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Uncovering the Shape of Violence: A Research Methodology Rooted in the Experience of People with Disabilities

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BEGINNING: A HUNCH

Our research agenda at the Roeher Institute is aimed at understanding the social and economic construction of inequality and the conditions for full citizenship and the exercise of human rights. Within this research agenda the study of violence and abuse experienced by people with disabilities provided us with an opportunity to reflect on the way in which research questions are constructed, often unconscious of the importance of a disability perspective. It also provided us with an opportunity to examine the relationships of specific forms of inequality faced by people with disabilities and the forms of violence and abuse this subjects them to.

One consequence of disadvantage is that issues affecting a group of people - issues that should be self-evident -are overlooked or ignored. This is not necessarily a deliberate omission but more likely the result of a failure to be sensitive to those who have traditionally been excluded. When we began this study violence and abuse in general had burgeoned into areas of concern in social policy and government spending and programs in Canada. However, only a very few studies had investigated the incidence of violence and abuse among people with disabilities. And although these studies provided some striking findings about the vulnerability of people with disabilities to abuse and violence, they also raised questions.

The stories we were hearing did not seem to be reflected in the studies we were reading on violence and abuse. And the safeguards and protocols and precautions that we would have expected in situations of high vulnerability were not only non-existent but were not even

identified as needed. It was reminiscent of the silence that surrounded violence against women in the home long after it ought to have been a public issue.

The reasons behind the silence and the indifference to the circumstances of people with disabilities prompted us to undertake a study in this area - a study that was subsequently published as *Harm's Way: The Many Faces of Violence and Abuse against Persons with Disabilities* (Roehrer Institute, 1995).

As we reviewed the literature and conducted preliminary interviews with people with disabilities as part of the development of our research design, it was evident that not only were traditional assaults and abuse not being investigated and resolved but that another whole area of investigation needed to be addressed. We could not find information on how people with disabilities themselves characterized abuse. In other words, as with so many aspects of their lives, in this area the experiences of people with disabilities were being appropriated and interpreted from the perspective of others.

A starting point for this study¹ was that we live in a society in which people with disabilities experience forms of marginalization solely due to their disability. Our interest was in the relationship between marginalization and their experience of abuse and violence. Moreover, this study was an effort to give people with disabilities a voice in naming violence and abuse. It provided an opportunity for speaking of their own experiences and of those events and actions that are abusive from the insider's perspective.

Within the parameters of the study people with a variety of disabilities from across Canada were interviewed in depth. The research instruments and interviews were designed to enable people to tell their stories. They were given an opportunity to say how various violent or abusive actions affected them, how the acts made them feel, how such acts had an impact on their lives and their self-esteem, and how these acts created a susceptibility to further acts of violence. The culture of being disabled in an ableist society resulting in a lack of confidence and control, isolation

¹ This study was carried out with the generous funding support of the Family Violence Prevention Division of Health Canada, the Women's Programme of Human Resources Development Canada and the Status of Disabled Persons Secretariat of Human Resources Development Canada

and desire for human contact and affection and lack of a sense of self-worth emerged in the chorus of voices and words.

From that perspective, violence and abuse look somewhat different. In the experience of those with disabilities, it is not only the traditional acts of hitting, sexually assaulting or verbally abusing a person that are being defined as violent. It is, in fact, a wide gamut of actions or lack of actions that create suffering or trauma. It is being pulled into an uncomfortable position. It is being isolated at home and not being allowed to go to school. It is being forced to eat or being denied food. It is being given medication that takes away one's sense of control. It is being left sitting on a toilet for long periods of time.

FROM A HUNCH TO A RESEARCH DESIGN

A literature review was carried out as a basis for determining the feasibility, need and design of the research. The literature review revealed a number of things. First that there was very little research with regard to people with disabilities and violence. Second, that the research that had been carried out tended to look at the problem from the standpoint of conventional categories, such as sexual abuse and sexual and physical assaults. From that perspective the results showed that disabled people experienced those forms of violence faced by others, but that they were at a disproportionately greater risk than many other people within society to even these conventional forms of violence. Third, the literature survey revealed that while existing research indicated that people with disabilities are particularly vulnerable to violence, very little comprehensive cross- disability research had not been carried out. Therefore it was difficult to estimate how widely such acts occurred.

The literature review was followed up by a series of interviews with people with disabilities to get a preliminary sense of their perception of what constituted abuse and violence and the circumstances in which they found themselves most vulnerable. The sample was purposive but provided us with a way to determine whether in fact the preliminary hypothesis we were working with was worth pursuing.

Adding to the challenge of understanding violence and abuse against persons with disabilities was the fact that research studies carried out in the fields of sociology, criminology and psychology had been based on small samples.

That made it difficult to generalize with confidence about the extent of the problem even when measured by conventional standards².

Moreover, much of the research was from the United States. The profile of violence in that country is somewhat different than in Canada, for example, homicide rates are much higher, firearms are far more prevalent, etc. In addition, legal provisions, social policy and social programs differ on the two sides of the border, which may have resulted in different conditions of risk and abuse for persons with disabilities in Canada.

Several large sources of Canadian research data available at that time were unable to shed light on violence and abuse against persons with disabilities. The data were not organized in a way that allowed for the systematic gathering, retrieval and analysis of this kind of information. For example, national crime statistics provided by police departments to Statistics Canada concerning complaints, arrests and convictions had not been classified according to whether the survivors had disabilities. These data did not, therefore, reveal the extent to which various actions proscribed by the federal Criminal Code were occurring in the lives of persons with disabilities. This limitation stemmed in part from the structure of Statistics Canada's Unified Crime Report format, which drives police data gathering and reporting for statistical purposes. As a result, few police departments had the means to systematically input and extract data from crime incident reports that related to persons with disabilities; few departments had set about to collect this data by other means³.

Research into patterns of criminal victimization based on large interview samples, such as Statistics Canada's General Social Survey on personal risk, did not, at that time, include questions about whether crime victims had disabilities. The electronic data for the Statistics Canada survey entered the public domain too late for analysis and inclusion in the report. The measurement of violence was limited to actions that were prohibited under the federal Criminal Code.⁴

² Some researchers had estimated that persons with disabilities are about one-and-one-half times more likely to encounter violence against themselves than the population at large. (Sobsey, 1994; Crosse et al., 1993; see also The McCreary Centre Society, 1993:5-6)

³ Most of these data limitations continue to exist in Canada

⁴ The structure of the survey instrument also made it difficult to differentiate between violence that occurred in prisons and violence that occurred in other institutional settings, such as rehabilitation facilities or hospitals. Patterns of violence at these various sites were considered likely to be different and persons with disabilities more likely than others to be involved with hospitals and rehabilitation facilities. It would make more sense for the survey questionnaire

Large databases with a specific focus on persons with disabilities, such as Statistics Canada's Health and Activity Limitation Survey (HALS), provided data on whether respondents' particular disabilities were caused by violence but not whether respondents with disabilities had been victimized since the onset of disability.

Another difficulty in assessing the nature and scope of violence and abuse against persons with disabilities were the contradictory research findings. For example, Westcott (1991) and the Roeher Institute (1988) had found that children with disabilities were at a high risk of abuse compared with other children. However, Benedict et al. (1990) found no such correlation between disability and victimization.

There were positive signs, however, that attention in the research community was beginning to shift towards violence and abuse against persons with disabilities. Statistics Canada, for example, in its recent survey on assault and sexual assault against women, collected raw data on female abuse survivors who had ongoing health problems that affected their daily activities. The data indicated that adult women aged 16 years and over with a disability or disabling health problem⁵ were considerably more likely than females without such limitations to be physically or sexually assaulted by their partners over the course of their married lives (39 as compared with 29 per cent)⁶. Examining the extent to which women in Canada had ever in their adult lives (i.e., since the age of 16) experienced one or more forms of assault or sexual assault as proscribed by the current Criminal Code⁷, the survey indicated that women with disabilities were more likely than women without disabilities to be subjected to violence of some kind: 60 per cent compared to 50 per cent⁸. However, no other research and analysis concerning the victimization of women with disabilities had yet been conducted on the basis of that survey data⁹.

not to lump together all institutions as if they are equivalent in terms of risks and harms that they present to their residents.

⁵ At the time this report was prepared, Statistics Canada had not completed classifying respondents' particular disabilities. All that was known was that the respondents had some kind of condition or health problem that limited their daily activities

⁶ Statistics Canada, Canadian Centre for Justice Statistics, 1994c: 6. The survey, however, did not clarify whether respondents sustained their disabilities as a result of the abuse or before or after the abuse as a result of other factors such as auto accidents or work injuries.

⁷ That is, the respondents experienced violence regardless of whether it was perpetrated by their husbands or male partners.

⁸ The Canadian Centre for Justice Statistics provided a special cross-tabulation to the Roeher Institute on this issue.

⁹ Because of the difficulties encountered in classifying respondents' disabilities, the data set was not available at that time when the research was undertaken

Although the current state of research provided only limited insight into the extent and dimensions of violence and abuse against persons with disabilities, it was nonetheless illuminating. The sheer accumulation of independent findings strongly suggested that, even when looked at from the perspective of conventional measures of violence and abuse, there was a problem of considerable magnitude (Stimpson and Best, 1991; Sullivan, Vernon and Scanlon, 1987; Jacobson, 1989; Jacobson and Richardson, 1989; Ammerman, Lubetsky et al., 1989; Statistics Canada, Centre for Justice Statistics, 1994; Pillemar and Moore, 1990; Ulicny et al., 1990).

THE RESEARCH OBJECTIVES

The literature review, the initial set of interviews as well as the focus groups indicated that people with disabilities are often at increased risk of similar forms of violence as other groups of people, as well as additional forms of violence. The lack of previous comprehensive research suggested a need for the development of knowledge about violence from the perspective of people with disabilities to understand all the forms of violence and abuse they experienced as well as their particular vulnerability. Four specific objectives for the research were identified:

- 1) To gain an understanding of the forms of violence and abuse experienced by people with disabilities;
- 2) To examine those factors associated with the forms of violence and abuse experienced by persons with disabilities;
- 3) To examine the mechanisms that exist to respond to violence and abuse; and
- 4) To examine how gender differences of victims of violence affects differences in the experience of violence, the factors associated with violence, and the responses to incidents and victims of violence.

METHODOLOGY

Because a central aim of this research was to gain an understanding of the subjective experience of violence, a methodology was needed that brought a focus to the experience of violence, without pre-determining or pre-structuring the categories of violence about which the research would inquire. Having recognized that people with disabilities had been left out of much of the research on violence and abuse, and acknowledging the particularities of their marginalized status, we needed

an approach that would enable a view of the world from their standpoint. An open-ended interviewing process, driven by the categories of violence and abuse in the current Criminal Code, or drawn from existing research, feminist and otherwise, was not adequate to the research task on hand.

For this reason, a 'narrative' research approach was intentionally chosen. As Mishler (1986) has pointed out, a narrative approach to research interviewing departs in important ways from traditional quantitative and qualitative data collection. Research interviewing is usually cast in terms of a 'stimulus-response' model, where the interviewer provides a 'stimulus' in the form of a question ('Have you ever been physically hit by a caregiver?') and waits for the response ('yes', 'no', 'I don't know'). As Mishler points out, this model of research establishes the researcher's frame as the dominant one, leaving the respondent to either find a place in that framework or remain silent. As Booth and Booth suggest in relation to people with learning disabilities, the predominance of such an approach has meant that 'informants with learning difficulties have been regarded mainly as sources of data for researchers' narratives rather than people with their own stories to tell' (Booth and Booth, 1996:56).

A narrative approach to research places the onus on the researcher to create an environment in which the respondent can begin to tell his or her story. The approach recognizes that people live their lives and construct their identities in narrative terms (Taylor, 1989), and that they make sense of their experiences as events that contribute to their own script(s), the plots that constitute their lives. Unless one is able to 'employ' events within a broader life history and life story they have little meaning. Cognizant of the risks of re-traumatizing individuals in the process of interviews about their experiences of violence, we also felt it important that the interview respondent control the dialogue so that they could bring as much meaning as possible to their experiences. Providing them an opportunity to recount in narrative terms their experiences was one way of doing this.

Interviews were conducted across Canada with self-selected individuals with disabilities. Respondents were interviewed in each province. The interview sample was constructed in consultation with a large number of disability and advocacy organizations. The organizations were asked to make the initial contact with individuals whom they knew had been victimized and who would feel comfortable being interviewed about the situations in which they had been abused. Only individuals who

volunteered to participate were invited to take part in the interviews. We considered the self-selection of respondents to be an essential ethical safeguard to avoid the possibility of re- victimization.

An effort was made to ensure an even balance between male and female interview respondents with disabilities. This proved more challenging than anticipated. It was more difficult to identify males who had been victimized and were prepared to discuss it. This may reflect the possibility that females are more likely than males to be victimized, or that males feel more inhibited than females discussing situations in which they have been abused. It may reflect a difference in how men and women think about abuse and how they characterize violence. Until statistical analysis based on a large sample of persons with disabilities is conducted, it is not possible to determine precisely why more females than males seem prepared to talk about violence and abuse in their lives.

An effort was also made to include interview respondents who represent Canada's racial diversity. Several Aboriginal persons were interviewed. However, people of colour and Aboriginal persons have a limited presence in the disability and advocacy organizations that provided assistance to the project. Therefore, the interview sample does not fully reflect the country's diversity. The statistical sources that were consulted, however, do include all individuals with disabilities in Canada. The statistical data and analysis provide insight into the social and economic situation of persons with disabilities as a group.

The open-ended narrative nature of the interviews required that interviewers be experienced and be trained to be as sensitive as possible to the responses of interviewees and to respect any limits required by interviewees who had been victimized, including wanting to end the interview. Although these precautions were taken, it was not possible to entirely shield interview respondents from the pain of reliving violent situations. Seventy-one persons with disabilities took part in the interviews and several of the interviews were terminated because the incidents were too painful for the respondents to recount. At least one of the interviewers used American sign language and all the interviewers were trained to interview people with intellectual and psychiatric disabilities.

Interviewers were told to probe any circumstances that the person being interviewed identified as abusive and to include any of the following:

- common forms of physical, verbal and psychological violence to which many persons in society are susceptible (date rape, crime in the street, family discipline, for example);
- those forms of violence to which people with a disability are more susceptible (for example, where they can't protect themselves, where they are isolated or where they depend on numerous caregivers in situations where there is a high turnover, etc.);
- those forms of violence which are considered socially acceptable or socially justifiable because the individual has a disability (for example, aversive therapies, withholding of medical treatment for newborns, sterilization, social isolation and segregation).

In particular we were looking for information that answered such questions as:

- What forms did violence against persons with disabilities take?
- What practices were associated with these forms of violence, and who was involved in violent victimization of persons with disabilities?
- In what environments did persons with disabilities experience forms of violence?
- How did forms of violence get understood by the victim, the family, the service system, the criminal justice system ?
- What were the impacts of violence on the victim?
- What were the factors or set of factors associated with the occurrence of violence and abuse and what was the relative significance of various factors in explaining the nature of the abuse and its impacts?

Interviewers were specifically instructed to include emphasis on seeking, through the interview process, gender differences in experiences of violence and abuse, and responses to violent victimization.

It was anticipated that some individuals would experience emotional stress while telling their stories, particularly in face-to-face interviews. Arrangements were made for the necessary counselling and other emotional supports and in several cases these supports were used. It was also expected that interviewers might experience stress and anguish while listening to people tell their stories. In some instances, interviewers were appalled at the level, scope and impact of the violence and abuse that had invaded the lives of interview respondents. Interviewers often

felt remorse at having to leave participants in situations that were far from ideal. Emotional supports were made available for interviewers.

Given that a qualitative research methodology was used in the interviews, the project proved to be a learning experience. A detailed interview guide was designed to capture both brief and discursive interviewee responses concerning the abuse they had encountered and others' responses to their victimization. The development of the guide involved considerable deliberation and care with respect to ensuring that questions were appropriately and respectfully worded, given the sensitivity of the subject. The interview questionnaires were also reviewed by a number of people with disabilities who were advisers on the project. Due to the sensitive nature of the subject and the depth of feeling and scope of memory that opened up, many of the interviews, as expected, took on a life of their own.

Interviewers sometimes used the guide in one of two ways. In some instances, it served as an interview questionnaire. In others it served as a reminder to pursue issues that did not surface during the natural flow of the conversation. After the interviews were concluded, many of the respondents' comments were classified according to the data categories used to design the guide. However, several kinds of interviewee response were not anticipated during interview design and pre-testing and so could not be made to fit into the established structure. Coding procedures were revised to include these responses.

Another development during the interviews was the readiness of not all, but many, participants to tell their story. It was initially assumed that respondents would perhaps need some time to feel comfortable and safe enough to respond to questions concerning abusive and violent actions they had personally experienced. Participants were asked several questions as ice breakers, which had them speak about their life in general and about abusive situations that had occurred to one or more people whom they knew. Several participants were impatient with this approach and wanted instead to get to the details of their own stories. Interviewers moved with the natural dynamic of the interviews. In most cases, the interviews went beyond the ninety minutes initially planned.

Interviews and focus groups were also conducted with counsellors and social workers involved in fielding complaints of abuse and violence against persons with disabilities. Several of these individuals also had disabilities. Interviews and focus groups were held with a sample of

police officers and police administrators from across the country, as well as with community advocates, administrators and service providers attached to community agencies that serve persons with disabilities. Family members of persons with disabilities who have been subjected to violence were also part of focus groups and interviews. In all, the interviews and focus groups involved 120 respondents.

In addition to a two-day orientation and regular debriefing sessions with interviewers, a day-long session was conducted with the interviewers towards the end of the interview process. This allowed them to share with the research team and one another some of the insights that emerged during interviews. The transcript of the discussion served as another source of data that enriched the primary interview data. The discussion also helped in the development of a critical perspective from which to analyse these data.

FINDINGS

'Violence is a result of our so-called "idea" of where people fit in the hierarchy. These people [people with disabilities] are at the bottom. Consequently, doing violence to them isn't a big issue because they're not worth anything anyway ... We live in a violent society. And people who for one reason or another are unable to assert their own needs or their rights, or protect themselves - many of whom have a disabling condition - are susceptible to violence. Except they can't run away. They don't have any place else to go. Police don't necessarily listen to them, so the institutions that are supposedly there to protect us simply don't pay attention. So protection must come from their own efforts. And if they can't mobilize their own resources, or if there are no resources to mobilize, there's nothing anyone can do' [taken from an interview].

On the basis of the interviews, a working definition of violence and abuse of disabled persons was constructed:

'Acts of violence and abuse are defined as conscious and deliberate acts that cause, or that threaten to cause, harm. They are public or private acts that seriously violate the principle that disabled persons, like other persons are to be equally valued and protected as citizens. They are acts that ignore or hold in contempt the voice of a person and that exploit a power

imbalance, or that on other grounds are contrary to the free and informed consent of the person abused. Typically, these actions result in the suffering of the abused person, whether emotional or physical. Extreme violent or abusive actions result in the injury and even death of the person affected.'

Violent and abusive acts against persons with disabilities were found to involve any of the following:

- physical force (e.g. beating; aggressive caregiving);
- physical actions that take the form of care (e.g. administration of medications, restraint or other treatments);
- sexual assault or other forms of sexual abuse (e.g. non-consensual touching or fondling);
- the denial of rights, necessities, privileges or opportunities by persons in a position to promote or safeguard the well-being of the person affected;
- patterns of communication that may not involve physical contact but which are perceived as threatening (e.g. explicit threats or stalking), as tormenting (e.g. harassment), or as insulting (e.g. 'speaking down to' or using derogatory terms in conversation); and
- lack of proper action (e.g. the neglect or failure to respond effectively to harmful incidents).

The research found that people with disabilities are more likely than others to be subjected to acts of violence and abuse that are proscribed by criminal and civil acts. They are also subjected to acts of violence and abuse that do not meet legal definitions of violence but that the survivors perceive as harmful. These may include acts that are perpetrated in places where the abuse is shielded from the arm of the law. Contributing to the vulnerability is society's inability or unwillingness to clearly name and prohibit the problem. But equally important are the often radically unequal social and economic position of persons with disabilities that place them at a disproportionate risk, as well as the lack of individual control and choice that makes it difficult for the individual to avoid and escape situations of risk.

Many circumstances obstruct survivors from disclosing acts of violence and abuse against themselves. The lack of proactive community and system measures to anticipate and look for signs of potential abuse and violence prevents the problem from coming to light. The responses from family members, social workers, educators, counsellors, law enforcement

officers and the courts to respond to the problem, in a particular case and generally is random. Some individuals encounter empathic and effective assistance while the perpetrators are convicted, others face outright denial of the abuse and little if any assistance while the perpetrators go free.

The study concluded that the existing legal, policy and program framework is not working effectively, measured by the scale of violence and abuse and the reported response. It recommended that a holistic approach be initiated to address the issues, starting with a public commitment and recognition of the principle that assuring people with disabilities freedom from violence and abuse and proper redress is not a matter of charity but a matter of individual and citizenship rights. The legal and political structure entitles citizens, including those with disabilities, to live in safety and security and to be respected and treated equally.¹⁰ From that perspective, directions for change (see Roehner Institute, 1995: 183-203) were identified in social policy, administrative and programs coupled with community development initiatives that would strengthen the capacity of communities to identify and address abusive situations and circumstances. Statutory reforms were also recommended as well as effective public education and public awareness and systematic data collection and research.

FOLLOWING UP

We recognized that the release of the research report was an opportunity to spark public concern and awareness so we mounted a national press campaign which involved a press conference and wide distribution of the study. The press conference not only provided the research results but a number of people from the disability community told their own stories - people with a diverse perspective on the issue. In advance we sent out the press release and copies of the publication to all the major national disability organizations and alerted them to our press strategy. This enabled the study results to provide a forum for disability organizations to get some local press as well, and in the process raise the profile of disability rights advocacy generally.

Approximately 1000 copies of the report have been distributed. Of those about 100 were sent to journals -disability journals, social policy journals, feminist journals, and journals which have some interest in abuse. The rest have been distributed through our distribution service.

¹⁰ Canadian Charter of Rights and Freedoms

Since the publication of the study, which provides a blueprint for further action, we have used the information in it to create plain language information sheets, to run seminars about abuse and violence for disability organizations and for generic sexual assault centres as well as to facilitate police training and information seminars. In the past month, a plain language safety guide, *Out of Harm's Way*, has been published which provides a method of assessing risks in the physical, policy, and personal environment in which people with disabilities find themselves. An issue of the magazine, *entourage*, which we produce was devoted to the issue and we continue to work with advocacy organization to bring about change in federal criminal law, administrative procedures and protocols to be put in place to provide the protections to which all persons should be entitled in Canada. Several legal cases which were initiated by people after they were interviewed for this study are proceeding through the courts and one abuse shelter for people with disabilities and others has been established as a result of the study.

The piece of research would not have been possible without the cooperation of those interviewed and those who were willing to carry out the interviews. Canadians owe a great debt to these people and to those who continue the fight to ensure that all Canadians can live in security and dignity in our country.

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