance of self advocacy in building individual, social and political inclusion?

• Examined policy development and organisational history of self advocacy, personal and political experiences of self advocates – perspectives of allies, paid supporters and b'crts responsible for funding.

• History group work - collaborative group approach – shared and diverse tasks – equal value –, 27 participants, document review (291 items), reflective meetings (44) + 5 life stories

• PhD study - 6 groups (4 UK, 2 Australian, 25 self advocates, 6 supporters

• Qualitative analysis, inductive, thematic
Self Advocacy Groups - features

All independent - self governing – committee of management
Diverse, organisational forms, size, location, context, funding, support

Common Features

Sense of Ownership and Control by members
- belonged to members
- irrespective of extent to which tasks were undertaken or shared with supporters – members felt in control
- can be threatened by external context & internal strife

Collegiality
- people belonged on their own terms – not as service users
- groups’ offices and activities were friendly and accessible
- being in the office part of everyday life for some members
- place where members and staff had a strong positive regard for each other
- Inherently different from services – power – hierarchy - freedom
Self Advocacy Groups – Activities and Opportunities

Activities

Diverse range, scale, frequency, focus

• organisational management tasks, committee work, advisory/consultative roles, dvd production, training, information talks, self education, lobbying, campaigns, demonstrations, speaking at conferences, sharing experiences – speaking out

Opportunities for -

• friendship, making new social connections with b’crts, politicians, academics, advocates, new experiences, paid work, volunteer work, working with other organisations, being part of a bigger collective movement, acquiring status, gaining confidence, meaningful and purposeful occupation, having fun, helping others
Outcomes of Self Advocacy

**Individual Social inclusion** – learn, work, engage, have a voice
- Confidence
- Engagement in life
- Being an expert—identity as self advocate
- Socially connected
- Occupation
- Involvement in civic society - contributions to others and society

**Broader Society**
Means of achieving social inclusion for people with intellectual disability
- Demonstrates participation by people with intellectual disability for others
- Existence raises expectations about inclusion and consultation in research, policy, service development
- Provides experience in advisory roles for people with intellectual disability
- Source of expertise and resource for others to draw on
- Part of a wider social movement for rights and inclusion - means for influencing social change in collaboration with other groups
What has supported self advocacy

Relationships
- among core members – longevity & shared life experiences
- early days - with broad based flexible support of professional allies
- with senior government players–bcr’ts, politicians
- with other advocacy groups or service providers

Commitment – longer term core members

Structural
- participatory structures – committee and office bearers
- supporters with strategic intent
- professionals & academics with relative freedom
- opportunities and invitations to collaborate
- requirements or expectations of funding bodies, govt’s about consultation or inclusion of people with intellectual disability
- philanthropic trusts with flexibility

Serendipitous
- context - events - personalities
Pitfalls

I’d say it’s, to a certain extent, Community Services have possibly used Reinforce over the years for different things”. (David Banfield – self advocate)

Serving the agenda of others - used and abused

• govt – other organisations- workers- supporters
• co-option - illusion of inclusion, consultation - lend legitimacy
• tokenism – included but not supported to participate
• diverted from purpose by competing organisations and interests
• intermittent uncertain funding – project work
• survival - keeping the doors open

Impetus for growth undermine opportunities - optimal size?

Poor quality support – low skills, turnover, embezzlement

Absence of strategic advice and direction

Failure to attune to social and political context

Internal – keeping on track - cohesion, personalities, rule compliance
Things to think about

Clarity of purpose – mode of organisation

Transparent structure - independence from others with competing, conflicting interests or clear protocols re control

More smaller networked groups

Strategic support as well as day to day

Voluntary unpaid input

Broad network of high level supporters/advisers as well as paid workers

Attention to tensions between support/advice and control - training for support workers - standards

Clear ground rules and expectations of support in external groups/committees or work with other organisations

Positioning to maximise potential funding sources – advocacy, self help, community group, membership group

Attention to changing political and social context – opportunities
Resources from the project

**Speaking up over the years: The history of Reinforce**

**Papers in press**


See slide share for presentations

Self Advocacy History group Presentation at conference on inclusive research 2012  
**DVD of presentation**

Please contact us for earlier presentations on history of self advocacy

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Reinforce Self Advocacy

Speaking up over the years

Patsie Frawley, Chris Bigby, David Banfield, Norrie Blythman, Jane Hauser, Amanda Hiscoe & Janice Slattery