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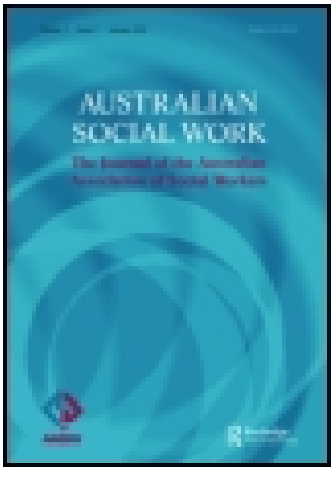

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Participatory and Inclusive Approaches to Disability Program Evaluation

Sally Robinson[a], Karen R. Fisher[b] & Robert Strike[c]

[a] Centre for Children and Young People, Southern Cross University, Lismore, New South Wales, Australia

[b] Social Policy Research Centre, University of New South Wales, Kensington, New South Wales, Australia

[c] personal

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Participatory and Inclusive Approaches to Disability Program Evaluation

Sally Robinson[a]*, Karen R. Fisher[b] & Robert Strike[c]

[a]Centre for Children and Young People, Southern Cross University, Lismore, New South Wales, Australia; [b]Social Policy Research Centre, University of New South Wales, Kensington, New South Wales, Australia; [c]personal

Abstract

Some evaluations of disability programs now apply participatory methods to include people with cognitive disability in the collection of data. However, more inclusive approaches that engage people with cognitive disability more fully in the decisions about the evaluation remain rare. We examined why this may be the case, using Weaver and Cousin's criteria for inclusive evaluation to measure the depth of inclusion of our methods in an evaluation that we did that included people with cognitive disability. We found that the participatory methods in the design supported some of the dimensions of inclusive evaluation–diversity, depth of participation, power relations, and manageability. Relying on other people to represent the interests of people with cognitive disability in the governance, data collection, and dissemination compromised the control dimension of inclusion. Resources and commitment to build the capacity of people with cognitive disability as team members, mentors, advisers, and direct participants is required to make inclusion feasible and an expectation in disability program *evaluations.*

Keywords: Disability Policy; Inclusive Research; Transformative Evaluation; Participatory Methods; Reflective Practice

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Few people who use social support programs are meaningfully engaged in the evaluation of programs relevant to their lives, including people with cognitive disability (Beresford, 2002; Mertens, 2009). Inclusive approaches to evaluation aim to engage the people who are intended to benefit from social support programs as active agents in evaluation processes with the transformative goals of improving the programs in their interests. The approaches can offer opportunities for increased breadth and quality of data, an ethical schema, a clear conceptual and methodological framework for practice, and the potential for addressing the human rights and social justice of marginalised groups (Weaver & Cousins, 2004).

*Correspondence to: Sally Robinson, Centre for Children and Young People, Southern Cross University, Lismore, NSW, Australia. Email: sally.robinson@scu.edu.au
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Evaluations of disability programs in Australia make limited use of these approaches and of the substantial body of knowledge about the benefits of inclusive research, which promote the inclusion of people with disability in both research practices and processes (Bigby & Frawley, 2010; Goodley, 2004; Walmsley & Johnson, 2003). Instead, general evaluation practice is that if people are included, it is usually as program participants in consultation and data collection. There is little evidence of disability program evaluation that attempts to implement inclusive principles or to translate inclusive evaluation theory into practice. Barriers to participation are heightened for people with cognitive disability—the focus of this article. References to people with disability in this article are about people with cognitive disability, including people with intellectual disability, acquired brain injury, psychiatric disability, specific learning disabilities, and people on the autism spectrum (Jacobson, Azzam, & Baez, 2012).

In this paper, we look at possibilities for moving from participation in data collection by people with disability to more inclusive approaches in evaluation (Mertens, 1999, 2010; Weaver & Cousins, 2004). Through analysis of work we did that used participatory evaluation methods, and our reflections on our experience, we identify opportunities and challenges in moving beyond participatory mechanisms towards more inclusive evaluation processes, and discuss some tensions and considerations of such a shift within the constraints of commissioned program evaluation.

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Disability Program Evaluation and the Influence of Inclusive Disability Research

There is little academic literature about the experience of people with cognitive disability in evaluation, either as program participants or evaluators (Fisher & Robinson, 2010; Jacobson et al., 2012; Minkler et al., 2008). Two separate, but related sets of literature contextualise inclusive disability evaluation. The first of these is inclusive disability research, largely from the UK (Boxall, 2002; Goodley, 2004; Walmsley & Johnson, 2003). The second is the USA theory on inclusive and transformative evaluation, informing the ethics and practice of evaluators (Cousins & Whitmore, 1998; Mertens, 2009, 2010; Ryan, Greene, Lincoln, Mathison, & Mertens, 1998). These two approaches share the values of inclusive practice but come from different disciplinary starting points. Evaluation theorists distinguish evaluation practice as a specific type of research (e.g., Clarke & Dawson, 1999). As a result, disability research is broadly positioned within a continuum of participatory to emancipatory research, and evaluation within a continuum of participatory to transformative evaluation.

We think there are often differences in design and practice between evaluation and research that set them apart from one another in a number of ways. For example our evaluation work is often more tightly constrained by terms of reference, goals set by government, and short timeframes. The aims and methods of our research projects have been more within our control, and the timelines more negotiable. Below we

briefly explore both inclusive research and evaluation. We turn first to a discussion of inclusive disability research in setting expectations about the inclusion of people with cognitive disability, before introducing concepts from inclusive evaluation.

Inclusive Disability Research

Inclusive disability research has grown from multiple strands of the disability movement—from the social model of disability, normalisation and social role valorisation theory, and the self-advocacy movement (Barnes & Mercer, 2004; Walmsley & Johnson, 2003; Williams & Simons, 2005). People with cognitive disability have not always been well served by some of the broader inclusive research debates, which have not adequately problematised the impact of cognitive impairment to inclusion (Boxall, 2002; Stalker, 1998). Early inclusive research projects were predominantly from the UK, and many were based in life stories and the experience of self-advocacy (Atkinson, 2004; Williams, 1999). A second generation of research and critical reflection on inclusive research analyses some of the inherent challenges in doing research inclusively with people with cognitive disability, such as the role of theory generation, inclusive analysis of data, who benefits from the outcomes of research, and the importance of "unpacking" collegial support (Goodley, 2004; McClimens, 2008; Nierse & Abma, 2011). Bigby and Frawley (2010) provided valuable reflection and analysis of inclusive practice in their research relationship with their colleague Alan Robertson. The roles are heavily relational and rely on ongoing reflection and willingness by academic researchers to cede control and to commit resources to making the research relationship function well, as well as a long-term focus on capacity development at a range of levels.

Of the authors of this paper, Sally Robinson and Karen Fisher were academic researchers who conduct evaluations and Robert Strike, who has an intellectual disability, was a coresearcher. We have worked together as researchers and evaluators since the 1990s, including commissioned evaluations about programs that include people with cognitive disability. We have applied a participatory approach to the design of these projects, within the constraints of commissioned evaluation. Sally has also worked with Robert on disability research projects over the same period, including inclusive research. During this time, Sally has used her reflections with Robert through their ongoing research relationship to inform our evaluation practice, including projects Robert does not work on. The crossover of advice and reflection from our relationships and experience in participatory and inclusive research has changed our evaluation practice, as explored in this article.

More recently, we have talked about our experiences of working together on both inclusive evaluation and research in facilitated public workshops for people with and without disability (Fisher et al., 2011; O'Brien, Fisher, Robinson, Kayess, & Strike, 2011; Robinson et al., 2011). The role of people with cognitive disability in evaluation teams as coevaluators was discussed. Robert says that involvement as a coevaluator is important because from his perspective:

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- People have the right to be involved in finding out about their lives.
- It changes the way that people think about people with cognitive disability.
- It proves to people that you *can* do it, and you get the chance to do it.
- People with cognitive disability have a different way of doing things—they understand the way evaluation should be put together differently. They come at it from a different angle.
- People's experience is valuable—it's important to have lived experience.
- People with disability in the program may feel more comfortable talking to someone who has the same kind of experiences in their life.
- You get different information from people when someone with cognitive 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 more involved (i.e. those with and without cognitive disability).

Robert's comments are about the positioning of people with cognitive disability in key decision making, such as the way the evaluation is organised, and who does what part of the work to get the best quality information to evaluate the program. These points are also consistent with the findings of other coresearchers in inclusive disability research (Kramer, Kramer, Garcia-Iriarte, & Hammel, 2011; Williams, 1999; Williams & Simons, 2005).

Inclusive Evaluation and the Place of Transformative Evaluation Theory

In addition to these developments in inclusive disability research, parallel theory and practice changes have also emerged in evaluation. Inclusive evaluation principles are most strongly articulated in transformative evaluation concepts. Mertens (1999, 2009, 2010) described the evaluator working in the transformative paradigm as one who "consciously analyses asymmetric power relationships, seeks ways to link the results of social inquiry to action, and links the results of the inquiry to wider questions of social inequity and social justice" (1999, p. 4). The foundations of the transformative paradigm are a useful conceptual base for thinking about ethics, how evaluators understand reality, how knowledge is created, and how knowledge is obtained.

At a broad level, taking an inclusive approach to evaluation involves systematic investigation of the merit, or otherwise, of programs or systems, with the aim of enabling decision making and at the same time facilitating positive social change for less advantaged groups. It includes specific mechanisms to recognise and understand cultural norms and contextual complexity, to redress power imbalances, and to support and sustain the meaningful involvement of people who traditionally have been under-represented or excluded as stakeholders in evaluation (Baur, Abma, & Widdershoven, 2009; Mertens, 2010; Weaver & Cousins, 2004).

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Participatory and Inclusive Evaluation

Participatory evaluation encourages the participation of stakeholders in order to increase the quality of support in decision making, relevance, ownership, and utility (Cousins & Whitmore, 1998). Inclusive approaches engage more deeply with people (in this case with cognitive disability) in meaningful roles in evaluation, including as an evaluator, a member of a management or advisory group, adviser, or consultant. In these roles, their experience and expertise can inform the way the evaluation is designed and managed; data collection strategies and instruments are developed and implemented (e.g., plain English surveys, analysis or outputs); and data are analysed, presented and disseminated (e.g., accessible outputs and training) (Fisher & Robinson, 2010; Kramer et al., 2011).

In Australia, there appears to be little guidance for evaluators seeking to conduct "participatory" or "inclusive" evaluation in disability policy, and it is not uncommon to hear of evaluations referred to as participatory because people with cognitive disability are included in the cohort of people consulted or included as respondents. The terms themselves are contested as used by evaluators, scholars, and practitioners in different contexts (Mertens, 2010; Walmsley & Johnson, 2003).

In a database and policy scan of academic and grey literature about recent Australian evaluations of social support programs directed towards people with cognitive disability, we found that most frequently no methodological approach was described (rather, the range of data collection methods used in the evaluation were detailed). Where methodology was described, action research and participatory action research predominated. However, little evidence of inclusive methods beyond the inclusion of people with cognitive disability as respondents in data collection was found. A small number of evaluations involved people with disability on steering committees or advisory groups, but only one we could locate in this (admittedly small-scale) scan included people with cognitive disability in an advisory capacity (Milne et al., 2009), in addition to Bigby and Frawley (2010) above. This is consistent with Jacobson et al.'s (2012) analysis of the USA evaluation, which found that people with cognitive disability were more likely to be included in the latter stages of the process, and people with low support needs, rather than high needs, were more likely to be involved.

Framework for Measuring Inclusivity in Evaluation

Weaver and Cousins (2004) analysed a range of collaborative or inclusive approaches to evaluation and research, from which they developed a schema to measure the depth and quality of participation and engagement of stakeholders within the evaluation. They identified three primary goals for inclusive approaches to evaluation—the knowledge gained through inclusive inquiry should be useful; it should be concerned with ameliorating social inequalities; and it should be aiming to produce reliable or robust knowledge.

To achieve these three goals for inclusive inquiry, Weaver and Cousins (2004) provided a framework for measuring the depth and quality of inclusive evaluation. The dimensions of the framework are:

1. Control of technical decision making
2. Diversity among stakeholders selected for participation
3. Power relations among participating stakeholders
4. Manageability of evaluation implementation
5. Depth of participation.

This framework does not appear to have been applied to evaluation that includes people with cognitive disability. Daigneault and Jacob (2009) used three of these dimensions to assess the authority and influence of participants, diversity of participants, and extent of involvement as measures of inclusivity. Their work has been applied in participatory evaluation in other domains, such as education (Pietilainen, 2012). In this article, we used Weaver and Cousins' framework to highlight opportunities and challenges to inclusive evaluation for people with cognitive disability. We applied the framework to a case study of a participatory evaluation Karen and Sally completed of an Australian disability program to provide an exemplar case.

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Resident Support Program

The example we used is the evaluation of the Resident Support Program (RSP) in Queensland, Australia. We used it as an example here because it was complex, yet reliant on the perspectives of people with cognitive disability for evaluation results. RSP provides external support services to residents with disability living in private residential services (unfunded boarding houses and hostels). The support is community access, personal care, and health and wellbeing. The Government commissioned a mixed-method evaluation of the pilot program to develop cost and outcomes data to inform future development (Fisher, Abelló, Robinson, Siminski, & Chenoweth, 2005).

The RSP was run by two state government departments, with eight nongovernment organisations providing the support in five locations. Stakeholders included the people using the support (residents), premises owners, advocates, service providers, and policy makers. Many of the residents had complex needs—of the 32 people in repeat interviews, 42% had been assessed as having intellectual or cognitive disability, 73% with psychiatric disability, and 64% had multiple disabilities. Other residents not included in these figures had not received formal diagnoses of disability. While the evaluation included people with a range of disability types, our focus in this paper included people with cognitive disability, as this is where we found the barriers to participation highest.

The evaluation was conducted by a six-member university consortium over 18 months, using a mixed method participatory approach with the aim of

understanding the implementation of the program; the services provided to residents; how residents perceived services and the impact on their quality of life, health, and wellbeing; and the impact on residential facility operators and staff, as well as other human services providers and departments. One member of the evaluation was a person with psycho-social disability, but the evaluation team did not have a person with cognitive disability due to budgetary, travel, and time constraints. We addressed this constraint by drawing on our learning from our other more inclusive projects, but this omission limited our inclusivity in important ways.

The evaluation design was formative, including process, outcomes, and cost effectiveness measures. The mixed methods included interviews with stakeholders; observation of the program, meetings, and places of residence; and analysis of administrative and financial data. In addition to collecting quantitative data about service use, service users, and cost, 36 people who most recently entered the program participated in three semistructured interviews at three month intervals. This sample was selected to be large enough for a range of characteristics and to support the cost-effectiveness analysis.

The methods are described in full in Abelló, Fisher, Robinson, and Chenoweth (2004), although the evaluation method details are only indirectly relevant to the analysis in this article. During the design phase we incorporated inclusive goals by using participatory approaches in the plan, management, and conduct of the evaluation (Abelló et al., 2004). Our method of analysis for this article was to apply Weaver & Cousins' inclusive evaluation dimensions of form (above) to the public outputs from the evaluation (evaluation plan; data collection instruments; baseline, interim and final reports; and journal article) and reflective discussion between the evaluators.

Experience of the Dimensions of Inclusive Evaluation

Control of Technical Decision Making

On the spectrum from participatory to inclusive evaluation, involvement of people with cognitive disability ranges from participation in processes determined by people without disability through to engagement with the design, implementation, and sharing of outcomes. In commissioned disability policy evaluation, constraints on inclusive practice included the relationship between funder and evaluators, the terms of reference of the evaluation, and the scope for choice in evaluation methodologies. In addition, for people with cognitive disability, involvement in evaluation can risk their own interests if the evaluation framework inadequately considers social justice and human rights imperatives (Goodlad & Riddell, 2005).

In the RSP evaluation, control remained largely with the funding agencies and academic evaluators. To increase inclusivity, input from stakeholders representing the interests of people with disability were sought at multiple points, including design, reporting, and oversight. However, most control remained with people acting on behalf of people with cognitive disability. Strategies that went part of the way to

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redressing the lack of control included acknowledging the limitation and arguing for the formation of an advisory group with membership of advocates for people with disability; discussing the evaluation process with residents whenever we visited the boarding houses; and designing the evaluation process, instruments, and data collection with the same principles that we had learned from working with coresearchers with cognitive disability on more inclusive disability research projects (Robinson, Hickson, & Strike, 2001; Robinson & Walker, 1997).

Diversity among Stakeholders Selected for Participation

It is well recognised that inclusive approaches are often limited to people who are skilled, resourced, and supported (Boxall, 2010; Redley & Weinberg, 2007). At the same time, some people will not contribute to evaluation—either through preference, social circumstance, or through capacity. For people with high and complex support needs due to disability, the limitations of inclusive approaches need to be acknowledged, alongside creative strategies for maximising the participation of these people in evaluation. The RSP evaluation goal on the dimension of diversity among stakeholders was to reach people using the program who would not normally have an opportunity to contribute to the evaluation. Residents with a range of disability support needs participated in three interviews at three monthly intervals about their experience of the program. The data collection with residents was more detailed than from other stakeholders. We used easy-read information and consent forms, informed by our inclusive research experience, to make understanding easier.

The evaluation was reasonably inclusive on this dimension, particularly by including opportunities for observation, and strategies for diverse representation in governance. A benefit was that the methods revealed unexpected information that could be acted on through the formative evaluation, particularly about ill-treatment or poor practice. A limitation was that the contacts with residents were brief and occasional. Interviewing the residents three times helped to build rapport, as did holding interviews with diverse stakeholders in the same location to contrast multiple perspectives in the data.

Power Relations among Participating Stakeholders

Power relations for people with cognitive disability are often difficult to navigate. Supportive relationships that create conditions of alliance and respect for the contributions of coevaluators and program participants with cognitive disability are prerequisites (Bigby & Frawley, 2010; Walmsley & Johnson, 2003). Managing competing stakeholder interests and voices, addressing risks, and responsiveness to input are key issues for evaluators. Space precludes a more complete discussion of this important issue (addressed in more detail in Fisher & Robinson, 2010). The RSP evaluation goal on this dimension was to design and implement the evaluation in a way that acknowledged and addressed the power imbalances in the evaluation and program. The program was part of the reform of the private residential sector,

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a fraught policy context. In this climate, the voices of people with disability were not primary.

Using formative evaluation was helpful in addressing unequal power relations. On several occasions program managers responded in a way that enabled us to demonstrate to residents that sharing their experiences could improve their services. For example, in the first round of interviews, some people said they did not like having service providers shower them at 2 p.m., and preferred them to come at the beginning of the day to be ready to go out. This type of information from interviews informed policy makers' decisions to change the program during the evaluation in response to the feedback from people with disability (Fisher & Robinson, 2010).

However, little opportunity, and some risk, remained for residents (the stakeholders with the least power) to speak for themselves within decision making structures, both locally at the premises and in the evaluation committees. We attempted to address these limitations by thinking about the possible implications of our actions on residents—for example, briefing the Government and advocates about sensitive findings about conflict before the formal meetings that included multiple stakeholders, such as apparent unethical practices that needed further investigation, and implications of the evaluation findings for broader sector reform.

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Manageability of Evaluation Implementation

Commissioned evaluation often involves tight timelines, negotiated ahead of time, with little room to manoeuvre in response to delays or unexpected findings. These are often not conducive to inclusive evaluation processes. In the RSP evaluation, manageability also included ethical practices, such as a disclosure protocol to respond to apparent abuse, neglect, and harm; responsibility to manage privacy and confidentiality; assistance to people with complaints not related to the evaluation topic; and reimbursement for their participation in the evaluation. On reflection, in several areas we focused too much on manageability from a bureaucratic or organisational point of view, at the expense of more inclusive practice. For example, we arranged follow up visits for only some participants to explain the impact of their contributions; and the summary report for participants was not available in accessible formats.

Depth of Participation

The RSP goal for depth of participation was that it be sufficiently deep to reveal unexpected information useful for the evaluation questions. The year-long evaluation gave us the opportunity to talk with people in real time about their experiences, keeping the discussions concrete and developing rapport through repeat visits. Observing and meeting other people living in the same facilities while interviewing residents also gave us the opportunity to understand the environmental pressures and realities more clearly. However, the design did remain unreflective about the depth of participation. Engagement in the design, higher level implementation of the project,

and dissemination of results by coevaluators with cognitive disability would undoubtedly have enriched the depth and quality of inclusive practice.

Constraints on the Goals for Inclusive Evaluation

Returning to Weaver and Cousins' (2004) framework for inclusive inquiry, we asked whether the RSP evaluation met their three related goals for inclusive evaluation practice—utility, social justice, and inclusive practice. First, was the knowledge gained through the evaluation useful in solving problems, making decisions, or making policy? The program changed in response to the evaluation. The program operation is now more streamlined, and is more responsive to the expressed needs and aspirations of residents. In evaluations we have conducted subsequent to this one, government agencies have been increasingly receptive to participatory approaches in evaluation, indicating a growing confidence in the approach on the part of policy makers.

The second goal was that the evaluation contributed to the amelioration of social inequalities. Focusing on the voice of people with cognitive disability served to highlight problems that illustrated significant marginalisation, which motivated policy action about the program based on the evaluation findings. For participants, some personal level problems were addressed through being interviewed, such as access to services and advocacy. Howerever, most of the benefits came from their participation in the program itself, rather than the evaluation. The social impact of the evaluation was limited to changes to the program, while the policy and social context continued to disadvantage the residents.

Weaver and Cousins' (2004) final goal of inclusive evaluation was to contribute to the production of robust knowledge or to revealing underlying social phenomena from the perspective of the participants. On measurement of participation, the evaluation measures reasonably well. However, as an inclusive approach to evaluation with a goal of producing new knowledge from the perspective of lived experience, it is clear that partnership with people with cognitive disability was missing. The main shortcomings were the limited extent to which the evaluation design, governance structures, and dissemination directly involved people with cognitive disabilities. As a result, opportunities for generating different types of knowledge by and for people with cognitive disability living in these circumstances were likely to have been missed.

Ethically including people with cognitive disability in evaluation projects also raises questions about the development of capacity, if people are engaged in multilayered decision-making in evaluations. Without a strong political and social movement of people with cognitive disability, it is difficult for evaluators and for people with disability (and their allies) who are interested in programs and evaluation to influence the way in which social support evaluation is conducted (Bigby & Frawley, 2010; Walmsley & Johnson, 2003). Given the constraints of competitive tender processes in commissioned evaluations, terms of reference, government policy sensitivities, and tight timelines, tokenism is a clear risk. When academic researchers and

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coresearchers with disability conduct inclusive commissioned evaluation, practice and outcomes may change, but there is also a risk that the focus will narrow to government prioritised questions. In contrast, inclusive research can be an opportunity to address broader problems of social policy, social justice, or human rights (Finkelstein, 1999, in Walmsley & Johnson, 2003).

Considering the depth of participation of people with cognitive disability in evaluation raises other capacity questions. How do people get the information they need to make informed decisions about becoming involved in evaluations, either as coevaluators or as participants? This is particularly important for people who are engaged with the service system, who may need to consider potential risks from involvement in evaluations that are critical of services on which they rely for support. How can they contribute to the wider discussions on centrally important issues such as power relations between evaluators with and without disability; decision making about which knowledge is valued from their perspective, and important in collecting and analysing evaluation data; and benefit and reward for coevaluators (including career paths and tenuous employment contracts)?

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Implications for Policy and Practice

The application of the framework to this case study was a posthoc reflection on a completed evaluation. Applying the framework to develop an inclusive evaluation or during implementation would likely find different outcomes—particularly where policy makers are amenable to inclusive approaches. We anticipate the framework would also be useful for analysing the inclusivity of research as well as evaluation, and suggest that further research that continued to refine the framework would contribute to a critical understanding of inclusive evaluation and research.

The analysis found that incorporating participatory methods in a formative evaluation design contributed to dimensions of inclusive evaluation, such as diversity and depth of participation, power relations, and manageability. However, relying on other people to represent the interests of people with cognitive disability in the governance, data collection, and dissemination compromised the control dimension of inclusion. The implications are that resources and commitment to build the capacity of people with cognitive disability as advisers and direct participants in evaluation processes are required to make inclusive evaluation of disability programs feasible and an expectation of programs, evaluation, and disability communities.

At one level the capacity of people with cognitive disability to contribute as coevaluators needs to be supported. The transformative evaluation paradigm calls for control by stakeholders—in this case, people with cognitive disability. Capacity building requires investment to support people with cognitive disability to develop expertise in evaluative skills around design, advice on language, policy issues, and human rights. At another level the receptivity of professionals, evaluators, and commissioners of evaluations—usually government—needs to be developed so they are persuaded of the utility of inclusive evaluation for program and program

improvement, and addressing social inequalities. This requires acknowledging the implications of a shift in control and power relationships, and commitments to resources, time, and transparency to wider audiences before, during, and after the formal evaluation process. It also has implications for evaluators and social work professionals to be more creative in our approach—to find methods, strategies, and tools that are inviting and creative, and that engage people who do not participate in standard ways.

Locating people with cognitive disability who are interested in evaluation and social support programs is of course the beginning point so that developing individual skills in inclusive team-based evaluation can continue, consistent with philosophical, ethical, and methodological guidelines and developing skills as analysts and advisors. At the same time, social work professionals need to demonstrate to policy makers and decision makers that inclusive approaches can offer a fruitful avenue to evaluate disability programs. This article contributes to further developing robust evaluation frameworks that support and sustain the meaningful engagement of people with cognitive disability in evaluation of programs that affect their lives.

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References

Abelló, D., Fisher, K. R., Robinson, S., & Chenoweth, L. (2004). *Resident Support Program evaluation plan* (Social Policy Research Centre (SPRC) Report Series 10/04). Retrieved from http://www.sprc.unsw.edu.au/media/File/FinalEvaluationPlan.pdf

Atkinson, D. (2004). Research and empowerment involving people with learning difficulties in oral and life history research. *Disability and Society*, *19*, 691–702. doi:10.1080/0968759042000284187

Barnes, C., & Mercer, G. (2004). *Implementing the social model of disability: Theory and research*. Leeds: The Disability Press.

Baur, V. E., Abma, T. A., & Widdershoven, G. A. M. (2009). Participation of marginalised groups in evaluation: Mission impossible? *Evaluation and Program Planning*, *33*, 238–245. doi:10.1016/j.evalprogplan.2009.09.002

Beresford, P. (2002). User involvement in social research and evaluation: Liberation or regulation? *Social Policy and Society*, *1*(02), 95–105. doi:10.1017/S1474746402000222

Bigby, C., & Frawley, P. (2010). Reflections on doing inclusive research in the "Making Life Good in the Community" study. *Journal of Intellectual & Developmental Disability*, *35*(2), 53–61. doi:10.3109/13668251003716425

Boxall, K. (2002). Individual and social models of disability and the experiences of people with learning difficulties. In D. G. Race (Ed.) *Learning disability: A social approach* (pp. 209–227). London: Routledge.

Boxall, K. (2010). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, *39*, 173–180. doi:10.1111/j.1468-3156.2010.00645.x

Clarke, A., & Dawson, R. (1999). *Evaluation research: An introduction to principles, methods and practice*. London: Sage.

Cousins, J. B., & Whitmore, E. (1998). Framing participatory evaluation. In E. Whitmore, (Ed.), *Understanding and practicing participatory evaluation: New directions for evaluation* (p. 80). San Francisco: Jossey-Bass.

Daigneault, P.-M., & Jacob, S. (2009). Toward accurate measurement of participation: Rethinking the conceptualization and operationalization of participatory evaluation. *American Journal of Evaluation*, *30*, 330–348. doi:10.1177/1098214009340580

Fisher, K. R., Abelló, D., Robinson, S., Siminski, P., & Chenoweth, L. (2005). *Resident support evaluation: Final report* (SPRC Report Series 2/05). Retrieved from http://www.sprc.unsw.edu.au/media/File/RSPFinalReport.pdf

Fisher, K. R., & 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*, 207–220. doi:10.1017/S1474746409990339

Fisher, K. R, Strike, R., Robinson, S., O'Brien, P., Kayess, R., & Campbell-McLean, C. (2011, September 1). *Disability inclusive evaluation*. Symposium presentation, Evaluation and Influence: Australasian Evaluation Society Conference, Sydney.

Goodlad, R., & Riddell, S. (2005). Social justice and disabled people: Principles and challenges. *Social Policy and Society*, *4*(1), 45–54. doi:10.1017/S1474746404002179

Goodley, D. (2004). The place of people with learning difficulties in disability studies and research. *British Journal of Learning Disabilities*, *32*(2), 49–51. doi:10.1111/j.1468-3156.2004.00279.x

Jacobson, M., Azzam, T., & Baez, J. G. (2012) The nature and frequency of inclusion of people with disabilities in program evaluation. *American Journal of Evaluation*, *43*(1), 23–44.

Kramer, J. M., Kramer, J. C., Garcia-Iriarte, E., & Hammel, J. (2011). Following through to the end: The use of inclusive strategies to analyse and interpret data in participatory action research with individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*, 263–273. doi:10.1111/j.1468-3148.2010.00602.x

McClimens, A. (2008). This is my truth, tell me yours: Exploring the internal tensions within collaborative learning disability research. *British Journal of Learning Disabilities*, *36*, 271–276. doi:10.1111/j.1468-3156.2007.00485.x

Mertens, D. M. (1999). Inclusive evaluation: Implications of transformative theory for evaluation. *American Journal of Evaluation*, *20*(1), 1–14.

Mertens, D. M. (2009). *Transformative research and evaluation*. New York: The Guilford Press.

Mertens, D. M. (2010). Transformative mixed methods research. *Qualitative Inquiry*, *16*, 469–474. doi:10.1177/1077800410364612

Milne, C., Delaney, M., Ong, N., Maloney, J., Vej Hansen, K., Yorkston, E., & Thaler, O. (2009). *Evaluation of the self managed model in the Community Participation Program*. Final report to NSW Department of Ageing, Disability and Home Care. Downloaded 10/2/12. Retrieved from http://www.adhc.nsw.gov.au/__data/assets/file/0010/240886/Evaluation_of_SMM_July2009.pdf

Minkler, M., Hammel, J., Gill, C. J., Magasi, S., Breckwich Vásquez, V., Bristo, M., & Coleman, D. (2008). Community-based participatory research in disability and long-term care policy: A case study. *Journal of Disability Policy Studies*, *19*(2), 114–126. doi:10.1177/1044207308315280

Nierse, C. J., & Abma, T. A. (2011). Developing voice and empowerment: The first step towards a broad consultation in research agenda setting. *Journal of Intellectual Disability Research*, *55*, 411–421. doi:10.1111/j.1365-2788.2011.01388.x

O'Brien, P., Fisher, K. R., Robinson, S., Kayess, R., & Strike, R. (2011, March 31). *Disability inclusive research practice workshop*. Presented at Centre for Disability Studies, Sydney.

Pietilainen, V. (2012) Testing the participatory education evaluation concept in a national context. *Studies in Educational Evaluation*, *38*(1), 9–14. doi:10.1016/j.stueduc.2012.02.003

Robinson, S., Fisher, K. R., Kayess, R., Strike, R., O'Brien, P., Knox, M., & Young, E. (2011, July 6–8). *Walking the talk: Using disability inclusive research practice to influence policy*. Symposium presented at Australian Social Policy Conference, Sydney.

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Robinson, S., Hickson, F., & Strike, R. (2001). *More than getting through the gate: The involvement of parents with disability in their children's school education in NSW*. Sydney: Disability Council of NSW. Retrieved from http://www.disabilitycouncil.nsw.gov.au/archive/01/robinson.pdf

Robinson, S., & Walker, K. (1997). *Stand up and speak! Sit up and listen! Participation of people with intellectual disability in the management of advocacy services*. Sydney: Intellectual Disability Rights Service.

Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: Interactional impediments to political empowerment. *Sociology of Health & Illness*, *29*(5), 767–786. doi:10.1111/j.1467-9566.2007.01015.x

Ryan, K., Greene, J., Lincoln, Y., Mathison, S., & Mertens, D. M. (1998). Advantages and challenges of using inclusive evaluation approaches in evaluation practice. *American Journal of Evaluation*, *19*(1), 101–122.

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society*, *13*(1), 5–19. doi:10.1080/09687599826885

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and future*. London: Jessica Kingsley.

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

Williams, V. (1999). Researching together. *British Journal of Learning Disabilities*, *27*(2), 48–51. doi:10.1111/j.1468-3156.1999.tb00085.x

Williams, V., & Simons, K. (2005). More researching together: The role of nondisabled researchers in working with People First members. *British Journal of Learning Disabilities*, *33*(1), 6–14. doi:10.1111/j.1468-3156.2004.00299.x

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