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” Vulnerable, exposed and invisible?”

A qualitative study on violence and abuse against women with physical disabilities

by
Vigdis Mathisen Olsvik

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A qualitative study on violence and abuse against women with physical disabilities

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Part I Presentation of the Study

Introduction

This qualitative study on violence and abuse against Norwegian women with physical disabilities is the first part of a three year research project where I am using three different methodological approaches: qualitative interviews, a survey and focus groups. This research project is carried out in collaboration with the Network for Women with Disabilities and is financed by the Foundation for Health and Rehabilitation. It is also part of my doctoral work at the Institute for Social Work and Health Science, at the University of Technology and Natural Sciences (NTNU) in Trondheim, Norway.

In the present paper which deals only with the qualitative study, I will try to answer the following questions: What types of violence and abuse are women with physical disabilities exposed to, and how do they themselves describe it? What is the social context within which the abuse has taken place? Who are the abusers, and what are the arenas of abuse? What are the consequences of the abuse for the women, and in what way have they coped with it? And, finally, how do the women themselves explain the abuse, and what do they think are the main causes of the abuse?

Review of the Literature

In connection with the qualitative part of the research project I have looked at the research literature dealing with violence and abuse against persons with physical disabilities in general and against women with physical disabilities in particular. Generally speaking, women with disabilities have for a long time been a neglected group both within disability research, gender studies and research on violence. Disability research has only recently taken an interest in the life situation of women with disabilities, the same can be said about research on violence, while gender studies so far have not shown much interest in this particular group of women.

The international literature on abuse against persons with disabilities is still very limited and focuses mainly on abuse against children with disabilities and people with learning disabilities (Sobsey 1994, Brown 1994, McCarthy 1998), and only to a minor degree on abuse against persons with physical disabilities (Roher Institute 1995, Riox et al 1997, Mac Farlane 1994, Brown 1998, Shakespeare 1996, Calderbank 2000). The Roher report documented a fundamental lack of awareness as to the extent of abuse experienced by people with disabilities. Mac Farlane (ibid) discusses the more subtle forms of institutional abuse which takes place in hospitals and care homes, due to the unequal power relationship between the care giver and the person with a disability. Brown (ibid) describes the assumptions made by society about disabled people which legitimize the abuse of persons with disabilities, while Shakespeare (ibid) discusses several categories that identify disabled people as vulnerable to abuse. None of them have, however, dealt particularly with women with disabilities.

Only during the last ten years have we seen an increased interest in violence and abuse against women with disabilities. The interest augmented particularly after the UN‘s Women’s Conference in Beijing in 1995. There are, however, still few studies focusing especially upon abuse against women with disabilities. Two surveys, one done in Canada (DAWN 1989) and the other in the United States (Nosek et al. 1997) are of particular interest for this study. In the Canadian survey the women were mainly recruited from different interest organizations in

Canada. The findings of this survey showed that a total of 40 percent of the women in the sample had been exposed to rape or physical abuse. About 12 percent of the women had been raped, 15 percent had been physically abused and 30 percent had been violated. Some of the women had been victims of more than one type of abuse. In most cases the abuse had been committed by a person they knew and upon whom they were dependent. This study also showed that women with more than one disability had a greater chance to experience several types of abuse.

The American survey was based on a national questionnaire which compared women with and women without physical disabilities with regard to physical, emotional and sexual abuse. The findings from this survey showed that a total of 62 percent of the women in both groups had suffered one of these types of abuse. There was, however, no significant difference between the women with and without physical disabilities. In both groups the abusers of physical and emotional abuse were the women's marital partners followed by their parents, while the main abusers of sexual violence were in both groups a stranger. This survey showed, however, that women with physical disabilities had experienced physical and sexual abuse over a longer period of time than women without disabilities. In addition, women with physical disabilities were significantly more exposed to emotional and sexual abuse from health care personal and attendants than women without disabilities.

In the Nordic countries, we have no similar surveys on the extent of abuse against women with physical disabilities. We have, however, some retrospective studies on sexual violence against children with sensory disabilities (Kvam 1995, 2001, 2003). Experiences by the Network on Women with Disabilities in Norway also confirm that the problem of abuse among women with disabilities is more widespread than we think (Johansen & Madsen 1999). The report on"Women's Health in Norway" (NOU 1999:13) therefore recommends more research on abuse against women in general and against women with disabilities in particular. Recently, two literature studies have been carried out in Denmark, one with a focus on sexual abuse against people with disabilities (Muff 2001), the other with a focus on partner violence against women with disabilities (Bjerre & Jørgensen 2002). In addition, two qualitative studies dealing with abuse against women with physical disabilities have been published, one in Norway (Sørheim 1998), the other in Sweden (Finndahl 2001).

The Norwegian study had as its main focus the social significance of being both a woman and disabled, while sexual abuse made up a minor part of the study. It consisted of interviews with a total of 37 women with different physical disabilities. The findings showed that eight of the women had been exposed to sexual abuse, and that some of them had experienced more than one incident of abuse. Most of the abuse was carried out by persons with whom they had a relationship of trust and dependence. All the women had visible disabilities, and they were also young, when the abuse happened. In addition, they all had frequent contacts with the health services. The majority of them had chosen to remain silent with regard to the abuse they had suffered. The abuse had, however, resulted in severe consequences for some of them, both physically and emotionally.

The Swedish study looked at the extent and the context of different types of abuse (both physical, emotional, and sexual) against women with mainly physical disabilities. The interviews included professionals within institutions and organizations together with interviews with 12 women with physical disabilities. The findings from this study show that the abuse took place in various arenas, both at home, in institutions and in the public arena. The abuse was performed either by a man in the family or a health employee or another

attendant upon whom the women were dependent. Most of the abuse was emotional abuse, but also physical violence occurred. The author explains that the abuse seems to a large part to be due to the women's dependence of assistance, which creates a vulnerability that can be abused by persons who desire to be in control. Furthermore, she underlines that women with disabilities often are more isolated than other women, simply because they are less frequently employed. In addition, the integrity of women with congenital disabilities seems to have been constantly violated during their frequent treatments at different health institutions, and they may, therefore, have difficulties in protecting the boundaries of their own bodies.

Method of the Study

In a qualitative study like this, the women's own subjective experiences are given priority, and the purpose is to secure an understanding of how people create a meaning of extreme experiences, like abuse and violence. In this research tradition, the in- depth interview is central (Kvale 1996). The interview guide had questions both covering the usual background variables (age, education, marital status, children), their life situation (work, leisure and health), in addition to their experiences of all types of abuse and violence (both physical, emotional, sexual and institutional). Due to the geographical spread of the informants the interviews were done by phone and not in person and consisted of two interviews of about an hour each. They were all recorded and typed out in their entirety. To ensure full anonymity an agreement was made that all the informants would get a copy of the draft of the paper to check that their anonymity was sufficiently safeguarded. The analysis of the data material was mostly done manually, but was also on certain issues checked by using the software program, NVIVO.

Since this was a qualitative study, I, therefore, wanted a qualitative sample based on variety rather than on statistical representation (Fog 1996). Letters of invitation were sent to members of the Network for Women with Disabilities, and ads were published in newsletters of a number of user organizations for persons with disabilities. As a result, I got in contact with 18 women with physical disabilities who had suffered different types of abuse, and who were willing to talk about it. After having interviewed 13 women I felt I had reached a point of saturation with regard to information about the abuse the women had suffered.

The main characteristics of the 13 women are that they are between 33 to 61 years of age. Four are married, four are divorced, four are single and one is a widow. Eight of them have children, and most of the children are above 15 years of age. Six of the women have nine years of elementary education as their highest education, six have college education, while one is presently studying at the college level. Furthermore, nine of them have had a job, but are now on receiving disability benefits, two are still working, and one is studying. Ten of the women are mobility impaired, one is hearing impaired, one is visually impaired, and one is speech-handicapped. Almost half of the informants have more than one disability, and more than half of them are dependent upon a wheelchair. Five of the thirteen women have a congenital disability.

How did the informants themselves look at their disability, and to what degree did they feel disabled? Several of the informants experienced their degree of disability as being related, first, to their state of health, second, to their phase in life and, last, but not least, to their access to help devices and services. ”Until last spring I managed practically everything on my own, but then my health worsened, and now I need help from my personal assistants 23 hours per week”, one women with muscular atrophy told me (Interview 9). Their degree of disability is, in other words, not a constant condition, but something that can worsen or improve over a period of time. But most of all it depends upon what services and what help devices they have access to. This was confirmed by an informant being dependent upon a wheelchair:”If I get the assistance and the physical support devices I need, then I do not feel disabled” (Interview 6). Another said:”I live a very active life, and I do not feel that I am disabled until my personal assistants get sick” (Interview 8). In other words, access to the necessary help devices and services are crucial for whether the women feel disabled or not.

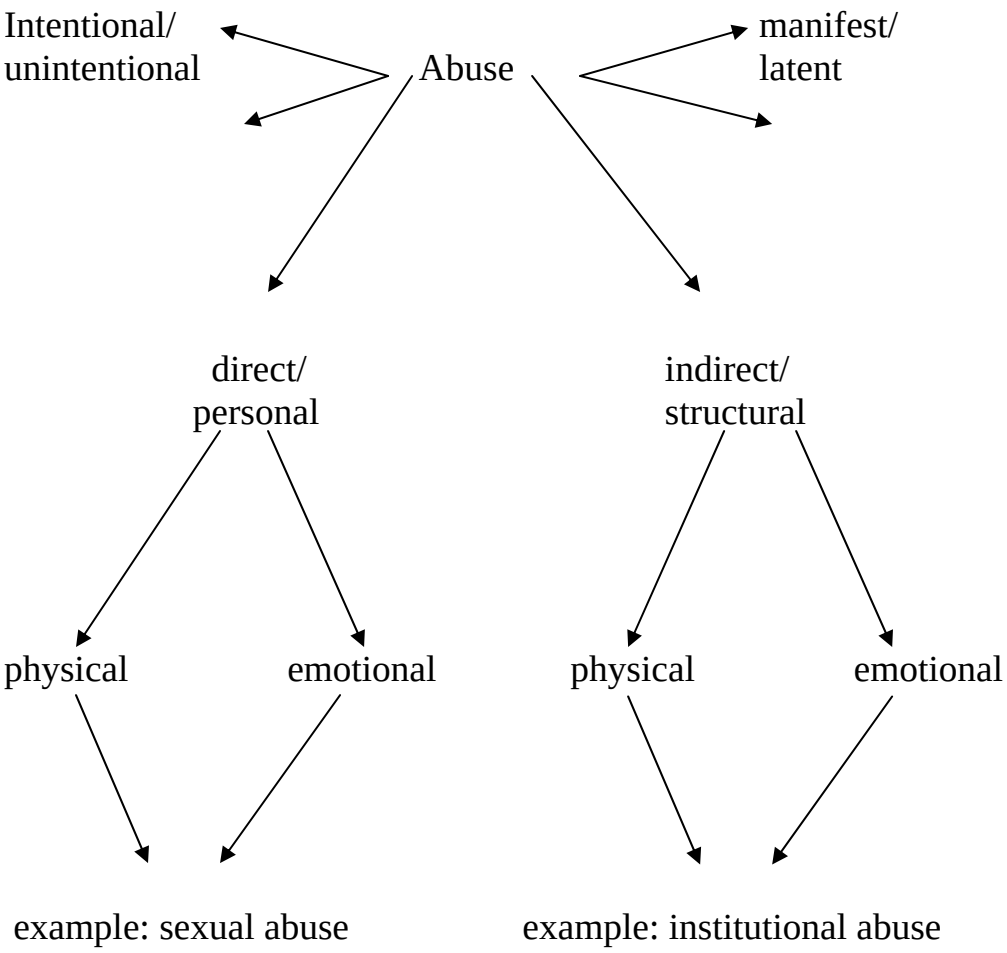
The concept of disability is, as we have heard, a relative concept dependent both on the phase of life, the state of health and the access to services and physical support devices. This is in accordance with the social model of disability, which looks at a disability not as a problem with the individual, but as a result of the individual’s relations to their surroundings (Thomas 1999, Morris 1996, Crow 1996). In other words, if the social context in which the women live, is functioning well with regard to adequate access to help devices and services, they will as a consequence be more self-reliant and feel less disabled.

Part II A typology of Violence and Abuse

In this study I use a wide definition of the concept of abuse which includes all the types of abuse mentioned by my informants, i.e. physical, emotional, sexual, and institutional abuse. I also include all degrees of abuse from rape and violence to insults and isolation. A few of the earlier mentioned studies have tried to define abuse (Nosak et al. and Finndahl) and, according to them, physical abuse includes all kinds of violence against the body, such as being beaten and kicked and raped, while emotional abuse consists of being verbally harassed and threatened, but also being isolated, and sexual abuse includes being pawed or raped, as well as being verbally intimidated. None of these studies, however, deal specifically with institutional abuse, and since this type of abuse was central in my data the need for a comprehensive typology became urgent for me. My main problem was to fit institutional abuse with the other types of abuse. It was not until I rediscovered the concept of violence by Galtung (1974) that the pieces fell into place. Inspired by Galtung's extended concept of violence I have created a typology based on the division of abuse into two main categories: personal (or direct) abuse and structural (or indirect) abuse, where the first one is committed by an individual, while the second is expressed through the power structures of society (p.35). Even if it can be objected that there is an element of structural violence within personal abuse and vice versa, there is all the same a logical distinction between abuse affecting people as a direct result of someone else's actions, and abuse affecting them indirectly through the power relationships of different institutions (p.47). As mentioned earlier, the main focus in the research literature has been on personal violence, while structural violence has been more or less absent. Therefore, the distinction between personal and structural violence has been very clarifying (see figure 1).

I am, furthermore, dividing both personal and structural abuse into the two dimensions of physical and emotional abuse. It is, of course, difficult to distinguish between them, because most abuse is a combination of the two, but I am treating them separately mainly for analytical reasons. Sexual abuse is an example of personal abuse that can be either physical in the form of pawing and rape or emotional in form of peeping and verbal intimidation. Another example of personal abuse is bullying at school, which also can be either physical or emotional or a combination of both. Institutional abuse is, on the other hand, an example of structural abuse that is affecting the victims mainly indirectly through laws, rules and power structures. The personal element of abuse is, of course, brought about by the employees whose job it is to put these rules and regulations into practice. Institutional abuse can also be either physical for instance in connection with medical treatment that results in unnecessary pain and even injuries or emotional with regard to negative attitudes and degrading comments by the staff of health institutions. Galtung (ibid) also distinguishes between intentional and unintentional violence that is an important aspect with regard to the motivation of the abuser. He also makes the distinction between manifest and latent violence, where the first one is violence that has been observed, while the second one is violence that is not yet manifest, but still potential.

Figure 1. A typology of Abuse



Physical Abuse

Several of the 13 women had experienced different types of physical abuse. Most of the physical abuse had been of a long duration, but there were also examples of single incidents. This type of abuse had taken place both in the natal and conjugal families, at school and in different health institutions, and also in a job related situation.

In the family setting the abusers were both the parents and the marital partner of the women. One of the informants who brought up the issue of physical abuse by her parents, said: ”They were always so heavy- handed towards my sister and me …I was very mad at my dad, because he was so strict, but we never dared to oppose him” (Interview 1). Other informants also commented upon the tough upbringing by their parents. But many more informants had as adults been exposed to physical abuse by their marital partners. An example of this was a woman who is speech-handicapped, as a result of medical malpractice, and who typed on her machine: “Abuse at home. By my husband. He got a new role that he tackled badly. He threatened me and beat me and pulled me by the hair. Hit me hard everywhere. It went on for years. He got worse, when I got ill” (Interview 3). Another example was a woman who

developed multiple sclerosis as an adult:" As my health got worse during the years we were married, he became more violent… I was hospitalised three times with clear signs of violence, but not one single doctor asked why" (Interview 7).

In the interviews there were also some informants who had experienced physical bullying at the school. One of the women, who is dependent on a wheelchair, described the situation in this way:"In elementary school I was a victim of physical bullying…It was always fun to push me, since I was not able to get up again. Many times I lay on the ground until the teacher discovered that I was missing and came and picked me up" (Interview 4). Another informant who was chased by a gang of boys in elementary school, said: "I remember the breaks at school very well. Some of the boys always chased me…But none of the teachers took action" (Interview 1). In both these cases the informants had visible disabilities, and, therefore, probably more exposed to bullying than other kids. Both of them shared the experience that the teachers did not react to the bullying, and, consequently, they both believed that "things were just supposed to be like that".

In my study there are also examples of physical abuse that happened in hospitals and at home in connection with treatment and nursing. One informant told the following story in connection with blood sampling:"they often missed my vein, seven or eight times they missed, but they went on and stuck and stuck ... It felt like an abuse. Yes, indeed it was. When they exceed your threshold of pain and choose not to see your pain, then it is abuse" (Interview 6). This was one of many examples of what the informants experienced as unnecessary invasive treatment. Another informant told about the lack of catheterization after an operation that resulted in both great pains and an infection. She concluded:"It was physical torture. It was a night in the recovery room that I will never forget" (Interview 2). This informant was not the only one to tell about poor nursing, which had caused her both physical pains and injuries. Since many of the informants are dependent on care and nursing several times a day in addition to treatments in hospital, they are, consequently, more exposed to this type of abuse than people without disabilities.

In my interviews there is also an example of an incident of physical abuse in a job related situation, where one of the informants who is dependent upon a wheelchair, experienced what she herself called "a physical kidnapping". In relation to a dinner after a class that she had given to a group of service providers, she experienced the following:"then suddenly this participant of the class came from behind, seized my wheelchair and pushed it out in the corridor. I was simply being kidnapped from the dining room and out in hallway of the hotel, without any one noticing it. After a wild tour he finally put me down. I was dumbfounded, and asked what was wrong with him…Then I realized he was very drunk and I became frightened, because I felt so much aggression from him" (Interview 8). Also other informants, who are dependent upon using a wheelchair, had been exposed to similar kind of experiences in the public arena.

Physical abuse by marital partners is relatively well documented in the research literature, while physical abuse by parents against children with disabilities is less documented. The same is the case with physical bullying at school, where bullying against children with disabilities are discussed much less than bullying against children without disabilities. However, being "different" probably makes children with disabilities more exposed to bullying than other children. To my surprise there were many descriptions of physical abuse in connection with medical treatments and nursing in health institutions in my study, while this type of abuse is rarely documented in the research literature. Because this group of

informants due to their disabilities is more dependent on treatment and nursing than any other groups, they are also potentially more exposed to this type of abuse.

Emotional Abuse

Several of the informants had been victims of emotional abuse, either alone or in combination with physical abuse. The emotional abuse took place both in the family, at school and in health institutions. One of the informants had, for instance, experienced insults from her father and older sister from childhood and up until today. She called it ”emotional terror” and said: ” I believed for a long time that things were supposed to be like that…it has taken me a many years to realize what happened and to understand why it happened”(Interview 5). Quite unexpectedly, a couple of informants told me that they had felt emotionally hurt by one or both of their parents, either because their parents had not accepted their disability or they had failed to support them in their painful encounters with the school or the hospital. The following quotation is an example of this:” For me the distrust began, I think, from very early on, because I did not manage to establish an early confidence in them. I felt they betrayed me from the very start, when they left me in the hospital at a very young age … and after that they continued to hand me over to the butchers. By doing that and accepting it, I felt betrayed, and I did not understand until much later that they too were victims of the system” (Interview 4).

In addition to physical bullying at school some of the informants also experienced emotional bullying in the form of teasing and gossiping and sometimes with reference to their disabilities. Social isolation is another form of emotional bullying. One of the informants had experienced this as a result of an early integration in ordinary elementary school. “In the so-called ordinary school, I was the only disabled child. There was no one else there with a disability, and I was completely isolated, because neither the teachers nor the parents of the other kids wanted me there. It became so bad that I at a certain time asked to be transferred to a special school, but, unfortunately, I was not given the permission to do so“(Interview 4). This informant was not the only one who had experienced social isolation as a result of her disability. Other informants had developed special strategies to hide their disabilities, such as this informant who was mobility impaired:”I pretended to be dumb, so that I could avoid having to walk to the blackboard” (Interview 9).

Some of the women, who had been exposed to physical abuse by their marital partners, often experienced emotional abuse in addition. One woman with a mobility impairment said:” In addition to the physical abuse I experienced, my husband also abused me emotionally all these years, actually ever since we were engaged…. I have reflected very much upon what happens with you emotionally, when you meet a sociopath like him” (Interview 9). Another woman felt brainwashed by her marital partner, which she explained in the following way:”at the end I was so brainwashed that I felt I had no value. It is quite terrifying to realize this in retrospect, especially since I have always looked at myself as being a strong human being who could tackle things very well. At the end I felt I could do nothing and had no self respect and no value”. This example illustrates what may happen as a result of a long time emotional abuse.

Several of the informants were exposed to emotional abuse by the staff in different health institutions. One of them described the employees’ attitudes to the residents in this way:”the most negative experience during my stay at this institution was caused by the staff that had a very degrading attitude towards the disabled residents. I was witnessing such comments as:

just you shut up and be happy that someone will care for you at all, since your parents will not do that. This attitude permeated their entire behaviour, their entire care. It was frightful". Another informant explained her experience with emotional insults by the staff this way: "it has to do with the attitudes of the staff and their lack of respect towards the disabled …they do not manage to put their job in the right perspective, to take the other person's perspective and to show simple human respect towards those concerned" (Interview 8). These comments illustrate how these attitudes were experienced as emotional insults by my informants.

In the studies by Sørheim (ibid) and Finndahl (ibid) there are similar examples of emotional abuse, especially emotional abuse committed by the women's marital partners or by bullies at school. As shown in the quotations, the informants used strong expressions to describe the emotional abuse, such as"emotional terror" and "brain washing". Contrary to my study, there are few descriptions in the research literature of emotional abuse carried out by the staff in health institutions, and also few comments about the emotional abuse by parents who fail to back up the informants in their often painful encounters with institutions, like schools and hospitals.

Sexual Abuse

Sexual abuse can take the form of physical abuse such as pawing and rape or emotional abuse such as obscene comments and peeping. Eight of the thirteen informants had experienced sexual abuse of one or more of these types of abuse.

Peeping is one example of sexual abuse that one of the informants experienced, when she was hospitalised at the age of fifteen. She woke up one night, because she felt cold and discovered that the night watchman had taken off her bedclothes and sat and looked at her lying there half-naked. She was paralysed and shocked. After what she felt was "an eternity", someone finally called for him. He then threw the blanket to her and left. Even though nothing more happened, the emotional shock has stayed with her. Another informant experienced being pawed by a doctor in a hospital, when she about fourteen years old. While she was resting alone in her hospital room after a tiresome treatment, a doctor came in and began to talk to her and fondle her thighs in what she experienced as "a very unpleasant way". She strongly felt that this was not a normal medical examination. The situation was the more traumatic, since she, due to her treatment, was barely able to move. When the doctor was interrupted by another patient, he simply left, and she never saw him again. She too described the duration of the incident as "an eternity". A third example of sexual abuse involved a fourteen year old informant who lived at a residential school for the deaf, and who was pawed by a ten year older night watchman over a period of about one year. These three examples of sexual abuse have three characteristics in common, first, they happened while the girls were in their adolescence, second, they happened while they were in a very vulnerable situation, and, thirdly, the abusers were all older men who had a job position at the institution.

A couple of my informants had experienced sexual abuse in the form of rape in their childhood. One of them had been sexually abused from when she was about 4 years old, and the other from when she was about 5 years old. The first one was later sexually abused as an adolescent, then again as an adult by her husband, and later by her father in law. The second woman was abused by a friend of the family, and this went on until she left home at around the age of sixteen. She did also later experience sexual abuse by other men. Both these informants said that they as children did not have a clear understanding of what was going on. One of them put it this way:"From early on I did not really comprehend what was going on. I

had no one words for it, no clear understanding of what actually happened. Except that it was something I did not like. I just felt it was nasty" (Interview 4). This kind of long-lasting sexual abuse at an early age had serious emotional consequences for both of them later in life.

In my study there are also a couple of cases of rape committed by the marital partners of the women and one case of sexual abuse by a friend of the woman. The first two women who are both dependent upon using a wheelchair, were raped by their husbands over a period of several years. A third informant who is sensory impaired, experienced the sexual abuse by a friend as a single incident. She was invited home to an old friend for dinner, and while they had coffee, she suddenly blanked out. Next morning she woke up in his bed his and felt very sick. When she found sedatives in his bathroom, she understood that she had been drugged and sexually abused. Afterwards she felt very confused and shocked, since he was a friend she had known for many years. But when he started to send obscene messages on her cell phone, she understood that he had mental problems. This incident was very traumatic for her and gave her various health problems some years later.

Sexual abuse against women with disabilities is relatively well documented in the research literature (Muff ibid). We find similar examples in the study of Sørheim which are in accordance with what has been reported here. The consequences of sexual abuse, and, especially sexual abuse that has happened early in life, have been serious for all of the informants, and have caused some of them to seek professional help.

Institutional Abuse

Institutional abuse is an example of structural or indirect abuse which means that the abuse is "built into the social structure, and become manifest as unequal power" (Galtung, ibid, p. 36). In my interviews I have several examples of institutional abuse both in connection with schools and with several kinds of health institutions. One such example concerns a woman who is hearing-impaired, and whose disability was not discovered by the school authorities, so that she could get the necessary assistance to follow the instruction. She solved the problem by sitting in the front of the classroom and by learning to lip-read the teacher. At the age of 21 she finally got her first hearing- aid at her own initiative. When I asked her what she felt about the situation, she said:" I never thought much about it, and since neither my parents nor the school did anything to help me, I assumed that this was how things were supposed to be" (Interview 1). Another informant who also got deficient training in elementary school has now applied for compensation for her lost education. Neglect from the school authorities resulting in a deficient education is an example of structural abuse.

The consequences of the school integration reform were also mentioned by the informants. "The reform was introduced without the proper preparation of the teachers and even without them agreeing to it. Therefore they were negative to the reform. For me it meant that they did not understand that my disability was not only physical. No one understood that, which had serious consequences for me," one of the informants said (Interview 4). Another woman who is hearing-impaired experienced much of the same, when she was integrated in the ordinary school, where she felt that she had to function on the premises of the non- hearing impaired. After a serious identity crisis it become clear to her that it instead would have been an advantage for her to attend the school for the deaf and to develop an identity as a deaf person instead of a hard of hearing person. These are some examples of institutional abuse that have had serious consequences for the women involved both emotionally and educationally.

Lack of access to home care and home nursing which the informants due to their disabilities have a rightful claim to, were also experienced by the informants as expressions of institutional abuse. One of them said: ”I had to fight all the way to the county level to get the home help that I needed…They refused me this assistance, because I was too young. They said they only had capacity to give such services to the elderly. I showed them the law, which says that I too have a claim to such services. Then, finally, I got one hour of home care every fortnight” (Interview 7). Another informant who wanted to have the amount of home services adjusted to her worsened health condition experienced the same kind of barriers. ”My situation has deteriorated the last year, and I have worked hard to get more assistance, but so far I have not succeeded. I have complained, but without getting an answer. They are not calling me back… You get so tired to try to locate the right people who can take responsibility and co-ordinate things…. The law says that I have the right to an individual plan, and that there shall be a person to co-ordinate it. I have been promised this for two years without any results, and now I have complained to the health authorities of my municipality. There is always a big fight with documents and phone calls just to get the smallest aid or service” (Interview 6). There were several similar examples in my data material about the lack of access to services that were rightfully theirs.

The procedures around the application and allocation of help devices from the centres for the allocation of help devices were by many of the informants experienced as a rigid and slow working system. One of the informants said: ”to get the physical support devices that I need to be able to function in my daily life, is the most tiresome thing with my disability. It has to do with the entire system from the beginning to the end. It is the entire procedure. It steals a lot of energy from my everyday life. Energy I need to do other thing. Nothing annoys me more than this” (Interview 4). The long processing of applications for help devices did indeed cause much frustration for the informants. One of them spent three years to get her last manual wheelchair. Another tried for twelve years to get a small dish washing machine for her kitchen. This application went all the way to the central authorities, and it was only when she threatened to inform the newspapers about the case, that she finally got it. The fight to get the help devices which they have a rightful claim to, literally wore the informants out, as this woman states:” Yes I do fight, but now I have stopped complaining, because I get so distracted by doing so…. Yes, completely worn out and now I am not capable of doing it any more. I must try to use the little energy I have for something more constructive, like living my life” (Interview 6).

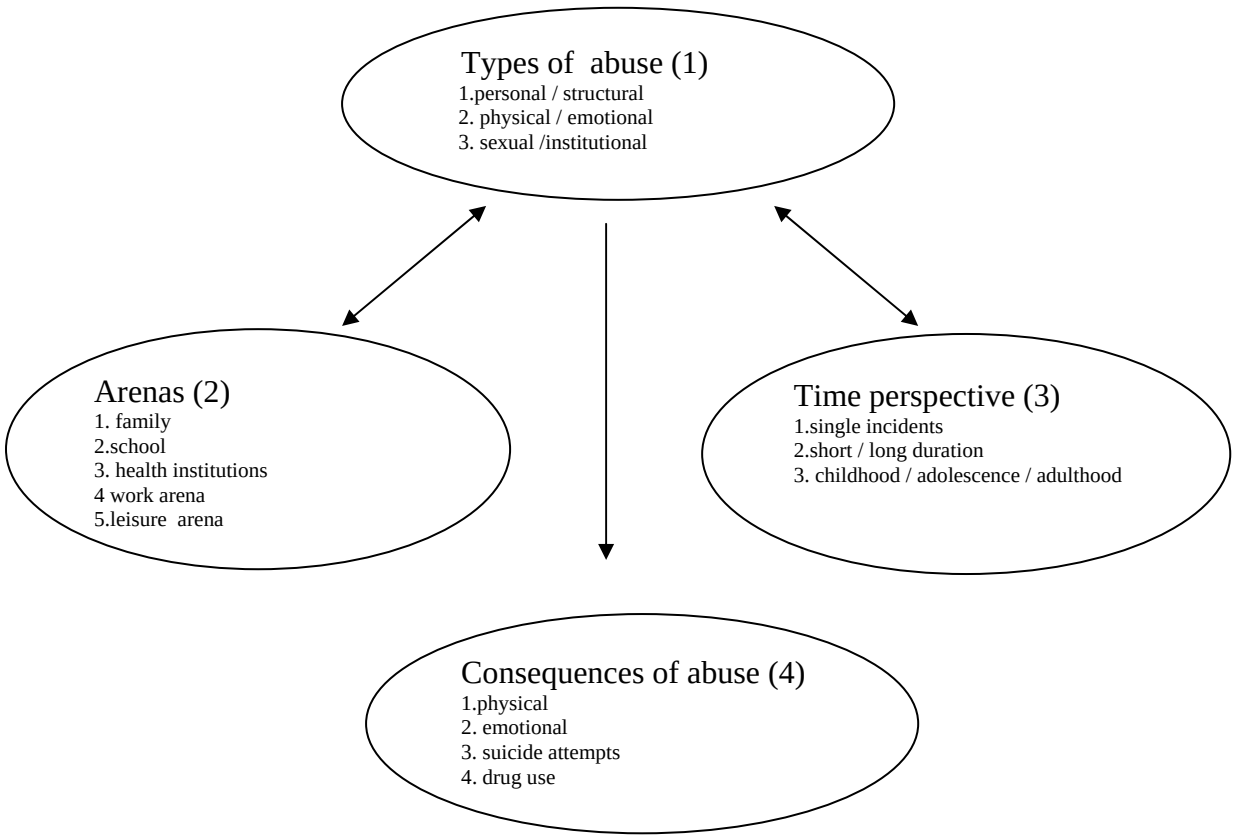
There were many examples of institutional abuse in my study, but few such explicit descriptions in the studies mentioned earlier. Institutional abuse in the form of neglect by the school authorities, lack of access to services and a rigid and slow working system of allocation of physical support devices are all examples of structural abuse which were experienced as discriminating and frustrating by my informants.

Part III The Context of Abuse

On the background of the information from the interviews, I have tried to visualise the context of the abuse by the means of a chart (see figure 2). In the first box, we find the different types of abuse, i.e. the two main categories of personal and structural abuse, followed by the two dimensions of physical and emotional abuse, and finally, the two examples of sexual and institutional abuse. In the second box we find the arenas where the different types of abuse have taken place, like the family, the school, the health institutions and the job and the leisure arena. The third box presents the different dimensions of the time perspective, if the abuse has been a single incident or if has been of a short or long duration. In addition, it is important to take into account whether the abuse happened during the informant's childhood, adolescence or adulthood. Both the different types of abuse, the time perspective and the different arenas where the abuse have taken place, have an impact on the consequences that the abuse has had for the individual. The consequences can be both physical resulting in bruises, cuts and broken limbs, emotional resulting in sleeplessness, anxiety and depression, and, even more seriously, they can result in suicide attempts and self harm or in a combination of several of these consequences.

In this part of the paper I will look more closely at each of the three last categories in figure 2; the arenas where the abuse have taken place, the duration of the abuse, and finally, the consequences the abuse have had for the informants.

Figure 2. The Context of Abuse



Arenas of Abuse

As we have seen, the family is one of the main arenas of abuse, both caused by the women's parents and siblings and by the women's marital partners. During the interviews a couple of the informants told me that they had been subjected to emotional and physical abuse by their parents and siblings. Some of this abuse had been made with reference to the child's disability, some had not. Among my informants there were no examples of incest, but we know from the news that this is more frequent than we like to think. A few women with congenital disabilities had felt emotionally hurt in their childhood, because they felt their parents had not fully accepted their disability. This had created an ambivalent relationship with one or both of the parents and had in one case led to a rupture with them. However, the majority of abuse that took place in the family was due to a former marital partner. This abuse consisted either of physical, emotional or sexual abuse, but was most often a combination of them.

We know both from the media and former research that the school is an arena for bullying (Olweus 1974). We also know that children who are ”different” in one way or another are more exposed to bullying than others. Therefore, children with disabilities may be victims of bullying more often than other children. In my study there were some examples of bullying, both physical abuse in the form of shoving and hitting, and emotional in the form of teasing and gossiping. In addition, I have one case of sexual abuse in the form of repeated pawing by the night watchman at a residential school for the blind. There were also some cases of structural abuse with regard to an early integration in the ordinary school without proper planning and preparation. Another case was about neglect from the school authorities by not adjusting the instruction for a hearing-impaired student who, therefore, had to learn to lip read the teacher on her own.

The third the arena for abuse was different health institutions, which the informants due to their disabilities had to use to a greater extent than persons without disabilities. The kind of abuse they were subjected to, was both emotional in the form of insults and degrading comments, and physical in the form of unnecessary tough treatment or lack of proper treatment which had caused physical harm to the informants. There was also one case of medical malpractice that had resulted in serious physical consequences like the loss of speech. I also have examples of sexual abuse in the form of pawing by a doctor and of peeping by a night watchman at a residential school. The structural abuse at the health institutions consisted of the informants not getting the services they had a legal right to (home nursing and personal assistants) or lack of adequate access to services (interpreters and home help) or not getting high-quality care and nursing services. A common complain was the rigidity and the slow processing of the allocation and repairing of help devices from the centres for the allocation of help devices, which one of the informants experienced as ”the most troublesome consequence of my disability”.

In my study there are only two examples of abuse that took place in the leisure arena. One of them was job related and happened during a dinner party at a seminar where the informant had spoken about her personal experiences with services for the disabled for a group of service providers. After dinner one drunken participant took the informant who was sitting in her wheelchair, off on a race through the corridors of the hotel. The informant experienced this as ”a physical kidnapping” which deeply upset her and resulted in her complaining to the man's boss, but to no use. Another type of abuse that also took place in the leisure arena, was in the form of sexual abuse by a trainer who arranged leisure activities for children with

disabilities. In this data set there are no reports of abuse at work, but there is no reason to believe that there is less abuse in the work arena than in any other arenas of society.

As we have seen, abuse takes place in all the arenas of society. One of the most upsetting finding in this study is that several informants had experienced abuse in several arenas and by several abusers. In the worst cases the abuse had begun at home, continued at school and then in their marriage, while they also experienced abuse in their encounters with the employees at different health institutions. For those of the informants who had experienced abuse in different arenas over a long period of time, the consequences were often serious and demanded professional help to mend.

The Time Perspective and Abuse

An important aspect of the abuse is the time perspective, i.e. when in the women's life span the abuse happened, and for how long the abuse was going on, especially with regard to the seriousness of consequences of the abuse. It also makes a difference, whether the abuse happened in the woman's childhood or her adulthood. The same is true with regard to whether the abuse took place as a single incident or was repeated over a longer period of time. It appears that the earlier the abuse happened and the longer the abuse went on, the more serious the consequences were for the victim.

In my study there are several examples of abuse that happened early in childhood. A couple of informants were exposed to sexual abuse at the age of four and five. Some had experienced physical and emotional abuse from their parents and siblings, while others had felt that their parents had not fully accepted their disabilities. For some the abuse had continued at school in the form of bullying by their fellow students or in the form of neglect by the school authorities who did not taking into consideration their disabilities. In addition, children with congenital disabilities had experienced both physical and emotional abuse in connection with their frequent stays in the hospital by being refused contact with their parents or by unnecessary painful treatments or due to deficient nursing and care.

Informants, who had acquired a disability later in life, had experienced the abuse as adults either by their marital partners or by employees in different health institutions. Abuse in adulthood is experienced just as degrading and hurtful as abuse early in life. The difference, however, is that as adults they are better able to cope with the abuse than children who often seem to blame themselves. Those who had experienced sexual abuse as adults seemed to be able to put the blame on the abuser and not on themselves and to seek help and support from friends, families or professionals.

It is the also decisive for the seriousness of the consequences of the abuse whether the abuse was a single incident or whether it was repeated over a long period of time. Four of the women had experienced the abuse as a single incident. Three of the four cases were of a sexual character, while the fourth was a physical kidnapping of a woman in her wheelchair. The remaining nine informants had been exposed to different types of abuse that had lasted for longer periods of time. The informants with congenital disabilities had for instance experienced repeated abuse during their stays in the hospitals. Only as adults were they capable of saying no to what they felt as abusive treatment and care. The informants who had acquired a disability later in life, and who, therefore, had not been socialized into the role of the patient from early childhood, found it easier to be critical and to voice their own demands with regard to the medical treatments they received.

In sum, it seems that the earlier the abuse happens in life, the more serious the consequences. The same seems to be true with regard to how long the abuse has gone on. The longer the period of abuse, the more serious the consequences are for the women. Even if this seems rather obvious, it is an aspect that often has been overlooked in the existing research literature.

Consequences of the Abuse

The consequences of the abuse for the informants can be classified in different categories, both with regard to physical and emotional effects and with regard to the duration of the abuse. The physical consequences that were mentioned by the informants were for instance fractures and cuts. Bruises and torn clothes were often the physical consequences after having been bullied at school, while fractures and cuts were the results of violence by marital partners. Injuries in the neck as a result of attempts of strangling or in the pelvis as a result of rape were also reported. The most extreme physical consequences of the abuse were suicide attempts by the women themselves. Two of the informants had made more than one suicide attempt. Physical self harm as a result of abuse over a long period of time was also mentioned by one of the informants.

One of the serious consequences of having experienced physical abuse either sexually or in other ways was a damaged relationship to their bodies. For instance, one of the informants who had experienced many invasive treatments in the hospital in her adolescence, said that she learnt very early that ”everybody can do whatever they want with my body” (Interview 4). Another informant who had had similar experiences, said that she realized from early on that:” I do not own my own body. In fact, I donated my body to the health services a long time ago” (Interview 2). A third woman was distrustful of men for a long time as a result of violence by her marital partner, and a fourth who had been sexually pawed in her youth, had still problems with sexual contact with men. A tragic consequence for children, who are exposed to sexual abuse in early childhood, seems to be that they believe this is the way things are supposed to be. This happened to two of my informants. Another serious consequence for children who are molested from very early on, is that they seem to loose their ability to say no to new sexual abusers, and, as a consequence, the abuse may continue.

The emotional consequences of the abuse are several and often serious. One of the informants, who was exposed to violence by her husband for several years, felt she became “brain washed”. Another who experienced the same kind of abuse, put it this way”at the end there was nothing left of me” (Interview 7). Other consequences were sleeping disorders both in childhood and later in life. One of the informants who has nightmares, as a result of a long-lasting bullying at school, said: ”I still have nightmares, and I have had them for many years…People are coming after me trying to kill me. In the morning I wake up drained and soaking wet and dread the thought of going to sleep again” (Interview 1). Panic attacks and depressions were also mentioned by some of the informants. ”I have had such awful depressions and have been troubled by lack of self confidence all my life,” one of them said to me (Interview 10). Use of alcohol and drugs as a means to forget the abuse, were also mentioned by the informants. Others described the emotional abuse as ”psychic terror” and ”brain washing”.

Not only abuse of a long duration, but also single incidents had left their imprints on the women. Even a brief incident was experienced as “an eternity”. ”The abuse was in itself small, but it left me devastated for a long time afterwards” said the woman who experienced

to be ”physically kidnapped” by a drunken participant of a course. The fury caused by this offence was as strong as was the feeling of helplessness. The two women, who in their adolescence had experienced sexual abuse during their stay in a hospital, also had an overwhelming feeling of helplessness. In addition, it felt especially shocking for them to be abused by a doctor and an employee at a hospital. Even though this happened years ago, it still upset them strongly. One informant, who was drugged and then sexually abused by a friend, experienced this incident as “a huge shock”. For her the after-effects came in the form eating and drinking disorders.

As we have seen, abuse has resulted in physical consequences in the form of bruises and cuts, and in emotional consequences in the form of sleeping disorders, panic attacks and depression. The consequences have also taken a more serious character in the form of suicide attempts, self - harm and mental problems. This seems to be the case if the abuse happened early in life and continued over a long period of time. Another serious consequence of the abuse was the fact that some of the women ended up with a disturbed relationship to their body. These are consequences that are very little discussed in the existing research literature.

The Causes of Abuse

How can we understand the abuse the informants have told us about? Is it mainly due to the informants’ disability or are other factors involved, like their gender, age or position? How do the women themselves explain the reasons behind the abuse they have suffered? If we first look at the bullying that took place at school, it seems like bullying in most cases is due to the victims’ ”difference” in one way or another. The informants themselves confirmed this, as they referred to the bullying as caused by either the way they walked or by their wheelchair, or because they did not hear or see as well as the other students. It seems not unreasonable to argue that this kind of abuse may indeed be caused by their disability, since other factors like gender and position seem to be less relevant.

According to the informants, disability is, however, not the main explanation, when it comes to sexual abuse of small children. This type of abuse seems mainly to be due to their age and the abuser’s sexual disposition, more than their gender or disability. One of the informants who had been exposed to sexual abuse as a small child, was very clear on this: ”No, it was not due to my disability, but more to the fact that I was a child. When it comes to sexual abuse of children, it has also less to do with gender than with power. When I got older, gender became more relevant, but I think it still mainly had to do with the need for power and control” (Interview 4). The main reason behind much of the sexual abuse of children, may indeed be, as this informant says, the issue of power and control.

Those of the informants who had experienced sexual abuse as adults by their marital partners, agreed that the need for power and control was an important reason why sexual abuse happened, but that gender and disability also played a part. The power aspect was central for this informant who said:”Power I believe - if he did not get what he wanted, the result was violence, and that included rape” (Interview 9). Another informant saw, however, her disability as the main reason for the sexual abuse and said: ”My disability was the reason that he got the upper hand. I could never offer him much resistance – and he knew that”. This was confirmed by a third informant who said:” He was not able to tackle the fact that I was disabled … The less functional I became during the years we were married, the more violent he became” (Interview 7). Some of the abusers were, according to the informants, alcoholics and sociopaths, and women used this as an explanation as to why they had been abused by

their partners. In the one single incident of sexual abuse experienced by one of my informants, mental illness was obviously an important factor, but by drugging the woman the aspect of power and control seems to have been an additional cause.

The informants who experienced sexual abuse in the hospital setting related this first of all to the unequal power relationship between patients and hospital staff. Both the doctor and the night watchman were misusing their positions in the hospital in relation to the patients. They took advantage of the vulnerable situation of the patients, and also of their young age and gender. Unfortunately, due to their disability, the informants found themselves quite often in similar vulnerable situations, and this vulnerability has been pointed by several researchers for instance Calderbank ibid, Shakespeare ibid and Sobsey ibid). The medical malpractice that one of the informants suffered in a hospital is an example of the ultimate abuse of power which, of course, had serious consequences both for her, but especially for her children. Being now speech- handicapped, she typed the following:”the malpractice put an effective stop not only for my work, but also to my role as mother. I felt an awful grief in my heart on behalf of my children, because I not was able to help them” (Interview 3). Such institutional abuse, of which we have seen examples both from the school in the form of neglect and lack of planning, and from health the institutions in the form of abuse of their power position, illustrates quite well the importance of power and control, when it comes to understanding the reasons behind the abuse.

Part IV The Conclusion

In concluding I will point to a couple of topics that I see as the most important contributions from this study. The first one is the attempt to create a more comprehensive typology of abuse, where the classification in personal and structural abuse is central. The second one is the mapping of a more complete picture of the context, within which the abuse takes place. The third one is the attempt to understand why abuse happens, and to take into account the reflections of the victims themselves.

The Typology of Abuse

Few of the studies mentioned earlier have tried to establish a typology of abuse, such as the one used here (see figure 1). The classification of abuse into personal/direct and structural/indirect abuse has not been made explicit, even though several studies refer to institutional abuse as a type of abuse of which people with disabilities are particularly exposed. The research literature mostly focuses on sexual abuse against people with disabilities (Kvam (2001, 2003), Muff (ibid)), but also to some degree on physical and emotional abuse (Calderbank (ibid), Finndahl (ibid), Nosak (ibid), Roher Institute (ibid)). Galtung's (ibid) classification of the concept of violence into the two categories of personal and structural violence has been helpful, since this classification makes us more conscious of the diffuse, but important structural aspect of abuse. In my study there were many examples of institutional abuse as part of the structure and routines of the institutions. According to the informants this was the type of abuse that was the most problematic for them, and it was, therefore, important to include it in the typology. I see my work as a small step in direction of a more comprehensive typology that will need to be developed further, especially with regard to the different aspects of structural abuse.

The Context of Abuse

In this study I have also tried to draw a more complete map the main components of the context within which the abuse takes place (see figure 2). I have tried to do this by drawing attention to the complexity of the process that a person who has been abused, will go through. Some of these components are the different arenas of abuse, the consequences of abuse, the time perspective of the abuse and the reasons behind the abuse. The time perspective has so far received little attention in the research literature. This is, however, an aspect of importance with regard to the consequences of the abuse. Abuse that has taken place early in life, or that has lasted over a long period of time, seems to have more serious consequences and to need more support from friends and families as well as professionals. Again former studies have included pieces of this context, but we are still far from having drawn the whole map.

The Causes of Abuse

In the studies mentioned earlier there have been several attempts to explain why abuse happens, but few of them have included the informants' own understandings of the reasons behind the abuse. Sørheim (ibid) who also included sexual abuse in her study on women with physical disabilities, says that it is important to study the circumstances of the abuse to understand why it happens, as I have tried to do in this study. In her opinion, sexual abuse is less about sexuality than about what she calls "unequal values", and the belief that you can do what you want with those who have less value. According to her, abuse can be seen as a demonstration of power, and as an expression of the hierarchical power structure in our

society, i.e. between men and women, children and adults, persons with and without disabilities, as well as between professionals and people with disabilities (p.100-101). Her assumptions are to a great degree supported in this study.

When it comes to explain abuse against women with disabilities, Finndahl (ibid) points to the following factors: the women's dependency and their need for help, the abusers' need for power and control, the women's feelings of quilt and shame with regard to their disability and their life situation, their limited possibilities to set their own boundaries, and the women's social isolation partly due to their lack of work (p. 67-69). Muff (ibid) in her study of the literature on sexual abuse, underlines that most of the factors that have an influence on the risk for sexual abuse against women with disabilities, are either directly related to their disability or are consequences of the relationships that women with disabilities are part of due to their increased need for medical treatment and support by professionals (p.12).

In this study, I have, by including the informants own explanations, tried to illustrate that the reasons for abuse against women with physical disabilities may vary from situation to situation. In some situations the main explanation may be the women's disabilities, while in other situations it may be gender or age, but that the underlying reason is related to the hierarchical power structures of our society and our institutions. However, more research is needed, before we can say that we have a clear understanding of the typology and the context within which abuse takes place in addition to a better understanding of the reasons behind the abuse.

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”Vulnerable, exposed and invisible?” A Qualitative Study on Violence and Abuse against women with Physical Disabilities

This paper which was presented at the 20th World Congress of Rehabilitation International in Oslo in June 2004, is the first part of a three year study on violence and abuse against women with physical disabilities financed by the Foundation for Health an Rehabilitation. The main contributions of this paper are, first, an attempt to create a more comprehensive typology of abuse based on a classification of personal and structural abuse, second, a mapping of a more complete picture of the context of the abuse with a special focus on the arenas of the abuse, the time perspective and the consequences for the women, and, thirdly, an attempt to illustrate that depending upon the situation the reasons for the abuse may be related either to the women’s disability, their gender, age or to the hierarchical structure of the institutions with which they have to deal.

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