

# “NOTHING ABOUT US WITHOUT US”: THE IDEALS AND REALITIES OF PARTICIPATORY ACTION RESEARCH WITH PEOPLE WITH AN INTELLECTUAL DISABILITY

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*Abstract:* Undertaking participatory research with people with intellectual disabilities is becoming a much-discussed issue. Some researchers and self-advocates argue strongly that only participatory research can produce useful, honest research which assists people with intellectual disabilities to attain their rights. Others question whether such research is possible or indeed desirable. This paper describes a three-year action research project which sought to carry out participatory research on the sensitive issue of sexuality. The research grew partly from concerns of people with intellectual disabilities about this issue and involved them in its management and implementation as well as in developing workshops and publications arising from the research. The research process was consciously self reflective and raised questions about participatory research, representation and difference, and the dialectical relationship between individual life histories and institutional change. This paper discusses these issues and the contribution they make to current methodological debates.

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## Introduction

This paper is concerned with ‘participatory research’ a term variously referred to in the literature as Action Research or Participatory Action Research (Grundy & Kemmis, 1981; Kaplan & Alsup, 1995; McTaggart, 1997). The paper focuses on working with people with an intellectual disability and raises questions about the kinds of research

which seek to include people that are ‘subject to the research’ and to promote structural change from its results.

The paper is based on a three-year action research project, which involved working with people with an intellectual disability on issues affecting their sexuality and relationships. In the paper we explore the following questions: What is participatory research? Is it

possible to be inclusive all of the time? With all of the people? Who decides if research is participatory or not? How far can the ideals of participatory research be translated into practice when working with people with an intellectual disability? What strategies can we use to develop more participation in participatory research? In particular we look at the ideal which is established in the literature about forms of participatory research, at some of the issues that arose for us in practice and at how we developed strategies to manage these. At the end of the paper we come back to these questions.

The paper is organised around a dialogue between the chief investigators and a consumer advocate who was one of the members of the reference group that has worked with us on the project from its inception. All of the advocates on the project reference group were involved in shaping the research and were vocal in expressing their rights and their responsibilities throughout. As the project was drawing to a close we were all involved in reflecting on processes and outcomes. We invited Ria to summarise her experiences and that of other advocates and it is this text that we draw on in our dialogue. In this context she acts as an interlocutor, questioning the ideals of participatory research and their translation into practice. McTaggart has pointed out that the idea of participation is problematic ‘...in situations where people with different power, status,

influence, and facility with language come together to work on a thematic concern...’ (1997, p. 27). In this instance, the inclusion of the voice of the self-advocate in this paper raises questions about who participates in the processes of writing and publishing, a pursuit requiring particular and specialised skills.

### **What is participatory research?**

The literature on Participatory, Action and/or Participatory Action Research (PAR) is extensive and a review of this literature is not possible or necessary here. In this paper we focus only on the issues which seemed particularly salient in our research. The analysis touches on a continuing struggle over three years to find some clear meanings for participatory research from a literature which provided definitions ranging from the modest to the grandiose and often unattainable.

Falling into the modest category Rapoport describes action research as:

A type of applied social research differing from other varieties in the immediacy of the researcher’s involvement in the action process...[It] aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration with a mutually acceptable ethical framework (1970, in Foster, 1972, p. 532).

Such a definition can be used to describe almost any kind of social research that has an applied focus. While it may be reassuring to researchers who want to believe they are undertaking participatory research we did not find it a useful guide to practice and it left us uncomfortable about the undefined roles of those involved in the 'joint collaboration.'

Kaplan and Alsup are much more prescriptive in identifying the core components of Participatory Action Research as including: ...active and democratic community participation, non-traditional power relations, use of critical theory, emergent design, praxis, a focus on empowerment, and science as a tool for change (1995, p. 41).

In this common definition community members are involved from start to finish, from defining the problem to disseminating results. Kaplan and Alsup echo a strong theme in the literature (see Hall, 1979 for example) in seeing this approach as particularly suited to research with minority groups. As we discuss later in the paper this definition is somewhat problematic when working with people with an intellectual disability. While its rhetoric provides an in-principle guide to researchers, its failure to assist in describing how such research should be undertaken sometimes increased our uncertainty about our methodology and led to feelings of dissatisfaction and discomfort with our approach.

The last issue we wish to note here involves defining what participation actually entails. McTaggart, for example, differentiates between involvement and participation using definitions from Standard English dictionaries; to 'involve' meaning, amongst other things, to entangle or implicate and to participate meaning to have a share or take part. A modest claim that takes on a much more ambitious meaning when he goes on to declare that 'authentic' participation involves 'sharing in the way research is conceptualized, practiced, and brought to bear on the life-world' (1997, p. 28). The definition offered by Rajesh Tandon is similar to this latter definition identifying the determinants of 'authentic' participation in research as 'people's role in setting the agenda of the inquiry; people's participation in the data collection and analysis; and people's control over the use of outcomes and the whole process (1988, p. 13). These definitions offered some guides to action but their assumption that participation is somehow the same for all participants and is static rather than a dynamic state did not seem to be consistent with our research experience.

Sandra Hollingsworth has described collaboration as '...a complex and unpredictable swirl of power relations, and of constantly changing selves' (1997, p. 56). This definition seemed to reflect most accurately the experience of those involved in our research. In the following section we begin our dialogue, examining some of these

complex relations, the ideals of participatory research and how these ideals were worked through in our day-to-day research practices. The voice of one of the self-advocates on this project acts as a sort of ‘reality check’ for the other authors balancing theory, practice and institutional constraints in the messy process of doing research.

***The Living Safer Sexual Lives Project:  
An overview***

The Living Safer Sexual Lives Project consisted of three years of action research, which was carried out in two stages. In the first stage twenty-five people contributed life stories over extended periods of time to researchers with experience in qualitative research and in working with people with intellectual disabilities. The stories were taped, written in the person’s own words and taken back to them for approval. Two forms of each story were written, a short plain English version and an extended one. In the second stage of the project workshops for people with intellectual disabilities, families and service providers were developed, trialed and evaluated. Policy documents were prepared and sent to the relevant government department documenting the findings from the project and recommending changes to policies and practices. Educational resources including plain language stories and videotapes were made. As well, as a direct result of the research findings, a working group was established

to look at ways of lobbying for better social opportunities for people with intellectual disabilities.

The project was informed by a number of different principles, which were formulated by the researchers in the first instance but which were later revised and supplemented during the project. We began with the premise that the project should be based on the stated needs of people with intellectual disabilities. We were also concerned that action should accompany the research and be directed at changing unjust or oppressive policies, practices and social structures and at increasing the knowledge about sexuality of people with intellectual disabilities. Fostering partnerships between the academic institution and community based organisations working with people with intellectual disabilities was a priority. We were committed to the view that the sexual experiences and relationships of people with intellectual disabilities should be seen within the context of their lives, and that the stories contributed to the project should be in the participants’ own words. As a basic principle, the participation of people with intellectual disabilities was seen as integral to the success of the project. In recognition of the valuable contribution they would make to the research we made provision in the budget for payment of all unpaid workers and, because of the sensitive nature of the research, funds were allocated for counselling and support if needed.

## **Beginning the research**

### ***The Ideal***

The participatory research literature recommends that the research issues are generated out of the lived experience of a group or individual, the research should be led by them and should address their concerns. The researchers should be accountable to and preferably employed by this group (Shakespeare, 1996; Fals Borda, 2000).

### ***The Reality***

This research did not come from a group of people with intellectual disabilities. It originated with researchers who then consulted with them and with community representatives to check its relevance and to assist in the subsequent shaping of a research submission for funding. The research was conceptualised and the submission was written by the researchers.

It would have been extremely difficult for people with intellectual disabilities to have initiated this research for several reasons. First, sexuality and relationships are seen as problematic both by people with intellectual disabilities and those around them. Our research and other studies (Johnson, 1998; McCarthy, 1999; McCarthy, 2000) have shown that people with intellectual disabilities have learnt that these issues are not something that they talk about and decisions about their sexual lives are invariably made by

families and/or carers. These prohibitions and inhibitions would have prevented people with intellectual disabilities from naming sexuality as an object for research. However, when asked about its importance, their representatives affirmed that it was an area in which research was very much needed.

Second, people with intellectual disabilities did not have access to the information about where to go to actually get research assistance with an issue like sexuality even if they could have generated the research. In this instance the organisation which developed the research (in consultation with people with an intellectual disability) was one which was concerned in a general sense with community health issues and lay outside the formal disability areas. We believe that this auspice had real advantages for the development of the project and the work that was done with people with intellectual disabilities during the research. Because the knowledge base was situated outside of the disability area the researchers tended to focus on issues around sexuality and relationships and the impact of societal structures on people's lives rather than on the disability itself. Working within this framework meant that the experiences of other groups in the community could be used to inform the research findings.

Finally, and despite the advantages mentioned above, the funding body, which was normally sympathetic to

inclusive practices, expressed reservations about the likely success of this project. They did not believe in the first instance that we could work with people with an intellectual disability to gather stories and perhaps, mirroring the wider community, assumed that they did not have stories to tell. We were given a small grant to undertake a feasibility study in order to demonstrate that the research was possible. During this phase the methodology was tested and partnerships with advocate organizations and other interested groups were developed. The results of the feasibility study convinced the funding body that the project had widespread community support and that people with an intellectual disability were capable of participating in the research and, more importantly, had powerful and important stories to contribute to the field of knowledge on human sexuality.

### **Strategies**

Ria, our consumer advocate points to the widespread exclusion of the voices of people with an intellectual disability in research on sexuality stating:

I believe the Living Safer Sexual Lives project was absolutely groundbreaking. Often, people with an intellectual disability are seen as asexual. Either that, or our sexuality is seen as a problem; one that workers and families need to deal

with. Our own experiences, good and bad, our own voices –they’re just not heard. Living Safer Sexual Lives changed that. People were given a chance to tell their own stories – and those stories are now being used to change people’s attitudes towards relationships, sex and people with intellectual disabilities. I’m glad I was part of the process (Consumer Advocate, 2000).

People with an intellectual disability informed the initiation of the project because one of the researchers had become aware of difficulties and concerns around sexuality through her previous research with people with intellectual disabilities. These experiences made her committed to carrying out research which would include participants. All of the researchers began from a position in which they were concerned to hear people’s own stories, to avoid prevailing stereotypes and to take action on the basis of what people with intellectual disabilities told them. These concerns were generated by their research experiences with a range of marginalised groups and in some senses this ‘outsider’ perspective was advantageous because of the negative discourses surrounding people with intellectual disabilities. Consultation with representatives from advocacy organisations was the first step taken in the research and the feedback from this was used to inform the research submission.

## Managing the research

### *The Ideal*

The literature on participatory research strongly recommends that people who are 'subject to it' should manage and control its processes (Barton, 1998; Kitchen, 2000)

### *The Reality*

A reference group was established for the project. Representatives from self-advocacy and rights organisations and service provider groups were included. Numbers of participants changed over time for all of these groups as people dropped out. But this was more apparent for self-advocates who were in the minority to start with. Some of the original members wanted to contribute their stories and, for ethical reasons, this excluded them from being on the reference group. As well, some self-advocates only wanted to be involved in specific forms of implementation and were not interested in the research itself. Further, the research topic was embarrassing for some self-advocates and they needed extra support and encouragement to stay with the project. Ria expressed her concerns about the numbers of self-advocates on the reference group when she stated:

I think more people with an intellectual disability should have been involved in the project. Self-advocates always made up a minority of the Reference Group -

and the number of self-advocates dropped during the time of the project. Several people without disabilities left during this time; other people without disabilities joined it. When self-advocates left the Reference Group, though, or were unable to get to meetings - they were not replaced. There were one or two self-advocates at some meetings – not enough (Consumer Advocate, 2000).

In fairness however it would have to be said that at least two service provider organisations failed to be regularly represented on the reference group. In terms of consistency of representation people with intellectual disabilities were among the 'long stayers.'

Self-advocates did not chair the reference group although efforts were made to establish a rotating chairperson position. It should be said that people without an intellectual disability also resisted acting as Chair. Coming to decisions was invariably slow and complex and it was often difficult to keep to the agenda. For example over the three years of the project, the reference group sometimes became involved in activities and issues only peripherally concerned with the research, i.e. supporting a radio program for people with intellectual disabilities, and detailed discussion of rights issues. Sometimes people needed a lot of time to think and talk about an issue because they had not been

involved in research before and sometimes the explanations about research methodology took a lot of time to develop in plain English. Sometimes the chairperson prematurely ended discussions in order to move on to the next issue. As Ria said, ‘Working inclusively has some definite advantages - but it takes longer for your work to get to an end result’ (e-mail communication, 2000).

The researchers were responsible for the ongoing management of the project and it could be inferred from this that unequal power relations between researchers and self-advocates were reproduced in this process. However, the researchers’ practices were often challenged by self-advocates in reference group meetings. Ria acknowledged the contribution of self-advocates when she stated:

I think self - advocates did have an impact on the project. We kept the researchers honest. We kept them grounded in the experiences of people with an intellectual disability. We raised issues that might not otherwise have been raised, and made people consider things that might otherwise have been missed. We were more than just tokens (e-mail communication, 2000).

### ***Strategies***

People with disabilities are often exploited both as research subjects,

and as members of committees and Advisory Groups. We’re expected to share our expertise - but we’re not properly paid for our time and effort. The LSSL project didn’t make that mistake. They built consumer (and unpaid worker) participation into their budget from the beginning. The LSSL researchers genuinely attempted to involve people with an intellectual disability in the project. This is, unfortunately, still quite rare. I strongly believe that there should be “nothing about us, without us”. People with disabilities have a real expertise to share – an expertise that is often under-utilised, even when we do get a seat at the table. Too much jargon, difficult to understand meeting procedures, inaccessible minutes, and power imbalances - they make it hard for people with disabilities to contribute. In the LSSL project these barriers were kept to a minimum (Ria, e-mail communication, 2000).

In an effort to value the work of all unpaid workers (not only people with an intellectual disability) they were paid for their time on the reference group. The minutes of meetings were constantly being revised at the insistence of self-advocates in order to make the language and format accessible to people with an intellectual disability. Agendas and other papers were all written in plain language and large print format to increase their accessibility.

The contribution made by self-advocates on the reference group varied over time and with the stages of the research. Among the contributions were discussions of ethics, the development of strategies to safeguard the rights of contributors, assistance in finding ways to talk about sensitive issues around sexuality, design of advertising material, the shaping of the discussion starters and questions. Editing and developing resources were also part of the work of all members of the reference group. One woman's insistence on the importance of people knowing their legal rights which she reiterated throughout the project led to the inclusion of a pamphlet on legal rights (which she found) into the workshops.

Including people from a number of different organisations in the research process led to an increasing ownership of findings by members of the project. Workshops were run with organisations represented on the reference group, one organisation took up policy issues, organised a forum and a policy discussion paper and led the movement towards changing policies and practices. One organisation, which works in women's health, has been an active partner in developing workshops for women with learning difficulties. A self-advocate took responsibility for organising a working party to explore ways of increasing the participation of people with intellectual disabilities in social activities.

## Collecting the stories

### *The Ideal*

Those who are 'subject' to the research or participate in it should be included in its design, management and implementation (Clough & Barton, 1998).

### *The Reality*

Most of the project work was done by non-disabled researchers. We made suggestions through the Advisory Group - but the researchers put the ideas together and did most of the work. There may have been other things self-advocates could have done. We could have been co-researchers, rather than advisers. We could have been trained as interviewers, or co-interviewers and so on. [But] ...if (say) people with an intellectual disability were going to do the interviews the project may have stayed unfunded, and unapproved (consumer advocate, 2000).

People who contributed their stories were not present in the other parts of the research for confidentiality and privacy reasons. Further, people with intellectual disabilities were not co-researchers in collecting the stories as: the conversations demanded high levels of skill in interviewing because of the sensitivity of the issues. There were also confidentiality problems because so many people from the intellectual disability community knew each other and we were very anxious about ensuring the privacy of story contributors.

Finally neither the university ethics committee nor the funding body would have agreed to this process.

### ***Strategies***

While institutional and ethical constraints prevented full participation in the project by interviewees and prevented the involvement of self advocates in this process the methodology used did work towards reciprocity. The use of ‘long conversations’ required establishing a trusting relationship with participants and in this process researchers were self-disclosing about their own sexuality and experiences.

### **Whose stories are they?**

#### ***The Ideal***

The subject matter should be owned by those who contribute it and used by them to change social structures (Shakespeare, 1996; Fals Borda, 2000).

#### ***The Reality***

“Whose story is it?” The researchers, and those of us who helped edit the stories, made lots of decisions – what would be included in the written stories? What would be left out? How much would we fix people’s grammar? Would we add words to make the stories clearer? How would we change the stories to make sure people couldn’t be identified? What name would people be given? Where would we say they lived and worked? And so on.

The people who told us their stories could have been more involved in shaping the written versions. Some people may not have wanted that – but people should have been given the choice I think (Ria, e-mail communication, 2000).

The stories were central to the research. We were concerned that the integrity of the stories be maintained during the process of transcribing, editing and re-writing them. However there will always be problems with representation because of the differences between verbal and written communication and the need to make stories accessible to various audiences. We categorise them, choose titles from the text, shorten them etc. and this inevitably changes them. Ivor Goodson (in Hollingworth, 1997, p. 205) has referred to what he calls the ‘third voice’ which is that constructed by the interviewer and interviewee in interactive situations. No voice is truly authentic. The stories however are authentic in the sense that both the story contributors and other people with an intellectual disability recognised themselves in the stories.

The use of pseudonyms, a requirement for university ethics approval, became an issue when some participants wanted to use their real names. For example Gina, one of the storytellers expressed pride in being an actor and a survivor of sexual abuse and wanted others to know this story was about her. Here we are to a certain extent constrained by

ethical concerns that are imposed from above as well as by our own concerns about protecting the integrity of people's lives in a community where a lot of people either know each other or know of each other. This is a dilemma we face no matter who we do the research with, although the level of concern might be different because of the particular characteristics of this population.

The stories were never jointly owned. Contributors had a choice about adding to or changing their story or withdrawing it. However there was never any intention that we would not have final say over what was to be done with them.

### ***Strategies***

In an effort to maintain the integrity of the stories the following strategies were used:

The stories were read and edited by the reference group including representatives with intellectual disabilities. A series of workshops over three months was run where the stories were read and commented on by reference group members.

Explicit principles were established to safeguard the use of the stories to ensure that they were treated with respect. For example the working group which developed the workshops developed an explicit set of principles for the use of the stories.

These included the need to make the stories central to the workshop process, the need to treat the stories holistically rather than in a fragmented fashion and the need by facilitators to stress the sensitivity of the stories to workshop participants.

The reference group was collectively involved in deciding what should be done with each story. They assisted in drawing out themes for each story and in exploring how each one could be used in workshops or in other resources.

### **From research to practice**

More self-advocates definitely needed to be involved in the Resource and Workshop working groups. Those working groups were a chance for people with an intellectual disability to do something concrete - more so than the Advisory Group meetings. There were only 3 of us involved, though - and we were all trying to contribute to both working groups. Impossible, when they met simultaneously during Advisory Group meetings. And difficult anyway, it was just too much work. In the end the workshops were mostly developed without us (Ria, e-mail communication, 2000).

### ***The Ideal***

Action and research should go hand in hand and be shaped and implemented by the people who are the subjects of

the research (Aldor & Sandor, 1990; Barnes, 1996).

### ***The Reality***

Originally the project was conceptualised as leading to a peer education project. The focus was to be on working with people with an intellectual disability to assist them in leading safer sexual lives. However the stories revealed that the main difficulty experienced by contributors lay with the people around them and social barriers and discrimination. Consequently a greater focus was placed on workshops with service providers and with families. The focus moved from leading safer sexual lives to leading a sexual life! People with intellectual disabilities are not currently involved in running workshops though there have been suggestions that peer education may grow out of the workshops that have been developed. However, as we mentioned earlier people with an intellectual disability have been involved in editing stories. As well, they have been involved in dramatising the stories on video and in planning and evaluating the workshop activities, which have been developed.

### ***The Strategies***

Although people with intellectual disabilities have not been involved in running the workshops the stories have led their development. As well, people on the reference group have chaired working groups and have been paid

workers developing resources out of the project.

Workshops for service providers have started from the experiences of people with an intellectual disability and this means that it is their agenda/their concerns that set the scene, not the concerns of service providers (which are not always the same thing). Service providers have traditionally been part of the problem not part of the solution, as evidenced in the stories, in that they have often been instrumental in denying people with an intellectual disability the opportunities to live safer and more fulfilling sexual lives.

## **Results of the research**

### ***The Ideal***

The research should lead to changes in social structures of oppression and the removal of disabling barriers (Rahman, 2000).

### ***The Reality***

It is difficult to know what effects the research and the workshops will have in terms of long term change. Workshops for service providers, families and people with an intellectual disability have now been run with more than 300 people in Australia and there is evidence that they have effected change for those who have taken part. One of the clearest messages that have come out of this research, confirming our

own views, is that it is not people with an intellectual disability that need to change ‘...to conform to the social, political and legal structures already in place’ (Rioux and Richler, 1995, p. 377) but the reverse.

Members of the reference group have commented about how much they have learned about sexuality, relationships and the lives of people with intellectual disabilities. In some instances this has been a personal learning experience. For example, one service provider stated after reading a story that “This could have been me” and that listening to the stories had made her realise that she had more in common with people with an intellectual disability than she had differences. A representative from The Community Visitors Program, a voluntary organisation, who is a member of the reference group has described the profound personal effect the project has had on her and others in her organisation and the influence this has had on her practice. In other instances it has led to organisational changes. A representative from the Public Advocate’s Office, who is also a reference group member, organised a public forum at which the research findings were presented and has taken responsibility for the preparation of a discussion paper which has been distributed to the Department of Health and Community Services and the Minister responsible for Disability Services.

The reference group members who have stayed with the project over three years have remained enthusiastic and supportive. They have constantly engaged with the material and have been willing to volunteer for work outside of their paid time for the project.

## Conclusion

Returning to the original questions with which we began this paper, our experience suggests that current conceptions of what may be called participatory research are often too rigid and static to adequately describe the processes involved in it. Consequently answers to the questions will vary with the research focus and the participants. Current views of this research suggest that people with intellectual disabilities know the problem, the goals of the research, how to do it and what should be done with it. There is also an assumption that researchers involved in this kind of research know how to do it from the beginning. In our research project we all learned something new from the process as we progressed, often stumbling along the way.

Doing participatory research on issues around sexuality is always a difficult process given the strong cultural taboos around sexuality and the strong public/private distinction in operation. This is exacerbated by the tendency to infantilise this group and construct them as asexual or not in control, while at the same time they are paradoxically

invested with a ‘dangerous’ sexuality. This brings about a sort of enforced silence on the subject.

The small sample size also hindered truly participatory research because the interviewees were often well known in their community and concerns about maintaining their confidentiality prevented them being members on our reference group. Paradoxically, the narrative approach that we used which elicited detailed stories of people’s lives and was designed to be more inclusive actually left people vulnerable. A survey approach would have retained their anonymity but would not have been able to elicit such rich data.

Finally, this research methodology was new to us and we did make mistakes. With the benefit of hindsight we could have involved the participants in editing their stories and choosing their names. We were lucky in the sense that the project funders allowed us a level of freedom to pursue new ways of working but in the end time-lines and dwindling resources defeated us.

Ria has suggested that there should be “nothing about us, without us” and her comments, although critical at times, suggest that for the most part we achieved levels of participation rarely present in research ‘on’ people with an intellectual disability. However, this acknowledgment leaves no room for complacency.

Rahman (2000, p. 2) uses an African term 'uglolana' which translated means “sharpen each other” - it refers to researchers and participants having a lot to learn from each other. This is particularly apt in the context of our research. It can be applied both to the research process and to what people learn from the research content. And it is in mutual reflection and recognition of our needs for each other’s knowledge and skills that we can work to develop participation in participatory research.

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