

Melrose, S. (2013). Action research: Supporting the developmentally disabled and their caregivers. In *Sage Research Methods Cases*. Thousand Oaks CA: Sage. [DOI <http://dx.doi.org/10.4135/978144627305013500015>

ABSTRACT

In 2012, I worked with agencies serving the developmentally disabled to implement and evaluate a mental health promotion intervention. Responding to the problem of managing clients' mental illness mainly through crisis intervention, we hoped to improve practice by trying an alternative approach. Previous studies indicated the problem was also occurring on a national and international level and solutions were urgently needed. Our yearlong intervention involved monthly meetings with clients and teams of their staff and family members. We evaluated our intervention by analyzing interviews with clients and team members. By framing our project from a strengths based world view and an action research design we were able to integrate practical wisdom, published literature and critical reflection.

This case study illustrates challenges and setbacks that can occur in busy practice settings where precarious funding and staff turnover are a reality. Research with vulnerable populations requires deliberate attention to ensuring consensual, respectful and ethical participation. Ethical considerations must be magnified with populations such as the developmentally disabled and even more so when co-occurring mental illnesses are present. Communication with participants is critically important and explanations of practical strategies that work are presented

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Learning outcomes

- This case illustrates an everyday example of an action research project undertaken by busy healthcare practitioners who work with the developmentally disabled. Reading the case will provide a snapshot of methodological challenges that can occur.
- To appreciate the role of establishing a common philosophical orientation among the research team and following through with this guiding orientation during

communication with participants.

- To analyze jurisdictional regulations that guide research with vulnerable populations in relation to protection, recruitment and retention in potentially helpful projects.
- To critique small scale action research projects as a viable approach to strengthening practice knowledge among disciplines who work with the developmentally disabled.

Action Research: Supporting the Developmentally Disabled and Their Caregivers – Project Overview and Context

Persons with Developmental Disabilities (PDD), who are also known as individuals with intellectual disabilities (ID) or more pejoratively as mental retardation (MR) are a vulnerable, marginalized and often poorly understood group. As a nurse specializing in the psychiatric area, I did not feel well equipped to care for those with PDD, particularly when they presented with a co-occurring mental illness. When a local Canadian funder, the Collaborative Research Grant Initiative (CRGI) issued a call for projects addressing the complex needs of those with PDD, I reached out to two agencies who serve this population, Calgary Alternative Support Services (CASS) and Progressive Alternatives Society (PASC). Working together, and with the goal of improving practice, we created a project where we could offer a mental health promotion activity to clients and then evaluate the effectiveness of our intervention. The yearlong project was implemented throughout 2012.

We chose to frame our project from an action research design because we wanted to learn more about both the topic area and the research process. Practitioners at the agencies wanted to be involved in research, but their high caseloads and hectic schedules left little time for activities not directly related to helping clients. Thus, an action research design, with its emphasis on implementing and then evaluating a client intervention was an excellent fit.

One ongoing priority we attended to throughout our project was to situate our research in relation to existing publications. From the design through to the dissemination stages of our work, we consistently turned to the literature for guidance. We made a point of incorporating seminal works by established authors in the field as well as any recent work. Our reading led us to understand that a high prevalence of mental illness existed in the PDD population and that a gap in services for this population is a national as well as an international concern. Further, we learned that working conditions for caregivers are problematic. These insights supported our contention that our project was significant and that reporting our findings would contribute new ideas.

Another ongoing priority we attended to throughout our project was to ensure that any research involvement with our vulnerable participants was consensual, respectful and ethical. We made certain clients' capacity for informed consent was assessed and obtained during all stages of the project and all participants were given the opportunity to discontinue their involvement at any time. We obtained approval from my employing university's ethics board and we reviewed relevant policies on research ethics. In Canada, a key policy is the Tri Council Policy Statement (TCP 2, 2010), which states:

“Respect for Persons implies that those who lack the capacity to decide for themselves should nevertheless have the opportunity to participate in research that may be of benefit to themselves or others. Authorized third parties acting on behalf of these individuals decide whether participation would be appropriate. For the purposes of this Policy, the term “authorized third party” (also known as “authorized third party decision makers”) refers to any person with the necessary legal authority to make decisions on behalf of an individual who lacks the capacity to consent to participate or to continue to participate in a particular research project. These decisions involve considerations of Concern for Welfare and Justice” (p.27).

Incorporating this key policy into our project, we included ‘authorized third party decision makers’ in our consent process. Although specific policies will differ among jurisdictions, researchers working with vulnerable groups must always seek out and then incorporate the ethical review regulations specific to their area. For example, in the United States, Katherine McDonald offers important guidance to action researchers working with the developmentally disabled (McDonald & Keys, 2008; McDonald, Keys & Henry, 2008; McDonald, 2012; McDonald, Kidney & Patka 2013).

We implemented our mental health intervention, which consisted of twelve monthly health promotion meetings with six clients (diagnosed with PDD and co-occurring mental illness) and a team of individuals who they chose to support them. Then, we evaluated our intervention by interviewing these clients and their team members. The interviewers were not associated with the agencies serving the participants. Thirteen interviews were transcribed and analyzed for themes. Overall, our participants did find the intervention was helpful. But, we were prepared for the possibility that our intervention might not be as effective as we imagined. We reasoned that an action research design would give us the flexibility to critically reflect on our work, find value in what worked as well as what did not and if necessary, go on to try other approaches.

Research Practicalities

Our research group included busy practitioners from the disciplines of nursing, spiritual care, social work, psychology and education. Our group shared a common commitment to advocating for persons with developmental disabilities and it was this commitment that sustained us through a series of challenges. These challenges, mainly stemming from regulatory requirements, are discussed below.

Challenges

From Proposal to Implementation and Dissemination – Dealing with Delays

In line with a worldwide recession, precarious CASS and PASC funding left agency employees and clients feeling uncertain whether contracts for services, programs and even staff jobs would be renewed. From proposal to implementation and dissemination, we faced delays. In particular, attendance at face to face research planning sessions where researchers came from two agencies and two universities posed a challenge. When assessing priorities, overwhelmed agency staff often had to re-schedule our planning sessions to provide crisis intervention for clients. Assigning research project tasks such as scheduling/re-scheduling meetings, record keeping and coordinating client interventions, to one member of the group, in our case, the Primary Investigator (PI), helped our project progress. Also, working online whenever possible was also helpful.

Another delay occurred with our research funding. Our research proposal, initially submitted in 2010, was not immediately selected by the CRGI funders. It was not until later the following year, in 2011, when additional funds became available, that we were invited to re-submit our proposal. Thus, two years after its inception, our proposal was accepted, allowing us to begin implementing our intervention in January 2012. By this time, all but two of the original eight member research team had left the agencies and a new research group needed to form. However, as we reflected on our project, we considered the impact staff turnover had on our research process. In turn, these reflections opened our thinking to the impact staff turnover has on clients.

Respectful Recruitment and Retention-Overcoming Disinterest and Attrition

Throughout our recruitment and retention processes, we grounded our project in an abiding respect for our participants and we were careful to adhere to jurisdictional policies governing research with vulnerable populations. Our ethics approval board and our funding requirements all emphasized that our participants must understand the research project and feel free to discontinue their involvement at any time. But, these requirements also had a negative influence on our ability to recruit, retain and overcome disinterest and attrition in our project.

For example, our consent form was two pages long. This was in accordance with university ethical approval board requirements. A series of explanatory points had to be included.

Despite using simple language and having agency staff or family members explain the forms, the experience of obtaining informed consent was confusing for clients. At the beginning of

the project, we invited and hoped to include ten participants. But, only six consented to the intervention, only five attended consistently and only two consented to tape recorded interviews.

Similarly, in accordance with funding requirements, our inclusion criteria for our PDD participants stipulated that they present with accompanying complex needs, specifically a mental health concern. Our exclusion criteria stipulated that clients in crisis would not be included. Many agency clients with complex needs (our target population) lived reclusive lifestyles, were reluctant to engage in new activities and had consistently withdrawn from previous programs. Ameliorating our responsibility to both sustain client participation in an activity we believed was helpful and to respect clients' decisions to discontinue was particularly difficult.

In both these instances, we overcame these challenges by including participants' staff and their family members in the project. Staff transported participants to intervention meetings, families hosted meetings in their homes and these caregivers were more comfortable than clients when it came to sharing their views about the project in tape recorded interviews.

Research Design

As we crafted a research design for our project, we first established that we would approach our work together and with our participants from a strengths based world view. That is, rather

than focusing on disabilities and deficits, we were more interested in abilities, clients' strengths and approaches that could and would work.

Next, we reviewed established definitions and explanations of action research methodology. We consulted general research texts, action research texts, journals devoted to action research and publications addressing action research with PDD individuals. Through this review, we were introduced to seminal authors, and we acquired their original publications (primary sources).

Defining Action Research

We developed a definition of action research that worked for our project. In our view, action research is a reflective, spiral process where practitioners use research techniques to examine their own practice carefully, systematically and with the intention of applying their findings directly to their own and others' every day practice. Kemmis and McTaggart (1988) offered the seminal explanation that action research is deliberate, solution-oriented investigation that is group or personally owned and conducted. It is characterized by spiraling cycles of problem identification, systematic data collection, reflection, analysis, data-driven action taken, and, finally, problem redefinition. The linking of the terms "action" and "research," first coined in the 1940's by social psychologist Kurt Lewin, highlight the essential features of this method: trying out ideas in practice as a means of increasing knowledge about or improving practice.

Kemmis and McTaggart (1990) also suggested that the participatory nature of action research, where researchers collaborate with participants in order to understand and improve events, can reduce the distance between researchers and participants and the “. . . problems they intend to solve, or the lived experience they intend to interpret” (p. 28). Rather than being ‘researched on,’ in action research, service users can be included appreciably more than in traditional research (Koshy, Koshy & Waterman, 2011). Finally, in our definition, we incorporated educator Steven Corey’s (1949) emphasis on how the change action research can initiate in everyday practice is more important than the quantitative goal of generalizing findings to a broader audience. Developing a definition of action research that worked for our project helped us sort through the plethora of information available on this methodology and gave us the direction we needed to move forward.

Implementing the Project

Knowing our goal was to improve practice and that services were not adequate for PDD clients with mental illness, our research question emerged as we imagined what we could do better. Simply hospitalizing clients once a crisis occurred was not working. Our research posed the question: What can we do better to prepare PDD clients to anticipate and prevent a psychiatric mental health crisis before hospitalization occurs? Our objective was to implement and evaluate a mental health promotion intervention (monthly meetings with clients and those who cared about and for them) that could potentially prevent unnecessary hospitalization. Findings not only indicated that our intervention was helpful, but also that constant staff turnover was exacerbating clients’ mental illnesses. We also discovered how paying staff only for face to face time with clients left them no opportunities for professional

development and networking. By disseminating our findings in reports, conferences and refereed journal articles we may have extended the influence of our project beyond just our own locale.

A Strengths Based Worldview – What Does That Look Like?

Throughout our project, we reflected on our strengths based worldview. A philosophical orientation emphasizing what worked, what was going well and what we could do to celebrate success guided our thinking. But how could we translate this thinking into our connections with participants? In the following section we share strategies that helped us communicate our worldview into action.

First. Establish Time for Client Concerns

Our research design afforded us the opportunity and the privilege of spending considerable time communicating with persons with developmental disabilities, their staff and their family members. Our health promotion intervention meetings were held in coffee shops, agency rooms and private homes. On a personal level, our engagement with our participants was critically important. Co-occurring PDD and mental illness can leave some individuals feeling discouraged when they are unable to understand lengthy explanations. Everyday literacy tasks such as reading notices, financial statements, bills, and forms that must be filled out can be very frustrating. Solutions to problems with contacting legal aid or food insecurity services such as a community kitchen can seem overwhelming. Knowing these client concerns, the intervention meetings established time to address them. For example, one participant living in

a subsidized apartment set aside notices he received from his landlord and brought these to his meetings.

Second. Intentionally Attend to Our Own and Our Participants Nonverbal Cues

We found that few elements of communication were as important as non verbal cues when working with our participants. In one instance, when a researcher less familiar with the field inadvertently used words that were difficult to understand, a participant seemed comfortable enough to roll her eyes and sigh. When the researcher responded to this with laughter at the mistake, the participant also laughed. But, in another instance, when a family member frowned while describing a concern, our participant clearly showed her feelings of hurt and belittlement by lowering her head, drawing her knees up and sinking into her seat. We did not feel the content of the message was as harmful as the non verbal expressions of disappointment that seemed to accompany it. Simple attending behaviours of smiling, leaning forward, affirmative head nodding and allowing sufficient time for clients to respond served us well in engaging our participants.

Third. Articulate and Enjoy Achievements

Following through on our commitment to approach interactions with participants from a strengths based worldview, the experience of articulating and enjoying achievements took centre stage in our intervention meetings. Problematic behaviour was acknowledged, but

researchers promptly shifted the focus away from admonishing the client and toward problem solving strategies. We strategically brought up past achievements and examples of what clients had done well. In one instance, a participant's goal of laundering his clothes was not achieved. When a family member began iterating other issues related to laundry, researchers commented that the goal was ongoing and moved the discussion to how he had accomplished additional exercises at the gym. The participant was invited to explain the exercise and what was involved. Researchers made sure that more time was spent articulating and enjoying the achievements than on goals not yet accomplished.

Some staff and family members found this modelling helpful while others did not. A sibling of one participant privately expressed frustration to researchers that the meetings "weren't changing anything." However when encouraged to view the meetings through the eyes of his sibling, he indicated an openness to the approach. In conjunction with ensuring time was available for client concerns and remaining mindful of non verbal cues; we believe articulating and enjoying achievements were key communication strategies for engaging participants. We hoped the intervention meetings were safe, pleasant times where participants looked forward to enjoying what they had done well with people in their lives who cared about them.

Action Research with Persons with Developmental Disabilities: Practical Lessons

Learned

Action research is not for everyone. As the preceding sections have illustrated, the realities of practice, especially practice with vulnerable clients, can leave little time for formalizing a process of implementing and then evaluating an intervention. Practitioners in all areas of health care are likely to have no shortage of problems in practice that are in immediate need of research attention. Any yet, carving out time to seek funding, review literature, write proposal(s) for review by rigorous ethics boards and disseminate findings, in addition to framing out a workable project design can seem daunting. The following practical suggestions represent lessons learned during our project:

- Before beginning any research project with vulnerable clients, identify the approvals that will be needed in your jurisdiction. All research in health care requires proposal submissions to agencies employing the researcher and/or providing services to participants. Proposal submissions to agency or academic ethics boards are also routine. When working with vulnerable clients, further submissions may be required. Carefully review policy documents, such as the Tri Council Policy Statement (TCP2, 2010) in Canada for specific direction. Include excerpts from these policies to strengthen the proposals.
- Work with like minded research collaborators. Action research is often implemented by multidisciplinary, multiagency teams. Teams may form in response to opportunities provided by employers or funders and individuals may not know one another. It's important to take time initially to establish common beliefs and come to an agreement about the philosophical orientation or worldview that will drive the project.
- Expect delays. Issues such as precarious funding, overloaded work schedules and staff turnover are expected in healthcare. Expect and prepare for them in research. When

the primary investigator assumes responsibility for record keeping, scheduling and delineating tasks, it becomes easier to sustain the project when members leave the team and new researchers come on board.

- Anticipate and plan to address challenges recruiting and retaining participants. Clients who are members of vulnerable groups such as those with PDD or PDD and co-occurring mental illness can seem difficult to engage. Establishing trust takes time. Designing the project to include participants' staff, family members and friends can help. Attend to non verbal as well as verbal communication.
- Researcher –participant contact time can be fun. Too often researchers are preoccupied with project issues that are not relevant to clients during their time together. For PDD clients, time with a friendly and attentive researcher can be meaningful. Certainly any presenting crisis must be addressed by notifying appropriate staff. But, in the role of researcher, practitioners are in a unique position to genuinely enjoy and appreciate clients in new ways. Find out what participants' interests are. If both of you are interested in scrapbooking, consider ways to scrapbook together while collecting data. If both of you are interested in hockey, talk about favourite teams and players when opening research discussions and closing interactions.
- Celebrate setbacks. Interventions implemented to solve practice problems may not work as well as researchers hope they will. Student researchers bound by academic timelines and practitioner researchers bound by employer or funder deadlines can feel immense pressure to have projects succeed. It is important to note that success in action research is not just about what went well. Action research is a spiral process where problems are identified and interventions are implemented and evaluated.

Throughout the process, researchers reflect critically and deeply on their actions.

Without setbacks, reflections would simply be superficial. The importance of celebrating setbacks should not be underestimated.

Conclusions – Action Research Supporting the Developmentally Disabled and Their Caregivers

Our project illustrated a yearlong action research project where a multidisciplinary multiagency team of researchers implemented and evaluated a health promotion intervention with persons with developmental disabilities. We situated our work in relation to existing literature and we were careful to adhere to ethical guidelines in our jurisdiction. At the beginning of our work together, our team agreed we would approach the project from a strengths based worldview. We faced challenges such as delays, disinterest and attrition. All but two of our original research team members left the agencies and we recruited fewer participants than we hoped. Including participants staff and family members helped sustain our project.

Following through with our commitment to a strengths based worldview, we believed three strategies were helpful during our communication with participants. First, we ensured time was available for clients to express their concerns. Second, we intentionally attended to our own and our participants' non verbal cues. Third, we emphasized articulating and enjoying achievements. A key practical lesson that resonated with us when we closed our project was

the importance of expecting and even celebrating setbacks. Action research calls researchers to reflect deeply and critically on their actions, and setbacks nourish critical reflection.

Exercises and Questions

1. This project described a health promotion intervention that provided an alternative to responding to PDD clients mainly when they experienced a mental health crisis. In your field or workplace, are there activities you could engage in that might prevent problems before they become a crisis? How could an action research project explore these activities?
2. Jurisdictional requirements related to ethical treatment of vulnerable populations can require researchers to include a series of points on consent forms. This project used a lengthy consent form and participants found it confusing. What accommodations could be made to conventional consent forms to suit the needs of developmentally disabled people?
3. Findings from action research projects are not intended to be generalized. And yet, findings can yield important practice knowledge. How can researchers 'defend' the trustworthiness and authenticity of their action research findings?
4. Sample size for this project included only six participants. Each participant included a further group of staff and family members, thus enlarging the sample size nominally. However, the sample was small. What role do you think sample size plays in action research? What influence does sustained contact, such as meeting monthly for a year have on making sampling decisions in action research?

5. This action research implemented and evaluated an intervention. Action research can serve as a beginning or starting point for researchers. Certainly the methodology extends well beyond the relatively simple process of intervening and evaluating. How could a small action research project serve as a starting point for a research project you are interested in? What other action research approaches could you incorporate to extend your project (for example, participatory action research)?

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