
Participatory and inclusive approaches to disability program evaluation

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Outline

- Background and inclusive evaluation framework
- Framework for analysing inclusion in evaluation
 - Control of decision making
 - Diversity of participation
 - Power relations
 - Manageability
 - Depth of participation
- Implications and resources

Background – inclusive approaches

Inclusive approaches - engage the people as active agents

- opportunities for increased breadth and quality of data
- ethical schema
- clear conceptual and methodological framework for practice
- addressing the human rights and social justice of marginalised groups
- governance, design, conduct and dissemination

Background – reasons for inclusion

Reasons it is important to include people with intellectual disability

- People have the right to be involved in finding out about their lives
- It changes the way that people think about people with intellectual disability
- It proves to people that you CAN do it, and you get the chance to do it
- We have a different way of doing things – we understand the way evaluation should be put together differently. We come at it from a different angle
- People's experience is valuable and important
- People with disability in the program feel more comfortable talking to someone who has the same kind of experiences in their life
- You get better information from people when someone with intellectual disability asks them
- People can understand what they are being asked, because you don't use too many big words – it makes it easy
- More people find out about evaluation and research and get involved

Research question and method

Reflecting on work we have done together

- how inclusive was it
- what was the depth of inclusion
- what were the limits to our approach
- what would we do differently next time?

Analyse public outputs and reflective discussion

Disability inclusive research and evaluation

Disability inclusive research

- research that is relational, reflective and requires willingness by academic researchers to cede control and to commit resources to mutual capacity development

Inclusive and participatory evaluation

- to increase the quality of evaluation to support program, policy, or organizational decision making; relevance; ownership and use
- meaningful roles in evaluation, including as team member, management or advisory group, adviser or consultant to inform design; data collection strategies; analysis and dissemination

Inclusive evaluation

Measures of inclusivity

1. Control of technical decision making (stakeholder – evaluator)
2. Diversity among stakeholders selected for participation (diverse – limited)
3. Power relations among participating stakeholders (conflicting – neutral)
4. Manageability of evaluation implementation (unmanageable – manageable)
5. Depth of participation (deep – consultative)

(Weaver and Cousins 2004)

Residential Support Program (RSP) Qld

Pilot program

- Support from 8 NGOs to >700 residents with disability, living in 20 private residential services (unfunded boarding houses and hostels) in 5 locations
- Community access, personal care, health and well-being
- Complex needs – 42% intellectual or cognitive disability, 73% psychiatric disability, 64% multiple disability

Evaluation

- Mixed method, longitudinal, formative evaluation of pilot
- Process, cost and outcomes data to inform future program
- Participatory approaches in plan, management and conduct
- interviews with stakeholders, observation of meetings and residence, analysis of administrative and financial data

1. Control of technical decision making (stakeholder – evaluator)

Design of governance and conduct of evaluation

- Consultative design phase with PWD
- Critical comment from stakeholders on draft design and outputs
- Steering committee, Advisory group
- Data collection – interviews and observation
- Formative – responsive feedback

Limits

- Control remained with people acting on behalf of PWD
- Acknowledged limits, governance, formative, earlier experience

2. Diversity among stakeholders (diverse – limited)

Reach people who not normally contribute to evaluation

- Others not difficult – providers, owners, officials
- Longitudinal, detailed data, multiple formats, location
- Incidental engagement and observation eg. relationships, abuse
- Unexpected data and consequent action

Limits

- Brief and occasional contact – repeats to build trust and triangulate data at location

3. Power relations among stakeholders (conflicting – neutral)

Acknowledge and address power imbalances in program and evaluation

- Boarding house reform conflict
- Governance (representatives), participatory methods, explicit value to PWD first
- Formative – changes demonstrated impact to PWD eg showers

Limits

- Capacity and risk locally and in committees – confidential briefings on ethics and conflict

4. Manageability of implementation (unmanageable – manageable)

Logistical, time and resource challenges

- Finalised time after consulting stakeholders in design
- Delays – ethics approval, accessible materials, intensive interviews
- Ethical practices – disclosure protocol, confidentiality, assistance with complaints, cash reimbursement
- Diverse participation rather than full inclusion

Limits

- organisational management at the expense of inclusive practice
eg. follow up visits to explain the impact of contributions or accessible formats

5. Depth of participation (deep – consultative)

Unexpected information with utility for evaluation questions
(not technical control)

- Governance and data collection
- Longitudinal – trust, concrete real time experiences
- Observational context data

Limits

- No direct participation of residents and people with significant cognitive impairment at decision making levels of evaluation

Met inclusive approach criteria?

Knowledge utility

- Streamlined program , more responsive to expressed aspirations
- Assisted travel, link community participation and personal support
- Later evaluations government receptive to participatory approach

Social justice

- Policy action about significant marginalisation
- Program addressed personal level problems eg. access to services, advocacy and complaints about mistreatment
- Context continued to disadvantage residents eg. housing and mainstream and specialist services

Underlying phenomena

- Lives of people in the program and context
- Extended evaluation and policy practice but not inclusive

Improvements?

We could have done a better job

- Including community evaluators with experience in boarding house in governance and advisory structures
- Seeking advice from community evaluators about the points of conflict and presenting these views in formal meetings to privilege the voice of residents
- Including PWD in evaluation team and in writing the reports
- Planning for more meaningful dissemination eg. advice or dissemination by community evaluators

Requires local capacity building, time and resources

Implications for policy and evaluation practice

Support and resources in evaluation processes to:

- build the capacity of academic and community evaluators as team members, mentors, advisers and direct participants
- make inclusive evaluation of disability policy feasible and an expectation of policy, evaluation and disability communities
- include people with intellectual disability in evaluation about programs which are about their lives
- use methods that build on everyone's strengths
- support self advocacy and disability activism to develop capacity and participate in big issues

Resources

Fisher, K.R. and Robinson, S. (2010) Will Policy Makers Hear My Disability Experience? How Participatory Research Contributes to Managing Interest Conflict in Policy Implementation. *Social Policy & Society* 9, 2, pp.207–220

Fisher, K.R., Abelló, D., Robinson, S., Siminski, P. and Chenoweth, L. (2005), 'Resident support evaluation: final report', report prepared for Disability Services Queensland, SPRC Report Series 2/05,
<http://www.sprc.unsw.edu.au/media/File/RSPFinalReport.pdf> .

Weaver, L. & Cousins, J.B. (2004). Unpacking the participatory process. *Journal of Multidisciplinary Evaluation*, 1(1):19-40.

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