

Women Speak

A Participatory Research Project

by Denise Young and Brenda Aries

Récemment, une étude sur les aspects les plus évidents de la vie des femmes atteintes d'un handicap a été conduite avec pour but de donner le contrôle aux femmes qui faisaient l'objet de cette étude. L'auteure examine le succès de la méthode utilisée et elle explique comment les participantes se sont senties en contrôle de soi et des connaissances qu'elles ont partagé.

We know violence against women with disabilities exists. The violence and abuse can occur in very obvious ways, such as overt physical and sexual abuse. Women with disabilities may be further violated by the very systems they depend upon. In more subtle ways, they are labelled as "difficult" consumers, not given information on all available services or denied reasonable access to transportation.

Research on disability has often added to the victimization of persons with disabilities. Again, this has occurred in more and less obvious ways. Probably the most obvious example is the use of scientific methods to support eugenics arguments. This resulted in the incarceration and involuntary sterilization of hundreds of thousands of people with disabilities (Woodill).

Research has been seen as oppressive because it often reinforces on persons with disabilities the notion that the difficulties they face are the result of their *individual* limitations or inadequacies rather than, for example, the limitations or inadequacies of society (Oliver, 1990). The typical approach of science also objectifies persons with disabilities, who usually have no control over the research process or outcome (Woodill). As a result, the experience of disability has been profoundly distorted. Much of the research that has been conducted has been of more benefit to the lives of the researchers than the persons with a disability (Oliver, 1992).

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Some research has been conducted on the issues around violence against persons, and in particular women, with disabilities. Unfortunately, as with research in general, much of this research has been done *to* or *for* rather than *with* women with disabilities. Traditional styles of research, where the researcher has control of the entire research process and the people being researched are treated as little more than a subject pool, can be very disempowering to those individuals.

Participatory action research (PAR)

PAR researchers attempt to break down the distance between the "researcher" and the "researched." In fact, PAR projects are often led by a research team which is composed of some researchers with traditional training and some without traditional training. Each researcher brings her or his knowledge to the process and everyone participates in some way. One of the goals of the research process is not merely to observe reality, but to change reality through the process of observation.

The Independent Living Resource Centre of Calgary (ILRCC) wanted to conduct a research project which looked at violence in the lives of women with disabilities. The ILRCC philosophy focuses on consumer control and choice. Therefore, an Advisory Committee was created which was composed of a variety of women from different backgrounds and interests, including women with and without disabilities. Keeping the Centre's philosophy and the overall goal of consumer empowerment in mind, our Committee generated three major research objectives: to allow women who had been silenced to speak for themselves; to use a method which empowered everyone involved; and for the research to lead to positive social change with respect to violence against women with disabilities.

Meeting our objectives

A combination of women with disabilities and traditionally trained social researchers made a very effective team. The women with disabilities anticipated difficulties which might arise in the research process and offered solutions which were subject to scrutiny from a research perspective. In a process of give and take, the social researchers suggested other options which, in turn, were subject to the same scrutiny. This process of give and take which recognized everyone's expert knowledge, was captured in the following words of one of the research team members.

As a researcher I could bring my training to the process as my contribution to the team. The women with disabilities could bring their expertise in terms of their own experience. Together we learned from each other.

Planning a conference as a research venue

We were interested in the topics of violence and abuse, but we had some concerns about how to approach women to speak on these topics. Some of the dilemmas we faced are probably best described by one of the members of the research team.

The first difficulty was how to locate women who might be interested in taking part in the research project. Mail out surveys could go astray, and in the hands of an abusive partner/caregiver the women might be at higher risk.... Second, if many women were in denial, they would not come forward. Some process to heighten the awareness of women was necessary. Third, transportation would be a difficulty as drivers have often been abusive and might feel threatened when women went to support groups for [women who were] abused or were part of a research study on abuse. Fourth, the use of other agencies to locate women was deemed inappropriate. We did not want the influence of other agencies, whether good or bad, to affect women's participation.

We decided that a conference was the best way to approach our research. The theme of the conference was "Human rights and women at risk." We felt this theme was vague enough that if information about the conference fell into the hands of an abuser we would not be putting women planning to attend the conference at risk. The conference would provide a place for women with disabilities to learn about common issues, how to become involved in other women's groups, and how to develop support networks with each other. Most importantly, it would give the women a chance to speak.

Our next problem was to determine how a conference could be used as a research venue. A research project has to generate some kind of data. Since one of our goals was to provide a place for women to speak, the obvious solution was to record what they had to say and use this as our data. We decided that some of the members of the Advisory Committee

would spend the day writing down what people had to say (which we thought would be less intrusive than tape recorders) while the others acted as facilitators of discussion.

People taking notes of the proceedings was an integral part of the conference. In order to encourage participation, allay fears of the misuse of information, and ensure an ethical and empowering approach to the research process, participants were made aware of the recorders' role and they were assured that they would be consulted on the part of the report related to their discussions prior to the release of the report. Further, if they were uncomfortable at any time, they could ask the recorder to stop writing. This created an environment where people felt they could speak freely on the things which were concerning them. They also knew

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that they had the prerogative of controlling the use of the data after the conference.

Researchers transcribed as much of the conversation as was possible at the conference and later classified this information according to themes. The conference participants then checked the classifications and interpretations for accuracy. While not all of the content is directly related to the usual conceptions of violence, it does provide some valuable insights into the lives of the women who participated.

Emergent themes

Control, or more precisely lack of control, over many facets of the women's

lives was probably the most pervasive theme of the day. Areas of concern included control over life choices, the body, daily activities, money/resources, and services and information.

My parents gave me legal guardianship but they still control me. I'm trying to move out. If I do my mom will move in with me.

They [parents] just assume I don't have a life [so they drop in unexpectedly].

The nurse does not like me too much. She is awful to me. She puts me in a diaper (which is something that she is not supposed to do). I had to sit in it all day.... A man washes me down below and I hate that. I don't want him around me.

Others commented on how a lack of resources prevented them from taking control or making changes.

People who have dealt with me, they know that I am limited. I can't go to authorities over someone's head because my resources are limited, and they know it.

I'm angry! [Government service providers] have this book and they sit there and tell you, "You can have this."... They play the authority and don't give us any information.

Relationships and interactions with others was another common theme. By far, the most discussed relationships involved interactions with parents and siblings. The main concern was family members' attempts to control these women's lives. One woman said that when someone asked her a question, her parents always answered for her. She said that this went on until she was about sixteen years old when she finally said, "I have a tongue. I can talk for myself."

Siblings often felt free to give all kinds of advice and make many choices for these women, but this relationship was not reciprocal. One woman said that her brother was constantly trying to "advise" her on financial matters. She found this ironic because he had been bankrupt twice.

Advice was also offered on daily activities such as what to eat and how to dress. Many women had to fight for the right to make the most basic decisions in their lives, decisions that most adult women take for granted.

My parents didn't want me to marry my present husband. They took me to court to get legal guardianship I won.

I have been struggling with the issue that I respect my sister and her life but she does not do the same for me.

Others described a lack of reciprocity in their relationships with service providers.

If we ever talked to them [the staff] like they talked to us, boy, we would get put in our room and left there.

This has important power/control implications. If relationships are not reciprocal, or perhaps even more important, not seen to be reciprocal, those who feel that they are taking and not giving in the relationship may be disempowered. They may also feel that they are at the mercy of those who are seen to have something to offer.

While disability communities were seen as either supportive or potentially supportive, the broader community was not seen in such a positive light. The most common experiences described at the conference related to feelings of difference, separation, exclusion, and even outright discrimination from the broader community.

There is a lot of discrimination against people. They form ideas just by looking at you.

Out in society, I feel like society's biggest disgrace.

There was much discussion about the relatively poor quality of services available. Many comments were made about a particular residential facility, ranging from concerns about poor service to what could be considered abusive treatment of consumers by the staff.

Frustration was also voiced in regard to provincial government services. One

woman talked about the "treadmill" people encounter when attempting to gain access to government services.

[You ask them], "Can you help me with such and such?" and then they send you to another group and it goes on and you're back at the first [one]—It's horse shit!

Other women talked about the lack of accessibility of workers. A woman said that she could not even get five minutes to speak with her (government) worker. "How do I get my needs met if I can't communicate my needs?"

A few people mentioned transportation services. Poor quality transportation services were seen as a barrier to greater participation in the broader community. One woman talked about sitting on the

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telephone for up to two hours in order to access a local transportation service. Another said: "Taking [a transportation service] is enough to make anyone want to walk."

The types of abuse typically identified in research on violence were not discussed a great deal at the conference (but have since been discussed by the support group formed afterward by conference participants). Most of the examples of abuse recorded relate to maltreatment by service providers. This seems to apply especially to those in a more total "care" situation. One woman described others who lived in the same facility she did being unnecessarily moved by a lifting device (although they could manoeuvre themselves). This eventually resulted in

the person being unable to walk at all. More than one woman talked about not being able to refuse to have a male attendant give them baths.

People expressed or spoke about a variety of emotions during the conference. The dominant emotion was anger. "I'm afraid of my anger and lock it up and then I blow. [I] must find a better way to release my feelings." A number of women spoke of how they felt they had to cover up their emotions.

You need caregivers so badly you don't express your feelings [because] you feel you'll be abandoned.

Women feel that we don't have the right to express how we feel.

I can't say what I really feel [out in society]. People say you can't say that because you don't have feelings.

The attempt to cover up feelings and emotions may be related to the way the women tended to focus on others' feelings before their own. "I think we consider others too much. Gradually you count yourself out."

Human rights were also discussed. These included things such as privacy, access (e.g., to things such as housing and transportation), and independence, particularly independent living.

We have the right to [have] access to whatever is around. How many compromises do people who have to get around differently have to make? If it is open to the public, we are part of the public as well.

Many of the participants identified the need to take action in order to make change.

Be true to yourself, even if it is difficult and you fail. Speak up.

Another thing is to take control of your situation, whatever your disability or need.

Results

The women involved in this project were empowered to continue to take action, both in their personal lives and in the

ongoing work of the project. The women at the conference spoke about it as a starting point. As a result of the conference a support group for women with disabilities has been formed. Presently they meet twice a month. The group has two major purposes: 1) to discuss and act on personal issues and concerns, and 2) to create an opportunity for social activities. Through the support group, many women have made changes in their personal lives in order to gain control. In addition to promoting the personal growth and development of its members, the group has been giving some generic service agencies feedback on how to provide better services for persons with disabilities. The group is presently involved in using interactive theatre as a means of working through some of the issues faced by the members. The theatre work will hopefully lead to the production of a video to educate police on the issues around violence against women with disabilities. We can only hope this action will continue long into the future.

The report titled Proceedings from the Conference "Human Rights and Women at Risk" (Independent Living Resource Centre of Calgary, 1992), contains a more detailed discussion of the project. For more information, write to the ILRCC at Suite 302, 501 - 18th Ave. S. W. Calgary, Alberta T2S 0C7.

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LORINDA PETERSON

November Rain

I wait for the poem to form
like the lump in your tender breast,
benign and afloat.

A clump of words
carries the early morning
roar of wind through roof eaves,
rain in aluminum troughs.

A steady splash of traffic
moves you away from me,
carries you through this city
humming softly, familiar tune
you play again and again
on the car cassette

until you're sure of its rhythm,
anxious to tap out the next refrain,
the steady beat of fingertips
against steering wheel
reminding you of what you already know,

the lump in your breast
benign, and floating
like leaves swept away
in November rain.

Lorinda Peterson's work has been published in The Fiddlehead, Quarry and The New Quarterly. She spends part of the year writing in Bickerton, Nova Scotia, and part of the year doing literacy work in Kingston, Ontario.

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