



Life after violence

A study on how women with intellectual disabilities cope with violence they experienced in institutions



Representing people with
intellectual disabilities and their
families in Europe

Life after violence

A study on how women with intellectual disabilities cope with violence they experienced in institutions

Rue d'Arlon 55, 1040 Brussels, Belgium

Telephone: +32-2-502 28 15

secretariat@inclusion-europe.org

www.inclusion-europe.eu

This study was funded by the Open Society Foundation.

The OSF bears no responsibility for the contents of the report.

Text:

- Juultje Holla
- José Smits

Research consultants:

- LFB (www.lfb.nu)

Pictures:

- Juultje Holla

2018, Inclusion Europe



For easy-to-read version of the report please visit www.inclusion-europe.eu.

Foreword

As a woman who spent part of her life in an institution myself, I feel very strongly about the subject of this publication.

And I am proud to be part of this research and to present to you this publication.

At the beginning of this study was a question:

“What happens to women with intellectual disabilities after they had experienced violence in an institution?”

How does their experience shape their lives once they leave the institution to live in the community?

There is no better way to find the answers than to speak to the women themselves. But would they trust us, speak to us, and open up about their very painful experiences?

We found some very courageous women who did speak to us and share their stories. They told us about the violence and abuse they experienced. They shared with us the fears and worries they still have today. And they showed us the strength they have to overcome even the most impossible situations.

What we see in their stories is that violence to women happens everywhere – in institutions, in families and in the community.

Indeed that is what was my personal experience too.

This publication gives you the opportunity to listen to what the women are saying about violence that happened to them mostly in institutions.

It starts with understanding what violence is, through learning how the women dealt with it, to recommendations on how we can improve the situation.

Sometimes it is difficult to read about all these bad experiences. But we should not close our eyes and ears from what women have to go through.

Perhaps we can take courage in the examples these women set in dealing with the violence and abuse, and in not allowing it to shape their whole lives.

There is life after violence.

I would like to thank Juultje Holla who has written this publication. Through taking the time to really listen she has empowered our sisters to speak out. Through writing their stories down, she helped them to be heard all over Europe.

Thank you also to my colleague José Smits. She did much of the desk research for this publication.

And of course I will not forget to thank my friends from the LfB, the self-advocacy organisation in the Netherlands. Without their contacts and support this publication would not be possible.

I would also like to thank the Open Society Foundation. They gave us the money to do this work. They helped us to make sure that people all over Europe know more about women with intellectual disabilities who have experienced violence.

The biggest thank you goes to the women themselves.

For giving us their trust and for talking about what they had gone through.

I like to believe we are repaying them by this publication and by working to reduce the number of women who have to go through similar experience.



Senada Halilčević

Vice-President of Inclusion Europe

Chair of the European Platform of Self-Advocates

Index

Introduction.....9

Violence against women.....13

Women in institutions.....25

Experiences with structural violence.....29

Experiences with violence through carelessness.....37

Effects and consequences of experiencing violence.....42

Life after violence.....49

Methodology of the study.....66

Desk Research Report69

1.

Introduction

Violence against women and girls is one of the most systematic and widespread human rights violations. It is rooted in gendered social structures rather than individual and random acts. It cuts across age, socio-economic, educational, and geographic boundaries, and is a major obstacle to ending gender inequality and discrimination globally.¹

The United Nations (UN) defines violence against women and girls as “any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life”.² This also includes forced medical treatment without consent.

States have the obligation to ensure that women and girls are not subjected to violence, and to eliminate structural violence. Inclusion Europe and its members stand united in the fight against all forms of violence and abuse.

Compared to non-disabled women, women with disabilities are at a greater risk of severe forms of violence; they experience violence at significantly higher rates, more frequently, for longer, in more ways, and by more perpetrators; they have considerably fewer pathways to safety, and are less likely to report experiences of violence.³ Yet programmes and services for women with intellectual disabilities either do not exist or are extremely limited.⁴

¹ UN General Assembly, 2006

² General Assembly Resolution 48/104 Declaration on the Elimination of Violence against Women, 1993

³ See UNHCHR, *Thematic study on the issue of violence against women and girls and disability*, Report of the Office of the United Nations Commissioner for Human Rights, UN Doc. A/HRC.20/5, 30 March 2012.

⁴ Women With Disabilities Australia (WWDA), *Submission to the UN Analytical Study on Violence against Women and Girls with Disabilities*, December 2011.

Nearly 1.2 million children and adults with disabilities are living in long-stay residential institutions⁵ across the European Union (EU) Member States and Turkey.⁶ Institutions are any residential care facility where residents are isolated from the broader community and/or are compelled to live together; residents do not have sufficient control over their lives and over decisions which affect them; and the requirements of the organisation itself tend to take precedence over the residents' individualised needs. Inclusion Europe and its members are committed to ending institutionalisation, and to promoting living independently and being included in the community as described in Article 19 of the United Nations Convention on the Rights of People with Disabilities (UN CRPD).⁷ This includes supporting people living in institutions to move into the community, and preventing new people having no other choice but to move into an institution.

Knowing that the incidence of disability is higher in women than in men,⁸ hundreds of thousands of European women are at a very high risk of different forms of violence in such places. Some of these forms of violence are common to all women, while some are specific to the institutional settings they live in. For example, women in institutions are systematically deprived of their right to found a family, by being exposed to involuntary contraception and sterilisation.⁹

Some research has been done in terms of gender-specific violence against women in institutions,¹⁰ as well as domestic violence against women with intellectual

5 See European Expert Group on the Transition from Institutional to Community-based Care ('the EEG'), *Common European Guidelines on the Transition from Institutional to Community-based Care*, November 2012, p. 25.

6 Mansell J., Knapp M., Beadle-Brown J. and Beecham J., *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*, Volume 2: Main Report (Canterbury, United Kingdom: Tizard Centre, University of Kent, 2007), p. 97, as per United Nations Office of the High Commissioner for Human Rights, *Forgotten Europeans – Forgotten Rights: Human Rights of persons in institutional care*, October 2012

7 <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19>

8 See e.g. WHO, *World Report on Disability*, 2011, p. 52.

9 In Hungary, for example, women in institutions are routinely being administered IUDs in the absence of informed consent and despite registered protests of some of the women concerned. For more info on forced sterilization of women worldwide see e.g. Open Society Foundations, *Against her will, Forced and Coerced Sterilisation of Women Worldwide*, 2011.

10 For example: Human Rights Watch, *Treated Worse than Animals / Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India*, Report, 2014.

disabilities.¹¹ There has also been plenty of work done regarding the unfavourable effects of institutions on individuals. Many people have already left institutions to live in the community. However, the discourse seems to stop once women with intellectual disabilities have left an institution. It seems to be considered enough just to relocate people from institutions or institution-like settings, where they were subjected to different forms of violence for long periods of time, into the community. However, for many of them, this is where another struggle starts.

The research project “Life after Violence” has shed some light on these issues. Across a period of two years, we had the opportunity to interview and work with women with intellectual disabilities in the Netherlands. We were able to freely develop our methodology, adapting it to help women with intellectual disabilities to open up about their experiences of violence. They were more open to talking about their experiences than we had initially expected.

As documented in the Desk Research Report in Chapter 10, the Netherlands’ extensive legal and policy framework related to people with disabilities establishes an approach intended to foster active, independent living for this part of the population, and to ensure their inclusion in the social fabric of the country. However, the reality for women with intellectual disabilities often does not live up to the promise of these policies. The specific situation of people with intellectual disabilities needs to be a continuous focus of government concern; the needs of women with intellectual disabilities are often not adequately addressed in policy for people with disabilities in general, and the programmes intended for their benefit fail to produce significant results. While the overall number of people using personal budgets¹² has increased and the number of placements in institutional care facilities has dropped, people with intellectual disabilities continue to be placed in institutional care facilities. Due to the unavailability of data disaggregated by disability, it is unfortunately not possible to draw general conclusions.¹³ Additionally, given that the Netherlands only ratified the CRPD in January 2016, it will be important to explore if this will be of any influence to the development of policies for persons with intellectual disabilities.

11 University of Kent is currently conducting a two year research project on Domestic Violence and Women with Learning Disabilities. For more info see <http://www.kent.ac.uk/tizard/news/index.html?view=895>.

12 In Dutch: PersoonsGebonden Budget (PGB). Personal budgets allow individuals to decide for themselves what kind of care they purchase, from which source.

13 For the latest available data, see: <http://mlzstatline.cbs.nl/Statweb/publication/?DM=SLNL&PA=40055NED&D1=a&D2=0&D3=0&D4=1,3-4&D5=13&D6=0&D7=a&HDR=G5,G1,G2,G3,T,G6&STB=G4&VW=T>

We worked with the following research questions:

- What violence do women experience, and what violence is specific to institutions?
- What do women do to deal with this violence?
- What happened when they move to a smaller setting or out of the institution altogether?
- How do their experiences influence their opportunities to develop a life included in the community?
- What would support them to deal with these traumas?

Please note that the names and circumstances of all women with intellectual disabilities mentioned in this publication have been changed in order to guarantee their privacy and avoid further harm.

2.

Violence against women

The definition of violence has been the subject of many scientific and legal publications. Our study started with desk research about these definitions, and the detailed results can be found in Chapter 10 of this publication.

Violence has been defined in three different perspectives:

- From a legal perspective, violence is defined as all the violations and crimes that are described in criminal law.¹⁴ Specific acts may be described in criminal law, such as rape, beating, abuse etc. A specific punishment may be described when these acts are committed.
- From a psychological perspective, violence is acknowledged to be all the acts that are perceived by the victim as violent, intimidating, and forms of hurtful behaviour that cross ethical boundaries. With this perspective, violence can include much more than the acts described in criminal law.¹⁵
- The sociological perspective looks at violence within the context of societal structures and power balances between groups and individuals.¹⁶ For instance, relations between care workers and persons living in institutions are strongly influenced by the extreme dependency of the care receiver on the caregiver, as well as by the organisational demands, institutional culture, and legal status of the person living in the organisation.¹⁷

In research and policy reports on violence at national level, emphasis usually lies on physical and sexual violence. However, in the norms, rights, and values laid down in many covenants of the international community,¹⁸ much more emphasis lies on societal structures and imbalances of power. Violence against women is

¹⁴ Beperkt weerbaar, een onderzoek naar seksueel geweld bij mensen met een lichamelijke, zintuiglijke of verstandelijke beperking. Utrecht, 2011

¹⁵ Beperkt weerbaar.

¹⁶ Factsheet Seksueel geweld, MOVISIE, 2009; Höing & Van Oosten, 2004).

¹⁷ see for effects on behaviour of people living or working in institutions: Goffman, E. (1961), Asylums: essays on the social situation of mental patients and other inmates, New York: Anchor books.

¹⁸ For example the Convention on the Elimination of All Forms of Discrimination Against Women CEDAW (adopted 1979 by the General Assembly of the UN):

acknowledged as discrimination, which hinders women in the exercise of their human rights and their ability to develop on an equal footing with men.

The Council of Europe adopted the Convention on preventing and combating violence against women and domestic violence, in 2002. The Convention describes violence against women as “a form of gender-based violence that is committed against women because they are women.”¹⁹ The Council of Europe explains: “Stalking, sexual harassment, sexual violence (including rape), physical, and psychological abuse at the hands of intimate partners, forced marriage, and forced sterilisation are deeply traumatising acts of violence. The overwhelming majority of victims are women. Adding female genital mutilation and forced abortion as forms of violence that only women can be subjected to, shows the shocking level of diversity in cruel and degrading behaviour that women experience. If we consider the fact that most violence is carried out by men, it is just a small step to understanding that violence against women is structural violence – violence that is used to sustain male power and control.”²⁰

Violence against women with disabilities

In General Comment No.3, the UN Committee on the Rights of Persons with Disabilities emphasises the effect of societal structures, power imbalances, cultural attitudes, and family structures on the enjoyment of human rights, especially the right to be free from violence: “Women with disabilities are at a heightened risk of violence, exploitation and abuse compared to other women. Violence may be interpersonal or institutional and/or structural. Institutional and/or structural violence is any form of structural inequality or institutional discrimination that keeps a woman in a subordinate position, whether physically or ideologically, compared with other people in her family, household or community.”²¹ This was confirmed by the report of the UN Special Rapporteur on the Rights of Persons with Disabilities addressing sexual and reproductive health and rights of girls and young women with disabilities.²²

¹⁹ Council of Europe Convention on preventing and combating violence against women and domestic violence, Council of Europe Treaty Series (CETS) 210, 11.V.2011

²⁰ <http://www.coe.int/en/web/istanbul-convention/about-the-convention>

²¹ CRPD, General Comment No 3 Article 6: Women and girls with disabilities (Adopted 26 August 2016), para 29.

²² UN Special Rapporteur on the Rights of Persons with Disabilities: *Sexual and reproductive health and rights of girls and young women with disabilities* (A/72/133).

Violence against women with intellectual disabilities

Several societal factors contribute to putting women with intellectual disabilities in a vulnerable situation, especially when they are living in institutions. For example, these women may be directly dependent on possible perpetrators - legally, financially, or emotionally. They are often isolated, often with little or no outside social interaction, and fear that reporting abuses may result in institutionalisation, retaliation, further violence (including verbal abuse and intimidation) and a loss of support and aids.

Their lack of effective access to justice, reporting, and prevention mechanisms makes it very difficult for them to fight against violence. Especially when they are deprived of legal capacity, the barriers in the justice system are almost insurmountable. Even when they report abuse, victims often are not perceived as credible.

Women with an intellectual disability are often in a vulnerable position in society, making it easier for perpetrators of violence to abuse them. This has its roots in their experiences of segregation. They may have:

- never had the opportunity to learn when someone is using them for personal gain or satisfaction;
- a lack of opportunities for education and dialogue, for instance on sexual intercourse;
- a feeling of inferiority, developing as early as childhood; a belief that others know better;
- never been empowered to express their opposition, to say 'no' to others;
- never been taught to physically defend themselves.

This is the experience of a woman we interviewed:

“When I was 18 I was raped. A man came over to speak to a friend and I. He said that if we didn't go with him he would spread gossip about us. About us being prostitutes. I was scared my mum would hear these rumours. So I went with him. He took me into a restaurant. He told me to go to the toilet. He came after me and raped me there.”

(Tanya, aged 25)

Violence happens everywhere; at school, in families, on the street with strangers, and in institutions. Although our research focused on violence in residential institutions, women told us about any violence they had experienced. We gathered a wide variety of examples of violence, both outside and inside institutions. We noticed that women identified different kinds of violence inside and outside of institutional settings.

Much, though not all, of the experiences of direct physical and sexual violence that women told us about took place outside the institution. Physical violence, for example, also took place in families where the women were deemed 'not good enough'. We were told of sexual violence perpetrated by family acquaintances, strangers on the street, and also by a therapist.

While we also found direct physical and sexual violence committed by staff or by other clients in institutions, the violence people experienced in institutional settings was more about power imbalance. For example, it involved:

- others making decisions regarding someone's life, without the person affected having a say;
- rules and regulations made by others without the input of the person concerned;
- being treated as part of a system rather than being an individual;
- people not getting the care they need or not having people in their lives who care about them.

The fact that most experiences of direct violence take place outside institutions most likely reflects that in the Netherlands, all residential institutions have rules and procedures for combating and dealing with direct physical and sexual violence. However, as all women shared violent experiences from their time in the institution, these rules and procedures are evidently not sufficient to ensure safety from other forms of violence.

Violence experienced by women with intellectual disabilities

When talking to women with intellectual disabilities in our study, they raised many experiences that did not fit well into existing legal categories of violence. The research team therefore decided to employ a psychological perspective, where violence is acknowledged to include all acts that are perceived by the person who has been harmed as violent, intimidating, and hurtful. This subject-led approach allowed us to take into account all the experiences that women with intellectual disabilities thought about when they heard the word violence, at face value. The common denominator between the experiences was that someone felt hurt by a situation or by the actions of others.

The most common first thoughts of women with intellectual disabilities were focused on physical violence, for example, ‘hitting people’, and sexual violence, for example, ‘touching without permission’. In discussion groups, we asked what else violence could be. Most of the time, someone would raise psychological violence. The list usually grew from there.

Through this process, the women came up with a wide variety of experiences of violence. We drew these examples on cards to see if they would help other women to talk about their own experiences. We illustrated new forms of violence, adding to the collection of cards, as women shared their experiences.

To date, the cards depict the following types of violence:

- physical violence;
- sexual violence;
- psychological violence;
- neglect;
- being forced to take undesired medication, or not being given proper information about the medication;
- financial abuse;

- being prevented from speaking up for yourself or others, for example being told to “shut up”;
- incarceration, having your freedom involuntarily taken away;
- violence through social media, such as stalking, and using your data or photographs without permission;
- not getting opportunities like other people, for example to be educated or find a job;
- not being taken seriously, not being listened to;
- being prevented from having your own family.



While the women were talking, many would pick up various cards in relation to an experience they had had. One participant explained: *“My experience doesn’t fit with only one card. There were many cards for that one experience.”*

They would also take a number of cards and relate them to their entire life story, including many separate experiences. For example, one participant said: “*I have had that one, and that one, and that one...*”

All of the women had also experienced exclusion and segregation before they came into a residential institution. Disempowerment and vulnerability due how they are treated in view of their intellectual disability and gender made them easy victims for violent behaviour, and indeed all ten women reported that they had experienced some form of violence.

Despite the range of illustrations available depicting various kinds of violence, the women nevertheless often felt their drawings were missing to relate to their specific experiences. The cards proved to be good conversation starters, but they do not offer a complete picture of what women with intellectual disabilities think about when they think of violence.

Participants discussed the words “violence”²³ and “abuse”²⁴. Some women felt that only physically harmful violence constituted violence, and all the other experiences were abuse. At the same time, we acknowledge that abuse is also harmful, so have included abuse as a form of violence. We are thus employing a very broad definition of violence, as anything that can be harmful and that can have long-term effects.

In some cases, women described situations in which they were the victim of another person who hurt them physically or psychologically. In other cases, there was no one clear perpetrator; women felt abused and neglected, for instance, because they were very limited in their choices as a result of their care provider’s rules and regulations. Women sometimes told us memories of what they perceived as abuse, which may have been meant by care providers as part of necessary treatment, such as putting someone in isolation, undressing them without permission, medicating without consent, and handling them with force.

With these case studies in mind, we identified three areas into which we can fit the violence that women perceived and remembered. We have called them:

- *Direct violence*: when someone intentionally tries to hurt someone, person to person.
- *Structural violence*: when someone is hurt through societal structures, systems of power and control, or rules and regulations.
- *Careless attitude*: when someone gets hurt because someone they depend upon does not care about them.

²³ In Dutch: geweld

²⁴ In Dutch: misbruik

Direct violence against women

Direct violence is what people usually mean when talking about violence. Statistics in the Netherlands reveal that 33% of women without disabilities experience sexual violence, compared to 61% of women with disabilities.²⁵ Direct violence is also called ‘personal violence’. It is when one person intentionally hurts another person. This can be done in many ways, such as sexually or physically, but also psychologically, financially, and through neglect. Violence in this category is a legal offence, often even under criminal law.

The women we spoke to clearly recognised direct violence. Yet sometimes, the boundaries between this type of violence and the other types are very thin. While women generally receive most recognition for reporting direct violence, many incidents still go unreported.

A lot of the cases of direct violence that we heard about took place outside an institution. The perpetrators were family, friends, friends of friends, or complete strangers.

The perpetrators of direct violence inside institutions were fellow clients, visiting friends of clients, or members of staff.

“I was abused by a man living in the same corridor as me. I was 10 or 11 when it started. I didn’t know anything about sex and things like that. He wanted to do more every time. He said we were playing mums and dads. I didn’t want to play. I did not say anything. I thought this was quite normal.”

Lucy, aged 32

The abuse was very hurtful to Lucy. However, the way the institution dealt with this violence also left a mark on her:

“I was always scared that he would come into my room. It got to the point where I was no longer sleeping. At some point I decided to tell one of the staff members whom I trusted. I got a psychologist and educational therapist. I had to have lots of talks with them. It was like I was being punished, even though I thought he was the guilty one. They even asked me if it had turned me on. I really felt like I was the criminal.”

Lucy, aged 32

²⁵ Beperkt Weerbaar, reference to Casteel, Martin, Smith, Gurka & Kupper, 2007; Powers et al., 2002; Reiter et al. 2009

Throughout the research, it appeared that violence is a taboo topic. People said we had to be careful talking about violence. Support workers thought talking about violence might bring up painful memories. Also, many said that they were not qualified to talk about violence. However, a lot of the women did not have a lot of people in their lives that they trusted. Due to feeling inept to discuss this topic, support workers often suggested only going to a therapist. This made the women feel like they were not being taken seriously or that support workers did not care.

“I was afraid of the consequences if I went to the police station. Nobody helped me with that. They just sent me to a therapist. He was moved to another place. I don’t know what happened to him, but I think he was not punished at all.”

Lucy, aged 32

Lucy mentioned that when the perpetrator has a disability as well people think it is because of their disability that they acted the way they did. But this is no excuse. Boys and men should be taught these things, regardless of their disability. She also said that if the perpetrator does not have a disability people often do not believe the person who experienced the assault.

Sometimes, people received support to bring charges against someone. None of the women in this study were successful in their cases:

“When I finally told someone what had happened, I was taken to a police station, quite far away. I was put in an interrogation room. It was a bare, grey room. My mother was not allowed to come with me. They asked me all sorts of questions. I did not feel comfortable at all. They told me they were filming everything. Later in the corridor they said: ‘Here goes our movie star.’ To this day I am scared of confined spaces. I always want to sit with my face to the door to see who comes in. That is the effect the police interrogation had on me. The man who did this to me was only in for a few hours. Then he was discharged for lack of evidence.”

Tanya, aged 25

Often the women realised relatively late that they could have gone to the police. Sometimes they were advised not to go. Other times, they were not told about the possibility. Knowing and understanding the options to address direct violence is an issue.

“My sister’s boyfriend came to my house drunk one night. It was very late. He wanted coffee. He was talking nonsense. I wasn’t sure what he wanted other than coffee. Suddenly he grabbed a knife and stabbed me in my leg. I got away and locked myself into the bedroom. I phoned the police. He ran off, but they caught him. He was in a cell for one night. I was in hospital getting stitches. My support workers did not support me. It was a lot later when I realised I could have pressed charges. Then he might have been in jail a bit longer. Then again, my sister was furious with me, even without her boyfriend going to jail. So I don’t know what I would have done. But it would have been nice to know I had a choice.”

Dorien, aged 50

When a woman has experienced direct violence, there are several potential kinds of support available, such as therapy and victim support organisations. As this is the only officially recognised form of violence of the three we have identified, it is also the only kind for which official help is available. This assistance needs to be accessible, and women need to trust that they will not lose anything by talking about what happened to them.

Violence from different perspectives

Sometimes, the women talked about situations that are not often recognised as violence. Those cases nonetheless had an impact on the women, who perceived what happened to be violent or at least harmful enough to have a lasting effect.

There were different reasons why care itself was sometimes seen as violence by the women:

- Women had received too little information to understand what was happening;
- Care staff did not have enough time or skill to get to know the women well enough to work with them;
- Care staff were being rushed;
- Care staff were not trusted individuals in the person’s life.

All of this may have led to situations where women were subjected to interventions or care measures without their valid informed consent. In the context of the Convention on the Rights of People with Disabilities, this is clearly “forced treatment” and in violation of legal norms. Some of these reasons that the women saw what was intended as care to be violence can also be classified as structural violence.

There seems to be a gap between what women with intellectual disabilities experience as violence, and the perceptions and intentions of the support staff. While most support staff are in their role to care, not to hurt anyone, it is important for them to listen to what women themselves experience as violence, even if they, from their perspective, do not recognise violence in the experience.

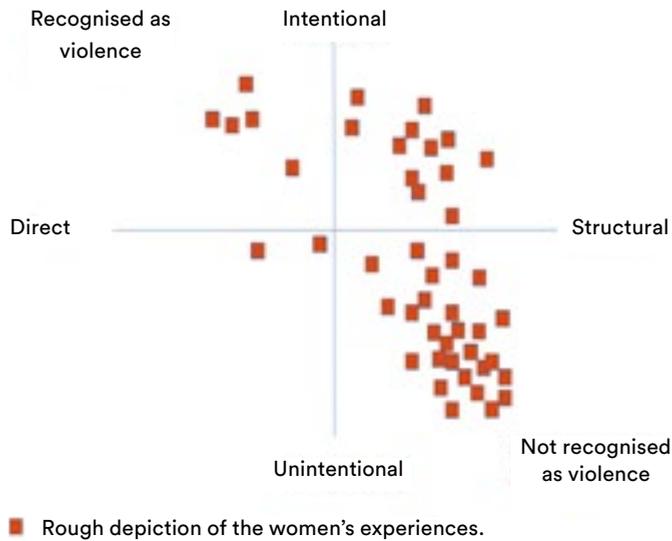
Understanding the different areas of violence

A lot of the experiences the women talked about were not straightforward examples of the personal and intentional violence we often think of when talking about violence. Following Johan Galtung,²⁶ we can best describe many of these cases as “structural violence” in the sense described by Lee: “It refers to the avoidable limitations society places on groups of people that constrain them from achieving the quality of life that would have otherwise been possible. These limitations could be political, economic, religious, cultural, or legal in nature and usually originate in institutions that have authority over particular subjects.”²⁷

With structural violence, there is no single person to blame. Structural violence can take place without one person intending to harm the other person. Much of the time, people are not even aware of their impact. Structural violence formed the largest part of the violence experienced by the women we interviewed.

²⁶ Galtung, Johan: Violence, Peace, and Peace Research. *Journal of Peace Research*, Vol. 6, No. 3 (1969), pp. 167–191

²⁷ Bandy Lee: Causes and cures VIII: Environmental violence. In: *Aggression and Violent Behavior*. 2016. pp. 109–114



Categorising the experiences reported by women with intellectual disabilities in the dimensions “intentional vs. unintentional” and “direct vs. indirect” shows a clear distribution:

- Direct and intentional violence is recognised as such, but is the form of violence least frequently experienced by these women.
- Structural and intentional violence is sometimes understood, but often described as inherently necessary in an institution.
- Structural and unintentional violence is often not recognised, although the women participating in the research reported it as the most frequent form of violence they experienced.

3.

Women in institutions

In this chapter, we describe the experiences of women with intellectual disabilities in residential care institutions in the Netherlands. It was not the purpose of our research to develop statistically valid results, nor did we have the access or resources to do that. We interviewed women after they had left their institutions and were living in the community.

One important aspect of the experiences of women with intellectual disabilities wvrelated in this chapter is the clarity of their analyses and their full understanding of their situations.

Experiences before institutionalisation

Many of the women we spoke to already had negative experiences prior to moving into a residential institution. For example:

“At home I was always beaten by my father. My brother and sister were never beaten. They were good enough. I was never good enough. My mother never protected me. Even though I ended up in hospital. Even though he broke the door by throwing me against it. Nobody protected me.”

Dorien, aged 50

People also had memories of being moved from one institution to another, or from childcare into adult care.

“I was placed in care at 11 months of age. As a child I was always moved around. Like a lost parcel in the postal services. Every time I reached a certain age, I had to move again. I just wanted a home. Somewhere I felt safe.”

Mary, aged 47

“I thought I could do everything as a teenager. I was always fighting with my mum. When I was 15, I went to live in a house for difficult kids. I went voluntarily. All the others were placed there by a judge. It was an open facility. Everyone could walk in and out. Including drug dealers and lover-boys.”

Saskia, aged 32

Women come to each new residential institution carrying a number of positive and negative experiences from previous institutions, which have already shaped them. In the institution, they come across many people they have never met before, who do not always understand what they have been through. This may cause vulnerabilities that staff and other residents do not know about.

Living in large residential institutions

An institution is any residential care facility in which people who have been labelled as having a disability are isolated and segregated from the wider community and/or are compelled to live together. In an institution, residents do not have or are not allowed to exercise control over their lives and over decisions that affect them. The requirements of the institution itself tend to take precedence over the residents' individualised needs. An institution is not defined merely by its size.²⁸

Many women with intellectual disabilities are placed in an institution at some point in their lives. In the institutional setting there is always a power imbalance, as the inhabitants are dependent on support workers. There are some very good support workers, there are many who try to be good support workers, there are those who just do not seem to care, and there are some who may intentionally hurt the people they are meant to support.

Furthermore, there are always rules and regulations. People living in institutions are to some extent separated from the rest of society. In institutions, there is a lot of focus on people's disabilities, as that is why they are there. The support workers get to go home at the end of the day, while the 'clients' are continuously living in this situation.

²⁸ Following the definitions of the European Coalition for Community Living (ECCL) and the European Expert Group EEG

Dependency on support

Due to their intellectual disability, and often also due to other additional disabilities or chronic illnesses, women with intellectual disabilities can be dependent on support for their whole lives. Support can be provided by family members, and also by support workers.

This dependency on support influences their lives. While most family members and other supporters are an indispensable source of inclusion and assistance, they can make life also very difficult for the person with intellectual disabilities. For example, in our study, it was found that some women gave up on building long-time relationships of trust with support workers because they changed so quickly.

“I never spoke to support workers about what happened. I was scared my dad would hurt me again. Support workers kept changing and the fear of my dad was bigger than the trust I had in my support workers.”

Dorien, aged 50

At the same time, when support is good, women are often scared of losing what they have. This fear often holds the women back from talking about violence.

“I told the staff that money had gone missing. They were quick to blame the one member of the team they did not get on with. She was my favourite support worker. And she had to leave, because I told them money had gone missing. I wish I had not said anything.”

Nina, aged 37

Also, the fear of being sent back to somewhere that caused bad memories can stop women from talking about violence.

“I was sexually abused. I had to go to therapy for that. The therapist touched me while I was having an epileptic fit. He did not know I could still feel and hear. He said: “I will help you get over your trauma.” I never told anyone. They would not believe me anyway. And because they already see me as crazy, the only thing they would do is send me back to the psychiatric ward. And I never want to go back there.”

Rebecca, aged 29

Dependency on support is a big part of these women's lives. They all wish to find support that suits them and allows them to live the lives they want to lead. Once they get closer to that, they are scared of having to let it go. We saw this fear in all of the women we spoke to.

Accumulating positive and negative life experiences

Every woman carries her past experiences and her dependencies with her when she moves into an institution. These experiences can sometimes be the reason for institutionalisation:

“Because of everything that had happened I was not doing well. I was moved from my home into a ward for people suffering from depression”.

Mary, aged 47

Some women did find support in their institution:

“My experiences have shaped the way I am. Even though I did not accept that these things really happened. Through my support workers I found a therapist. She helped me with EMDR²⁹. I had to remember everything. But it did help me deal with things in my head.”

Tanya, aged 25

Experiences in institutions sometimes led the women to become frustrated and angry. If they did not have a way to deal with these negative emotions, this only led to more bad experiences:

“I am not an aggressive person at all. The situation made me aggressive. Sometimes I need to go outside when my head is too full. I need to get some air and some rest. But to go outside, I needed to fill in forms. Then maybe, after a few days, I would be allowed out. But by then it was too late. I smashed quite a few windows while I was at the institution, just to get some air. I was punished for that, of course.”

Rebecca, aged 29

²⁹ Eye Movement Desensitisation and Reprocessing (EMDR) is a psychotherapy treatment that was designed to alleviate the distress associated with traumatic memories.

Every woman we spoke to obviously had her own experiences. It is important to understand what an individual has been through and how this has shaped her. It is also important to understand that experiences accumulate over time and form the character and worldview of a person.

4.

Experiences with structural violence

“Structural violence ‘is not carried out by individuals but is hidden to a greater or lesser extent in structures’ – it is ‘built in the social system and expresses itself in the unequal distribution of power and, as a result, unequal opportunities’. It occurs when ‘some groups, classes, genders, nationalities, etc., are assumed to have, and in fact do have, more access to goods, resources, and opportunities than other groups, classes, genders, nationalities, etc., and this unequal advantage is built into the very social, political and economic systems that govern societies, states and the world’. Therefore structural violence includes all forms of exclusion or inequality in distribution of income, education opportunities, participation in social/cultural life, medical care etc.”³⁰

Our society is filled with specific ways, customs, and rules and regulations. Some are determined by law, others are part of our culture. We interact with each other in accordance with these ways, customs, and rules and regulations, often without even knowing they are there. Especially when we are relatively equal to one another and when we each have a similar level of power, we do not particularly notice that we are living within these structures.

³⁰ From a summary of Johan Galtung's ideas of violence: http://iyms.info/iyms/?page_id=207 accessed august 2018

There was no relative equality between the women we spoke to and the people around them. Modern society puts a lot of value on being clever and completing the highest possible level of education. There is also a lot of value placed on independence. Women with intellectual disabilities generally do not get advanced degrees and they are dependent on the help of others. This may lead to fewer opportunities and discrimination. Ultimately, the way they are viewed and treated in society makes them more vulnerable to becoming victims of violence. One woman said:

“My mother died. She was very important to me. I was immediately taken to a psychiatric ward. Two days after her death, they gave me an IQ test. That is when I got my Intellectual Disability. After that, I was rejected from the school where I had been studying previously. I did not finish my studies. I also don’t have a job. I used to want a job. But that was taken away from me because I got this label. They never tested me again after I was feeling better. I know I am sometimes slower to understand things than other people. But whether I have an intellectual disability, I don’t know.”

Rebecca, aged 29

The women we spoke to dealt with a lot of bullying, ostracism, and other general negative behaviour. They also dealt with many misconceptions and prejudices.

Each institutional setting has its own culture, in which support staff work and inhabitants live. Support workers can always leave at the end of their working shift, whereas the inhabitants cannot. There is a big difference between having these structures in the workplace or in one’s own home. Furthermore, the women we spoke to are to some extent dependent on the support workers, not the other way around. This causes a power imbalance where structural violence can thrive.

The women involved in this research wanted to be as independent as possible in their daily life, they wanted to make their own choices and do something useful with their lives. The structures of the institutions in which they lived made these basic goals difficult to achieve.

Institutions often unintentionally strengthen deeply rooted societal ideas that people with (intellectual) disabilities are worth less than others. By using people’s disabilities to separate them, institutions can alienate people from society, opening the way for more prejudice. People’s dependency on care allows institutions to be as forceful in their regulations as they want, or feel the need to be. The women we interviewed said this left them feeling quite powerless at times.

Still, none of the examples above are generally classed as violence. Structural violence is not much recognised, especially not by people who are accustomed to the society it is taking place in, underpinned by shared structural issues and values.

Structural violence is hardly ever punished (except on rare occasions, through a human rights court), nor is it easy to change. In our research, the examples of structural violence that were raised centred around perhaps seemingly little things. However, we must remember that these things happen over and over and over again across the span of a lifetime. Then they are not little any more. In the case studies, structural violence was the most common form of violence that women identified as hurtful and having a huge impact on their life, personality, and future.

When asking the study participants about violence in institutions, we heard many stories of structural issues that left their mark on women, but which are generally not included in standard definitions of violence. There is often no direct perpetrator, and the violence is unintentional. We want to illustrate this by discussing four different issues:

- Rules and regulations;
- Powerlessness;
- Separation;
- Focus on disability.

Rules and regulations

Being made up of a number of people coexisting together, all institutions need structures to function. However, these same structures, rules, and regulations can be very debilitating and frustrating to a person when their entire life is spent within the confines of these structures. This is particularly the case when their role as a client gives them little power to make changes and choices in their own lives.

“When I was ill in the institution, I still had to go to work. It did not matter if I had a fever or anything. I was always sent to work, because there was no one to take care of me at home. Sometimes it was really irresponsible. They said this did not happen, but really it did. And not only to me.”

Lucy, aged 32

“There was no privacy in the institution. My mail was opened. There were cameras everywhere - not in my own room, but when the door was open, ‘they’ [support staff] could see my bed. If I had a visitor they would scream at me from downstairs to open my door. I wasn’t even interested in sex or anything. They just wanted to control everything.”

Tanya, aged 25

The research team found that the size of an institution is clearly related to the flexibility of its rules: the fewer people lived together, the more rules and regulations could be suited to the individual. Where many people lived together, the rules often became psychologically suffocating for people. This would be visible in their behaviour, often making the situation only worse, and making it all the harder for them to leave the institution. People could get stuck in a vicious circle.

“Nina lived in a group home with a man who had some behavioural issues. He was very different from Nina. She got on with him really well. But the staff could not work with him very well. They restricted him more and more, which only made him more aggressive. Eventually he was placed in a locked ward.”

Mother of Nina, aged 38

Structural power imbalance regarding women with disabilities

All of the women in our research had experienced having their living situations absolutely determined by institutions. The management decided who lived together, which support worker supported whom, and what liberties people had to live the life they chose. The women brought up a number of issues, again in the dialogue about violence, where it was clear how little power they had to control their own living environment:

“Nina lived on her own for quite a while. Then suddenly five people were added to the house. Nobody looked at whether this would be a match or not, they were just suddenly there. Nina became scared and withdrawn. Nobody tried to find out what she wanted. She was not allowed to have a good time with the others, not even with the one man she did get on with. The staff wanted to control everything.”

Mother of Nina, aged 38

“I tried to get out of the ward because it was too busy for my head. I needed to go outside. But because they couldn’t deal with that, they put me in a locked ward. I was no longer allowed to leave. They just shut the door behind you. And then you are stuck with people you did not choose to be with. Nobody cares if you fit in or not. I went to lie on my bed a lot, to be away from the others. This was not allowed. I had to be with the group. I felt unsafe and insecure all the time. The support workers said: “If you don’t fit with the others, that’s just bad luck for you’. I lived there for 5 years. This was not the right place for me to be. I did not get the care I needed at all.”

Mary, aged 47

All the women had personal experiences of feeling powerless. At the same time, many practices had become normal to them, even though they were hurtful and had a long-term impact. Most women did not bring these things up initially. Then once one woman would tell us something, all the others would share their own similar examples. For instance:

“A new support worker said that I should go to a behavioural therapist. I thought this was nonsense. Yes, lots of things have happened and I don’t talk about that often. Should I? There are new support workers here so often. Why should I tell each of them everything? Again and again and again. Why do they expect that of me? I want to get to know a support worker first and see if we connect. And not be sent to someone new again, if someone feels I don’t talk enough even though we’ve just met.”

Saskia, aged 32

Once Saskia talked about staff changing all the time, all the women had stories about staff changing, and about not being able to choose who works with you. All the women could point out certain staff members who were good to them and with whom they felt comfortable. Similarly, all had bad experiences as well. Many were very hesitant about meeting new people, immediately wondering when they would leave again and whether it was worth bothering with this person.

There were related issues around sharing confidential information. Saskia continued:

“When the new support worker told me to go to a behavioural therapist, I spoke to an old support worker who I trusted with the issue. She no longer works at our location, but she knows me well. But then, a few days later, my new support worker suddenly confronted me about this conversation. She could only know this from my old support worker. I thought our conversation was private, but apparently she told everyone. I really hate that. I do not trust her anymore.”

Saskia, aged 32

It is in an institution’s rules and regulations to share information in someone’s file, in various ways. This is meant to keep people safe, to provide the best possible care. Again, most women echoed Saskia’s story. They had all experienced what from their point of view, were breaches of trust.

Again, the women with intellectual disabilities clearly understood what confidentiality is and which information they wanted to share with whom. They were also fully able to take this understanding forward to personal and logical conclusions: for many women, this had led to not trusting anyone when it comes to personal issues. Support staff and psychologists need to understand these consequences of institutionalisation.

The effects of being segregated from society

All the women had also experienced the consequences of being labelled as part of a group that faces many misconceptions and prejudices in society:

“What I really disliked about all the places I lived when I was part of the institution was that every time we moved, people around the institution or house were told that we were people with intellectual disabilities. “They” are coming to live here. People with a learning disability are quite unknown, so people outside had their own ideas about us. They thought, for instance, that we all had Down’s Syndrome, or that we screamed all day, or that we all have extremely difficult behaviour. I don’t fit any of these ideas. We get a label stuck to us. It is widely announced that we have that label. And then we have to deal with all the prejudices. I wish they did not announce what label we had. That really has to stop.”

Lucy, aged 32

All women had experiences of being stared at, bullied, and generally having a hard time being accepted.

“Bus lines 63 and 28 are notorious, because they stop at the entrance to the institution. If you are waiting there for the bus, people stare at you with their mouths open. Just because you are waiting in that spot for your bus.”

Saskia, aged 32

The women found very little support, and some even opposition, for being active in society.

“Nina’s world was being kept small. She was not allowed contact with the neighbours, not even when there was a beautiful connection there. For instance, one woman living nearby made jewellery and dolls. I went to see her once to ask if she wanted to meet Nina, who also likes jewellery and dolls. She did. And she wanted to come more often. However, this opportunity was taken away. The lady was no longer allowed to come. They told us it was because she smoked. She never smoked in Nina’s house. But the staff said they could smell it off her clothes. Another neighbour offered to do chores around the house. He was also sent away. It seemed they did not want any outsiders snooping around.”

Mother of Nina, aged 38

Some institutions are also seen as places with bad, strange, or even dangerous people. None of the neighbours have an idea who actually lives in the house and there is no contact with them apart from when something goes wrong. Staff in the following example listened to the neighbours more than to the people they were meant to support:

“In the group home I lived in, there was a nightwatch. So we had 24-hour support available. That’s what I was told. They said: “call us if you need us”. When I did call them once, I was called into the office the next day. They said: “The nightwatch is here to sleep, not to be woken up!”

The neighbours were always allowed to phone when they thought something was wrong. But we were not allowed to phone. We stopped relying on the nightwatch. There was a burglar in the house once. Even then we did not phone. There was no point.”

Mary, aged 47

This made Mary feel very insecure and unsafe in her home and neighbourhood. She said she felt that people in her neighbourhood thought she was a safety risk, just because she lived in this institution. This made her feel worthless.

People with intellectual disabilities should be included in society and allowed to live without being assigned special roles or labels.

Focus on the disability and not on the whole person

The women we spoke to had many examples of not getting opportunities due to the assumptions people made about them due to the label they had. People come together in institutions because of their disability; there is a lot of focus on the disability. This is also relevant to how people with intellectual disabilities are perceived by the rest of society. These are some of the memories people told us about, from their time in institutions:

“I had no real diploma when I left school. I went to a sheltered workshop. I waited for work there. I waited, and waited, and waited. Waiting was my job. I could do so much more than that. I became very depressed.”

Joy, aged 32, at a meeting

“The biggest difference now is that every day is different. In the institution, every day was always the same.”

Lucy, aged 32

“In the first two institutions where Nina lived, neither Nina nor us as her parents had anything to say about what Nina did all day. Every day she had to go to the ball pit, then the Snoezelen Room³¹ and then sing happy songs before dinner. The staff denied that she wanted more in life. They said: “Doing more is not part of her disability.”

Mother of Nina, aged 38

³¹ Snoezelen Multi-Sensory Environments are relaxing spaces that can help reduce agitation and anxiety, and they can also engage and delight the user, stimulate reactions and encourage communication. However, sometimes these rooms are used to “park” people for hours without any staff involvement.

There were very low expectations and ambitions for what people could achieve. Institutions were trying to cater for groups of people with similar disabilities, rather than looking at individual potential and growth. These were issues that kept women very restricted in developing and growing as people and creating meaningful lives.

5.

Experiences with violence through carelessness

The women we spoke to were all to some extent dependent on the support they received. When looking at the illustrative cards during our research, some of the women told us about experiences of violence where the carer upon whose support they depended did not actually seem to care about them.

‘Carelessness’ and ‘neglect’ are closely related concepts, but ‘neglect’ is more intentional and a legal offence. We are using the concept of ‘carelessness’ to include situations where a person is not physically or emotionally neglected, but where nobody cares about, or cares to find out about, the will and preferences of an individual. For example, while all their physical needs are met, people can be profoundly lonely in an institution.

Needing support makes women vulnerable

The more dependent the women were on their support workers, the more examples they had of being neglected or not cared for. They were also less likely to speak up about it.

“I was a member of the parent council of Meike’s institution. As such I would pay surprise visits. I have written notebooks full of my experiences there. From finding my daughter in bed sheets yellow with urine and being totally not cared for to meeting my daughter on her own in a wheelchair in the parking lot.”

“One day we were in the garden. There was a group of us. It was really hot that day. A temporary staff member shouted: “Who wants a drink.” Nina was not able to react quick enough, none of the people there were quick enough, because none of them were able to use words. So nobody got anything to drink. If he had taken a bit more time he would have known they were thirsty.”

Mother of Nina, aged 38

It seems that neglect is generally accepted behaviour amongst some teams, while in others it is seen as entirely unacceptable. We do not know why. All the same, the nature of a support team makes a huge difference for the people living in an institution. We spoke to members of staff who were themselves part of teams where they struggled with some of the things they saw around them. However, they felt powerless to do anything about it.

Women with less severe disabilities also experienced staff not caring enough:

“One time I was really in pain, and one of the staff said, “I am sure there is nothing wrong. You do not need a doctor.” After a little while I started roaming around at night, keeping people awake, because I was in pain. Eventually they did listen and took me to the doctor. By that time I needed an emergency operation.”

Lucy, aged 32

“I went on holiday abroad. When I came back I was very ill. I had a 40-degree fever. The support workers said I just had to get help from my parents or sister [with whom I had a very bad relationship].”

Sylvia, aged 23

Violent and neglectful ‘care’ practices

In some instances, the care that was provided was very violent in itself:

“When I disagreed with something, or if I got angry, I was put in isolation. I know that some people like this, because it makes them calm. For me, it was horrible. I panicked when I was in isolation.

Also, before going into isolation, they made me change my clothes into clothes I couldn’t tear. Two people would watch as I got changed. This was very humiliating. Also, if I wasn’t fast enough, they would ‘help’ me. I hated this, because suddenly they would both be touching me while I had no clothes on.

In isolation I felt like a nobody. I really felt totally worthless.”

Rebecca, aged 29

Rebecca still shivers when she thinks of having to go into isolation. She says the memories still make her feel worthless. It is one of her main fears, having to go back to the institution and ending up in isolation. This is why now, after many years, she still does not show emotions such as anger or sadness. Even though putting her in isolation was meant as ‘treatment’, allowing her to calm down, from her point of view this was a serious act of violence.

Isolating people in this way is now widely seen as harmful and there are many tips on how to avoid this practice. It is interesting that some teams in institutions still use isolation a lot to deal with certain situations, while other teams facing similar issues hardly use it at all anymore. Again, it seems there is a culture within some teams that allows this to happen.

Dealing with emotions

Support workers generally seemed to find it hard to deal with difficult emotions:

“Support workers I have had don’t deal with emotions. For instance, they find it very difficult if I cry. If someone cries, you go and comfort them, right? Or you ask them what happened? But my support workers try to laugh the pain away by making jokes, or by changing the subject as if nothing happened.”

Dorien, aged 50)

Many of the women had learned that happy emotions were more acceptable than sadness or anger.

In a place where structural violence is prevalent, yet often goes unrecognised or unpunished, it is especially easy for staff to do things that are really harmful to the people under their care. Most of the women we spoke to had learned not to talk about their feelings or frustrations.

‘Not my problem’ attitude

In some cases, the support worker must have recognised the distress someone was experiencing, but they simply said it was not their problem to deal with:

“I met a man through social media. He seemed nice. We joked a lot. One day he asked me to send him a picture of me naked. I thought he was joking. I sent him a picture of a naked woman I found on Google. He started stalking me. He said he was going to find me. And then he said he knew where I lived. I did not know what to do. I closed my curtains and hardly went out anymore. He kept sending me messages. After a while I got so scared that I told my support worker what was going on. She said that it was my own fault, and now I just had to deal with it myself.”

Sylvia, aged 23

Dangers from lack of coordination

Sometimes care staff reported a person’s distress, but nothing was done with the report, so nobody noticed how bad a problem had become:

“We wanted to see her files, because we felt Meike was not doing well. Only after a long time of repeatedly asking for her files did we get to see them. We noticed many people remarked on how Meike was struggling, how she seemed unwell, but nobody ever re-read the files and nobody saw the connections.”

Parents of Meike, aged 33

The importance of people who really do care

All the women had examples of staff not caring enough. At the same time, most of the women also had one or a few support workers who they really had a special bond with. This often had something to do with breaking down some professional distance. Quite frequently, we were told, “I want support workers to be real.” The women wanted someone who really cared about them and who they could trust. These support workers made a huge difference in the lives of the people they cared for.

“I only got out because there was one staff-member who actually cared about me. She realised that I was not in the right place. She found another care organisation with small homes in the community, where I could start living my own life again.”

Rebecca, aged 29

It was clear that how support workers view their own job and the people they worked with made a real difference to the lives of these women. All the participants in our study had developed a feeling telling them when someone was there for them, caring, rather than just doing their job. They had a sense of who was authentic and who was putting on an act as part of their work. It was extremely important for everyone to have some people in their lives that really cared about them.

6.

Effects and consequences of experiencing violence

The violence experienced by women with intellectual disabilities had significant effects on their lives. Like any other people who have been subject to violence, they suffered for a long time after the event and developed coping strategies with or without help from other people.

When it came to personal violence, the effects were often quite specific. For example, not wanting to be close to men after sexual violence. After being sexually abused, including being touched by her therapist during an epileptic fit, Rebecca says:

“I don’t want any men near me when I have an epileptic fit. It takes me a long time to start trusting anyone.”

Rebecca, aged 29

Rebecca had never received any support over what had happened, and the effects on her were still quite tangible.

On the other hand, Tanya had EMDR³² treatment after being sexual abused. She was also supported by the Dutch Victim Support organisation. She was very careful about which men she allowed in her life, and whom she trusted, but it did not influence her life as much as Rebecca was affected by her trauma.

“I am really proud of how I am dealing with this now. I want to tell service providers about what I experienced so they can learn from it.”

Tanya, aged 25

³² Eye Movement Desensitisation and Reprocessing (EMDR) is a psychotherapy treatment that was designed to alleviate the distress associated with traumatic memories.

Getting support after someone has experienced direct violence makes a crucial difference in how they later perceive that violence and the world around them. Unfortunately, many of the women did not get the support they needed. This was due to several issues. We heard examples of:

- not having a person they trusted enough to talk to;
- fearing retaliation from the service provider;
- fearing not being believed;
- being too afraid of the person who hurt them to talk;
- not wanting to be moved again, to a new support team;
- thinking what had happened was normal.

Direct violence had especially severe consequences when a woman experienced the:

- same kind of violence by several perpetrators;
- for a long time;
- when similar violence occurred on different occasions in different settings;
- or when a woman did not receive support afterwards.

Structural violence always had the above characteristics, although this violence was far subtler. Incidences were most often not recognised as violence. However, it had huge consequences on the women's self esteem, self worth, ability to enjoy life and to interact with others, and how they perceived the world.

Research shows that direct, personal violence and structural violence are highly interdependent. When society sees and treats someone as "lesser", with little power, the barriers protecting that person from psychological, physical, or sexual harm are diminished. Especially when support staff do not really care, people living in institutions may experience more structural and direct violence.

How violence shapes the “worldview” of women with intellectual disabilities

“The experiences we have make us the person we are.”

Lucy, aged 32

A worldview is the fundamental cognitive orientation of an individual encompassing the whole of the individual’s knowledge, experiences, and points of view. A worldview refers to the framework of ideas and beliefs forming a global description through which an individual sees and interprets the world and interacts with it. Core worldview beliefs are often deeply rooted, and so are only rarely reflected on by individuals.

Our experiences and memories, and our interpretations of them, shape the way we view the world around us. This is equally true for the women we interviewed. We will use one example from our study to demonstrate the development of a particular worldview:

“Every time I got angry, support workers would say, “We’ll send you to a psychologist.” Every time I was sad, they would say, “We’ll send you to a psychologist.” They said this when I did not want my medication because it made me feel ill. Or when I wanted to go outside and they thought I wanted to escape. For anything that didn’t suit them, they would threaten me with a psychologist.

Then I was physically and sexually abused [pointing at the drawings]. And what did they say? “We’ll send you to a psychologist.” And they did. So for me, it felt like I was being punished for what had happened to me. It wasn’t my fault.”

Rebecca, aged 29

Rebecca was in therapy for three months. For two months she did not say anything at all because she felt she was being punished.

The threats of being sent to the psychologist in the first half of this experience are examples of structural violence. Her support workers wanted or needed her to do something and they used their power to threaten her, in this case with a psychologist. This ‘threat’ was also independently mentioned in a number of other women’s

experiences. It seems particularly easy for women who do not want to talk openly about themselves to perceive it as a threat when someone insists on their cooperation.

Rebecca started thinking of the psychologist as a punishment for not doing what the support workers wanted her to do. This is not something that happened overnight or after one incident. It is a part of a worldview that took years to form. Years of hearing the same, seemingly small, threat.

When she was assaulted, the support staff probably really wanted to help her and also followed the respective procedures in their institution. Thus they did send her to a psychologist. But the underlying damage was already done with the threats she had received so often in the past. So she was not in any way open to the therapy that could have helped her.

These processes are common to all human beings and are not specific to people with intellectual disabilities. The human brain tries to interpret and analyse the experiences of a person and forms assumptions on the basis of this. Once someone, anyone, has formed a worldview, it is not easily changed. The psychologist could not help Rebecca, even though she needed help, and the experience still bothers her in her daily life.

The worldview created after experiencing years of structural or personal violence, or people not caring, can be quite different from the view of someone who has not experienced this. The worldview does not only shape how a person looks at external things. It also affects their personality, how they perceive themselves, how they react to events. For these women, it has shaped how they cope with what happens to them, and the life they have built after living in the institution.

Coping strategies make women more resilient

When people are hurt by something, they develop ways to stop themselves from getting hurt in the future. This process is summarised in the concept of “coping”. Coping skills develop from infancy and are learned by watching others and by trial and error. People with intellectual disabilities develop coping strategies, as anyone would. Perceived control is an important resource for many in coping with stressful situations.

The coping strategies a person develops can be very diverse. They develop through the situation and the environment someone is in. They can be effective, or non-effective. A person will repeat especially effective strategies. They make a person more resilient, enabling them to deal with a situation.

The effectiveness of coping strategies in reducing distress is dependent on the strategies used and the self-belief that one can cope. Varied environmental conditions contribute to the diversity of individuals' responses to adversity. Resilience is the consequence of coping with stressful situations.

The strategies developed in the highly specific conditions of living in an institution may not be what we would expect. This is an example, which the researchers have encountered on several occasions outside of this study:

Someone receives 5€ per week as pocket money. She always spends it immediately. The care staff take that as proof that she can not handle money.

On holiday away from the institution, she also receives her 5€ per day. But she does not spend any of this money, even though there are opportunities. Only on the last day of her holiday she wants to go shopping. She now wants to spend all her money. When asked why she says: "Because if I don't spend it they will take it away from me."

Spending the money as soon as people get it is often a way of ensuring 'they' (the people who have control over their money) can not take it away. This is how some people cope with and avoid the pain of losing their money. It is quite a logical strategy in this situation, and it is effective and appropriate for the problem. However, it also reinforces the view that someone is not able to handle money. This way a vicious circle can form, which may be broken only if the situation is changed by someone who allows the person to try again with less restrictions.

Developing coping strategies in difficult situations is very normal for any human being. We experience something that hurts, physically or mentally. We will then try to adapt and find ways to avoid those situations in the future. The adaptation will most often be compatible with the worldview a person has created. In women with intellectual disabilities, coping will often be really "strategic", displaying a real understanding of different processes:

*"I usually found a way to get out of the closed ward. But I had nowhere to go. I had nothing to take with me. As soon as they would realise I had gone, they would send a telex to the police. That meant the police could see ALL my private information. Everything.
So I always made sure I came back before the police could come looking for me."*

Rebecca, aged 29

Coping strategies can be functional. By this we mean that they work to make life easier or to avoid being hurt.

“After a number of years in the closed ward I was allowed to stay the summer in a tent in the walled garden of the ward. It was so nice to get some space in my head! Slowly it became colder and they wanted me to move back in. But I did not go back until they assured me they would help me find another place to live.”

Mary, 47

“Getting angry always had consequences in the institution. Even today, I still do not dare to get angry with anyone. I do not want to be taken back into isolation in the institution. So I do not get angry. I show sadness instead.

Rebecca, aged 29

Sometimes coping strategies can also have negative consequences:

“I was going to move out of the institution, which I really wanted to do. But at that time my health deteriorated a lot. At one point I was almost blind. I was so scared that everything would be cancelled because of my health, and I would have to stay in the institution. So I kept my mouth shut. A friend of my mother’s met me, and I almost bumped into her without saying anything. She then told my mother she thought I was not seeing much. Luckily I was still allowed to move. And my eyesight came back too.”

Lucy, aged 32

Even in similar situations, people develop different coping strategies. Coping strategies are usually quite logical. They are a way to deal with a difficult situation. They are understandable when you start understanding someone’s history and worldview. The women with intellectual disabilities were mostly well able to explain why they did certain things, and what their thoughts behind this were.

However, coping strategies do not just disappear when the situation changes. In time, coping strategies can become part of a personality. Functional coping strategies in the institution can become quite dysfunctional in the community. Most of the women who had left the institution were scared to be sent back, and they were scared to lose the good things they now had in life.

“When I left the institution, I would still go to work when I was ill. I love my work, it is everything to me. And I know they got money for me being there. I thought the money would stop if I was ill and I would lose my job. If I do stay at home because I am too ill I feel really bad. I would say sorry a 1000 times if I could. Sometimes I go to work and the coaches say I should really go home because I am too ill. I think that is very difficult. It took me some time to learn that the coaches really wanted what was best for me, instead of looking at money.”

Lucy, aged 32

In order to cope, many women did not generally communicate their emotions. However, when they had little control over their lives they would communicate in some way. Several women said they were not violent people, but the situation in the institution made them violent. They did not want to be violent, because that would always have repercussions.

“I was angry with the situation that I could not get out of. I am not an aggressive person. The situation made me aggressive.”

Rebecca, aged 29

Another way of communicating a negative situation is falling asleep:

“Nina was volunteering in a second hand clothes store. She and another employee clicked really well. But when the other person left, Nina was ‘just there’. They allowed her to be there, but she was not being seen. She kept on falling asleep. Nobody minded. But actually this was Nina’s way to tell us she was bored.”

Mother of Nina, aged 37

Finding out what people are saying with their behaviour is an important part of understanding coping strategies.

Some coping strategies seemed to be fairly universal. Many of the women simply tried to forget the negative experiences, or kept a lock on their negative emotions as these had repercussions when they were still in the institution. Also, as care staff kept changing in the institution, it was hard for them to really make connections with people, thinking they would leave again anyway. Many of the women found it hard to trust people.

7.

Life after violence

The women we spoke to had already moved out of residential institutions. We selected them because they were no longer part of the institutional system and were thus able to speak more freely about their experiences, including how their lives have been affected since leaving. They now live different lives from when they lived with others in institutions. At the time of our study,

- 3 lived alone, supported by the same institution.
- 1 lived alone, supported by the same institution, but in an apartment block owned by that institution.
- 1 lived alone, supported by a very small care agency.
- 3 lived alone, supported through a personal budget.
- 2 went back to their parents' home, supported through a personal budget.

Following our discussion about violence, we wanted to know where they were now, how they got there, and what they still struggled with. We also showed the women a few more cards with drawings about inclusion, and asked what is stopping them from achieving these aspects of inclusion:



Struggles after the institution

In the previous chapter, there were a number of issues that most of the women we interviewed struggled with:

- Most women struggled with emotions. They still felt they should not show anger or sadness, because this would have had consequences in the institution.
- Most women struggled with trusting people, it took them time to build connections with new people.
- Most women had developed their own “sixth sense” to decide who actually cared for them or who did not.

The fear of having to go back

One issue we have not yet discussed was raised by all of the women: the fear of having to go back. Many of the women are still scared of one day having to return to their previous situations. The greater this fear, the more their lives are governed by doing what they think is necessary to stay out of the institution, or to hang on to the life they have built.

“I am still often scared that I will be sent back to the institution. I do not believe that I am allowed to stay in a place I actually like. I like where I am now. I like my work too. But I often think it will all be taken from me. “Now you are going to send me back there, I am not allowed to stay here anyway”. This makes me very insecure. I am always surprised when I am allowed to stay. I have been here for 3 years now.”

Rebecca, aged 29

The women said that every time they moved to a smaller setting, with fewer other ‘clients’, their situation would improve. And every time, they would remain scared of being sent back to the bigger setting. Seeing how little power the women have themselves, this seems a realistic interpretation of their situation.

Lucy told us:

“For ten years now I have been doing the same job. I really love it. I am still scared that I will lose this job due to my health. Even after ten years.”

Lucy, aged 32

Lucy has a metabolic disease and her health changes sometimes. She analyses that her experiences in the institution have caused her to

- pretend she is okay, even if she is not;
- go to work, even if she is feeling very bad or has a high fever;
- worry about her current work losing money if she is ill, and then not wanting her any more;
- worry about being sent back to the institution.

The people at her work confirm that they have had to send her home numerous times, because she has come to work unwell, for instance with a high fever. They have got to know her well enough to understand that she needs confirmation that she can stay at her work even though she gets ill sometimes, and that they are more concerned about her wellbeing than money.

For Lucy, it is not the sexual harassment that she encountered as a young girl which impacts her life now. She received help for that many years ago. Her current life is impacted by the way staff in the institution, and the rules and restraints of that institution, dealt with her illness. She copes by pretending she is fine. And like many women we interviewed, she lives in constant fear of losing what she has. Losing the things she likes and having no control over her own future have become normalised in her worldview.

Each of the women had different fears and coping strategies that got in their way of living healthy, inclusive lives, and they were all based on experiences that happened while they were in the institution. At the time, they were probably not noticed, or they seemed minor details in the care the women were receiving. These fears now hold them back from living an inclusive life in the community. Lucy, and the other women we spoke to, need constant reassurance that they are okay as a person, and that they are safe.

Meike's parents realised from their daughter's behaviour that something was wrong in the institution. First they decided to have her home every weekend instead of once every 4 weeks. Later they decided to use a personal budget to move her back home. Her parents told me:

"It has been 14 years now. Sometimes we still see the effects of the traumas she went through in the institution, even though she has been out of the institution far longer than she was ever in there. During the first years after the institution, we could not use the name of the institution when Meike was near us. We once drove towards the area where the institution is located. Meike flipped. We had to turn around and drive straight home."

Parents of Meike, aged 33

Although in Meike's case it will never be clear what happened in the institution, apart from the blatant cases of neglect that her parents witnessed on their visits, it is clear that she was severely traumatised by her experience. Not all women showed such strong reactions. However, we must assume that institutional life has left a mark. However, we must appreciate the impact of institutional life and remain sensitive to how each woman has different ways of coping with what has happened.

Re-learning independence

Many women had to re-learn basic skills when they left the institution. For instance, Rebecca said that she had to get used to living on her own:

"I used to be good at being on my own. But after living in a big group of people for years, I struggled to be on my own. In the institution I was never on my own. There was no privacy. Being on my own again was one of the many basic things I had to re-learn when I got out of the institution."

Rebecca, aged 29

After being segregated for a long time, the women said they found it hard to try new things in the community. When we talked about what holds them back from being involved in the community, the answers were:

- a lack of self-confidence;
- feeling worthless to others;
- feeling they have nothing to contribute,;
- having little experience of going somewhere and introducing themselves;
- seeing themselves as ‘disabled’ and having to mention that as the most important part of themselves;
- a fear of doing something wrong and somehow being punished for that.

Nina is a great example of a woman whose life has changed completely. In the institution, people said she was too disabled to do much more than listen to people sing, lie in the ball pit, and spend time in the Snoezelen Room³³. Now she has her own apartment and a very full life. With the assistance of support workers of her choice, she maintains good contact with the neighbours, and has various jobs and valued roles that have allowed her to meet many people and build up a caring network of her own.

Dorien, on the other hand, has a very different situation, having moved out of the institution years ago. She gets support for her finances, cleaning, and cooking, but not much else. She has no family to support her. She does not know how to maintain good relations with her neighbours. Her lack of confidence, also stemming from abuse at her parental home, is keeping her back from getting involved in anything in the community. She is profoundly lonely.

When we look at the women who participated in this research, those who received more support to build up their confidence, to make positive connections with others, and to express their own emotions and choices generally had a better network of people who cared about them. Not because they were paid to be there, but because they genuinely cared.

³³ Snoezelen Multi-Sensory Environments are relaxing spaces that can help reduce agitation and anxiety, and they can also engage and delight the user, stimulate reactions and encourage communication. However, sometimes these rooms are used to “park” people for hours without any staff involvement.

If we look at the history and current situation of the women, it becomes clear that deinstitutionalisation requires more than just merely placing someone in a home in the community. Personalised support to overcome past experiences and the resulting worldview and coping strategies is very valuable.

The perspectives of parents and family members

With the help of their families, friends, caring support workers, and the self-advocacy organisation Landelijk Federatie Belangenverenigingen (LFB), many women have achieved things in their lives that they and the people around them never knew were possible.

“After Meike came out of the institution, we used to visit the windmill with her. The miller would see her. We recently went again after not going for a very long time. The miller said he would almost not recognise Meike, the difference in her posture and self-confidence were so big. Sometimes when you see someone every day you do not see the small changes. It was beautiful to realize what differences this man saw in her.”

Parents of Meike, aged 33

“When Emma came out of the institution it took about 3 years for her to start believing her house was actually hers. That she was in charge of who came to visit, and who was not allowed in. It was a very slow process.

Emma has gone from a person in an institution who was regressing into a state of no contact with the world and harming herself, to a person who owns her own flat, has contact on a regular basis with neighbours and other people in the neighbourhood. She is capable of communicating what she wants to those who are willing to listen and she has a network of support around her to translate where needed. Harming herself is no longer her usual way of communicating.

Emma is now off her medication. She only takes extra vitamins. Her behaviour has calmed down.”

Mother of Emma, aged 38

Parents are also fearful of their child having to go back to the institution one day:

“We will never know what exactly happened in the institution. Sometimes we are scared that Emma has to go back one day, because the budget keeps changing and we keep on having to prove to the health insurance that our daughter really does have the right to her relatively high budget.

When we tell people she lives in her own home they think she does not need as high a budget. Because they think only people with less disabilities can live outside of institutions. Even though we want to talk about our daughter’s possibilities and abilities, we keep on having to prove how disabled she is. It is quite frustrating. Usually people are more understanding once they actually meet her.”

Mother of Emma, aged 38

“The budget we receive to organise her care is about the same or slightly less than what she would ‘cost’ if she were in an institution. As parents, we have to organise most things now. Emma stays with us every other weekend. If anyone is ill, we have to pitch in. It is not always easy. But we have managed so far. We will get older though.”

Mother of Emma, 38

Not all the women we spoke to had parents that we could contact. People close to them told similar stories of how much they had changed in the years after the institution, and especially how much they had grown in confidence.

Supporting someone in the transition from an institution to an inclusive life

In our conversations with the women, we discussed their needs and wishes to build lives where they are included in the community. They gave the following answers as to what helps with life *after* leaving an institution. We report them here in their original form:

- Let me be who I am. Give me the feeling that I am okay.
- Let me make mistakes and try again.
- I need people around me whom I trust and get on with.
- People need to understand there are things I have to re-learn or be reminded about often.
- Get to know ME. Then you will understand why I react in certain ways and what is important to ME.
- Help me ensure that I never go back to the institution.
- Take me seriously.
- Believe in me.
- Support me in things that give me more confidence.
- I need to feel safe.
- I want to make my own decisions. Let me do that.
- I want to be independent. Don't tell me what to do; talk to me.
- Even with good support, it may take a long time to let go of past experiences. Be patient with me.
- Help me to go further than I think I can, but not take on too much at a time. Small steps.

- Help me to achieve what I want in life.
- Help me to succeed so I see I can do it.
- Don't give up on me.
- I may test people to see how they react.
- Help me to find my place, where people value and respect me.

Despite of being troubled in many ways by their past, despite the fear of being sent back, and despite the coping strategies that hinder the women in their daily life, with support that takes these things into account, some women with intellectual disabilities have achieved things people thought would be impossible for them. Unfortunately, many women do not find this support.

Factors that contribute to successful inclusion

During our research, we met people who had developed a lot since their time in the institution. There were people who had exceeded their own expectations and those of others. We also met people who seemed to be stuck in very lonely places. We found this was not due to a lack of talent, or intelligence, or an anti-social character. There were four success factors we identified in the most positive examples.

Understanding and listening:

These women have people around them who understand what each one might have experienced. They are patient. They are also good listeners, not only listening to words, but also to body language and behaviour. They understand that behaviour can stem from coping strategies following personal experiences, and that a person's coping strategies and worldview might get in the way of living an inclusive life.

Reducing vulnerabilities:

The support people supporting are attentive to how the women are viewed by others. In promoting a positive image of the women in many areas, they reduce their vulnerability for structural violence.

“We always make sure she looks clean and fashionable in a way that suits her age. When Nina goes horse riding with people who are still living in an institution, you see such a difference. And it absolutely influences how people perceive Nina, and how they treat her.”

Mother of Nina, aged 38

We cannot take away the disability, but we can increase someone’s acceptability in the community.

Preventing hurt:

The people in these women’s lives prevented them being hurt further. Support people were very carefully selected, making sure that there were shared interests and passions, and that it was someone the individual woman could trust. Even though it did not work out every single time, these women found support workers who really cared for them and vice versa. These relationships are more personal and more durable than the ones they had known in the institution.

“Emma’s support-worker became ill. Luckily, Emma was able to visit her and be of meaning in her life. So the roles reversed a little when the supporter needed support. That is how well they had got to know each other over the years.”

Mother of Emma, aged 38

In this way, a caring and protective circle formed around the women.

Compensating:

The people in the lives of these women actively search for ways to involve the women in their community in such a way that:

- People recognise the talents they bring.
- People meet them as someone they can identify with, for instance because they share the same interest.
- Each women as an individual has a valued, positive role in her own community.

In other words, they find ways to positively compensate for the dependent roles and vulnerabilities that the women have because of their disability, gender and long stay in an institution. This reduces the occurrence of structural violence and also empowers the women.

As structural violence and the victim having a lower status makes personal violence much easier for perpetrators, all these steps also reduce the chance of personal violence taking place against an individual.

We have taken these four observed success factors into account in developing the recommendations of this research project.

8.

Conclusions and recommendations

We knew that women with intellectual disabilities experience a lot more violence than women on average. We knew that violence is everywhere for women. However, we wanted to know more about the violence women experience in institutions. We also wanted to know how these experiences shape their lives once they leave the institution to live in the community, and how best to support them.

Violence

Self-advocates told us about many different types of violence that women with intellectual disabilities experience. These were not limited to physical and sexual abuse. They also incorporated issues such as not getting the same opportunities and not being believed or listened to. We used drawings of all these types of violence as a basis to talk extensively to 10 women with intellectual disabilities who had been in a large institution and who were now living alone, with support, in the community.

Direct violence happened both outside and inside institutions. Institutions try to protect people from direct, or personal, violence. They have procedures in place to protect people, and there is support for those who have experienced such violence.

However, most of the experiences the women shared were about structural violence. This is violence that is not carried out by an individual against another individual. Instead, it is part of the social structure of society, through which some people have little or no power and unequal opportunities compared with others. It is often unintentional, and it is often not recognised as violence.

We heard about experiences where rules and regulations were stifling, experiences where women had no say in where or with whom they lived, and experiences where women were repeatedly made to feel useless. We found that the bigger the institution, the more traumatising the experiences of structural violence were. Support is just as necessary to overcome structural violence, as it is to overcome direct violence.

We highlighted another form of violence that is particular to people who depend on paid support. We found that being surrounded by people who are there because they are being paid to do their job has a huge impact if they do not actually care about you, value you, or believe in you. We found that when the women had someone in their lives that cared, that person immediately became hugely important. The women who had moved out of bad situations in institutions had all done so with the help of their parents and/or genuinely caring members of staff.

The women told us about experiences in various areas of their lives, but much of the structural violence and carelessness they talked about took place in institutional settings. The bigger the institution they had been in, the more experiences of violence they told us about.

Effects of violence

Our findings showed that direct violence is very traumatic. This violence is well recognised and support is available. However, many people were very careful to speak about direct violence they experience for reasons that have roots in structural violence. The women carried heavy burdens from everything they had been through. We noticed that they had adapted their worldviews, with very low expectations of themselves and of making any difference to the world, and of others making a difference for them.. Many women left the institution feeling worthless. Most of them remained scared of going back, even after 10 years of living in the community.

Furthermore, the women we spoke to had adopted coping strategies to prevent getting further hurt from structural violence and carelessness in the institution. They would adapt themselves to circumstances, communicate however they could, and avoid certain situations and people. These coping strategies were often intentional

and quite effective, until the situation changed.

Support to overcome any of these issues was not readily available.

Leaving institutional life

When the women moved into the community, they took their heavy load of experiences, their worldview, and their coping strategies with them. These beliefs and behavioural strategies did not change quickly. The lack of self-worth and self-confidence got in the way of getting into a more valued position in society. Their coping strategies, which may have been efficient in the institution, now stopped them from going out and meeting new people. People who leave an institution need support to start building or rebuilding life in the community.

We heard that the women who were well supported achieved very positive lives in the community, whereas women who did not have that support could get extremely lonely. We found that good support worked on a very personal level, understanding who the person was and what they had been through, preventing further harm, reducing vulnerability, and assisting them to develop valued social roles in the mainstream community. This supported women to build up a network of people who genuinely cared about them; these connections are what really keep a person safe. Unfortunately, this kind of support was not available for everyone.

Recommendations

Violence against women

It must be recognised that violence against women is a widespread problem affecting many women, and women with intellectual disabilities even more.

From an early age, men need to be educated not to commit violence against women.

The power imbalance between men and women, which plays a significant role in why this violence is so common, must be addressed.

Policies and practices aimed at protecting women from violence must be based on reducing the number of men committing violence, and on recognising men's responsibility for violence against women. Only teaching women to protect themselves is not enough.

Education

When it comes to direct violence against women with intellectual disabilities, we noticed that women and men with intellectual disabilities are often not prepared for certain situations. They have been kept out of mainstream education, which has given them a disadvantage in comparison to others when it comes to their level of education and their experiences in building up a social network.

Furthermore, they have received still less or no sexual education. More could be done to educate people. While sex is discussed more in the Netherlands than in many other European countries, more could be done even there. It is important to educate people about knowing their own boundaries. It is important for people to learn about saying no and standing up for themselves. At the same time, it is important to teach people about what is appropriate and what is inappropriate in regards to touching another person. Sex should not be a taboo topic. It concerns everyone, including people with intellectual disabilities.

Inclusion from an early age

It is important to start working on inclusion, and developing a valuable position in society and a caring network, from an early age. The less experience of structural violence a person builds up, the more they can reach their true potential. In an ideal situation, all people with intellectual disabilities would be able to choose to live their life in the community, independent of institutions. They would be able to live with people they want to live with, and would be assisted by people they select to support them, in ways they need and want to be supported.

Preventing violence in institutions

As this ideal is not a reality for many people in the Netherlands, it is all the more important to be aware of and prevent violence in institutions as much as possible.

The women's experiences told us that contrary to popular belief, institutions do not keep a person safe. The culture and structure of an institution leave individuals vulnerable to structural violence, without people in their life who are able to give them genuine care.

Institutions should have proactive strategies to combat all types of violence. Information about where to go when violence occurs should be easy to find and easy to read. But getting information is not enough. It is critical that women and men

who experience any type of violence are listened to. Counsellors actively involved in talking with their clients, listening to all they say or do not say. People should be able to get to know their counsellors well enough to trust them. Counsellors should take the initiative to talk with people about how they experience their daily life in the institution.

Institutions should undergo external evaluations and assessments, involving people with intellectual disabilities and parents in qualitative interviews in which individuals get a chance to talk about their experiences. The outcomes of these processes should support institutions to change their culture and practices, and should assist people with intellectual disabilities to stand up for their rights.

Institutions need to ensure their rules and regulations do not stifle opportunities for personal support staff to genuinely care for people and meet individuals' specific needs. Institutions should also make sure that support staff are able to work with people with whom they really connect, even if this makes less logistical sense.

We have found that the bigger the institutional community, the more people struggle with structural violence. Considering the imbalance of power that generally rules institutional life, we must recognise it is unlikely that structural violence will be fully eradicated from institutional settings. Even where institutions try to be inclusive, people have little choice over who supports them or whom they live with.

To reduce structural violence, it is imperative that care institutions transform their approach to provide person-centred support and assist people to live included in society. This involves organising caring support networks, and enabling individuals to choose who supports them and with whom they live.

We urge taking steps to ensure the rights to recognise the rights of people with intellectual disabilities to live independently and to be included in the community. We recommend incorporating the support described below.

Understanding

People working with and on the topic of people with intellectual disabilities need to understand what can be experienced as violence and its effects. This is important to minimise further violence, and better understand people's decisions, behaviour (including their coping strategies), and worldview. For instance, be aware that a person's history can stand in the way of them receiving therapeutic treatment, finding a sense of security with a support worker, or integrating in the community. We need to talk about violence against people with intellectual disabilities to really understand it. Always allow people to choose whether to talk to you or someone else if they

prefer, or say if it is a bad time to talk. Let them know that you will listen if they want to talk about difficult topics such as violence.

Working with self-advocates enabled us to open up the conversation on violence against people with intellectual disabilities. We have found that people are more likely to open up to those who they think will understand in virtue of their own experience. It works well to take time and create a safe environment for people to speak out. Self-advocates can train staff about different types of violence and the effects of violence. They can also have a leading role in opening up dialogue about violence in institutions between people with and without intellectual disabilities. To help start a conversation, the drawings and other materials from this research are available on the Inclusion Europe website.

Support

Support is required to overcome all types of violence, not only direct violence. Every person is different, and experiences things in their own way. Therefore, support needs to be very personal. It is vital that people giving support are patient. We should understand on a personal level what someone has experienced. We should empower people to recognise violence and to reduce that which makes them more vulnerable. We have a responsibility to prevent further harm happening to someone. We should also go one step further, and compensate for how individuals have been undervalued in institutions, by actively supporting someone to find her personal talents and interests, and develop her role in the community. Being able to contribute to society and to celebrate achievements helps people to regain some of their confidence. People in the wider community can identify and connect with someone through their role in the community, and their talents and interests. Building up a network of people in the wider community who genuinely care is key to keeping an individual safe from harm.

The women we spoke to, who had been out of the institution for a while, were able to tell us what they needed after experiencing violence. Again, we recommend listening to self-advocates and engaging with them to open up discussion.

Policy and research

It is important to make the situation of women (and men) with intellectual disabilities more visible. This can be done, for instance, by commissioning projects such as this one as part of mainstream research. Women in institutions should be included in European policy studies on social research. Furthermore, it is critical that information and recommendations regarding all types of violence reach all European countries.

Structural violence worsens when people are dependent on institutional organisations in which they have no control over their own lives. Rigorous policies need to be introduced to increase people's own power in deciding where to live, with whom, and on what conditions, regardless of their disabilities.

To reduce structural violence, care institutions across all European countries need to transform. Any residential setting where people are placed without being offered real options to choose other support and living arrangements is not compatible with reducing structural violence.

To reduce structural violence, residential care organisations must offer person-centred support. This needs to aim towards enabling people to live included in society. It involves organising caring support networks, and enabling people to choose with whom they live and who supports them. It also means supporting individuals to develop and maintain valuable social roles in society.

At the European level, goals could be set to work actively towards deinstitutionalisation. In combination, EU and national policies could do more than allow people with intellectual disabilities to leave institutional settings; they could ensure that person-centred support is available, assisting people to build constructive lives in society.

As long as deinstitutionalisation is not yet fully achieved, social policies at European level should include measures to ensure that remaining institutions have strategies to combat all types of violence. It is vital that these strategies are proactive. It is important that European social policies evaluate countries' policies and strategies to prevent structural violence while institutions still exist, as well as monitoring deinstitutionalisation processes.

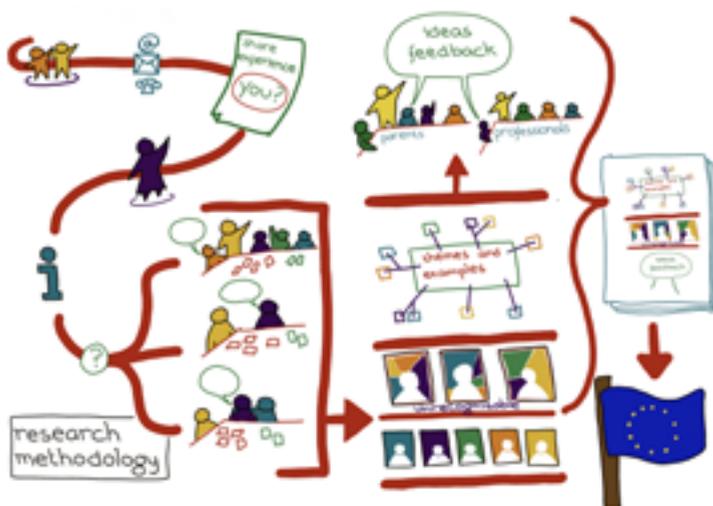
9.

Methodology of the study

The objective of the study was to do qualitative research, through very in-depth interviews with a few women. Our methodology was developed and carried out together with self-advocates. Their knowledge, experience, and the trust they received from the women who participated in the research made our study possible. Without the direct participation of self-advocates, its outcomes would have looked completely different.

We worked with self-advocates to define violence through making drawings of many different things that they considered violence. We did the same for inclusion. Those drawings were used as a basis for each discussion with the women. We have also used the drawings of violence in presentations and workshops. The details of these workshops are not included in this report, as the people participating did not receive all the information about the study and have not had the possibility to give consent to the use of their experiences.

Some of the women participating in the workshops organised with the Dutch self-advocacy organisation LFB spoke to us afterwards, as part of the research. Their stories are included. We also found women through the network of LFB, and through a network of people working towards inclusion known as Netwerk Perspectief and Inclusionlab. It was difficult to find women who had completely moved out of an institution. It seemed easier to find men who organised their own care in the community.



The drawings worked well to start up conversations about the topic. We realised that although violence is rarely spoken about, there were many people, men and women, who did want to talk about this. No one was in any way forced to talk, listen, or participate. We made clear that people could stop or leave at any point. It was also made very clear that their stories would not be recognisable in the report. We have changed their names, locations, and left out information that could reveal their identity.

With the women and parents who participated, we talked through the meaning of the research, what it is about and what it is for. On average, we spent about 6 hours with each woman overall, across numerous meetings. We asked every woman about what, where, when, and with whom they would like to speak with us. Some women decided they wanted to meet us together with other women. We worked with two small groups. A number of individuals preferred speaking to only one person at a time. We knew all this before the informal interviews started. We always met face to face for the informal interview. Everything happened on their terms and conditions.

The informal interviews were very open. The topic had already been explained. We expressed that we wanted to hear about the person's own experience. We would put the drawings of violence on the table, and discuss them a little first, as not all drawings meant the same for everyone.

We always asked if there were forms of violence that were not covered by the pictures. There usually were. That was the start of the conversation about the woman's own experiences. We also asked which other drawings were of meaning to them and how they could relate. Most women kept talking once they had started. All they needed was for us to really be there and really listen.

Sometimes we made space to just be quiet for a while. Sometimes we asked open questions or repeated something to make sure we understood correctly.

Once someone had told us all they wanted to about violence, we asked them about the effects of that violence on them as a person. We used drawings of inclusion to steer the conversation towards talking about what had helped them become increasingly included in society, and what obstacles still stood in their way.

We took notes during the conversations, so that we could use direct quotes from the women to tell their stories, not only our interpretations of their stories. By the time the conversations were finished, we had a loose bundle of quotes and descriptions. We sent these to the person we had been speaking with to read. Then we went through the notes with them to make sure everything was correct. We always asked if there was anything we missed out that they would still like to talk to us about.

We would try not to get upset ourselves when a conversation became quite emotional, but we would be empathetic. Where appropriate, we asked whether they knew what help was available and supported them to make arrangements, or we talked with them to someone they trusted. We also learned that it was good to follow up the conversations quite quickly with a phone call to make sure a person was ok. Most of the time they were, but they appreciated our concern.

For this research, we only spoke to women. As such, only a female perspective is addressed. We did speak to men who told us they wanted to participate, because they too had experienced a lot of violence.

10.

Desk Research Report

10.1 What is violence?

Several perspectives may be used in defining violence, including legal, sociological, psychological, and cultural viewpoints. Dominant perspectives may differ between countries and regions.

Forms of violence as defined in research and policies

From a legal perspective, violence is usually defined as all the violations and crimes that are described in criminal law.³⁴ Specific acts may be described in criminal law, such as rape, beating, abuse etc. There may be specific punishments for committing these acts. In a legal perspective, usually only those acts that are described in criminal law are recognised as violence.

From a psychological perspective, violence is acknowledged to be all the acts that are perceived by the victim as violent, intimidating, and crossing ethical boundaries. From this perspective, violence can include many more forms of violence than just the acts that are described in criminal law.³⁵

The sociological perspective looks at violence within the context of societal structures and power balances between groups and individuals.³⁶ For instance, relations between care workers and persons living in institutions are strongly influenced by the extreme dependency of the care receiver on the caregiver, as well as by the organisational demands, and the culture and legal status of the person living in the institution.³⁷

³⁴ Beperkt weerbaar, een onderzoek naar seksueel geweld bij mensen met een lichamelijke, zintuiglijke of verstandelijke beperking. Utrecht, 2011

³⁵ Beperkt weerbaar.

³⁶ Factsheet Seksueel geweld, MOVISIE, 2009; Höing & Van Oosten, 2004).

³⁷ See for effects on behaviour of people living or working in institutions: Goffman, E. (1961), Asylums: essays on the social situation of mental patients and other inmates, New York: Anchor books.

In the Netherlands, for instance, people living in institutions have the legal status of a 'patient'. That status denies them any control over the organisation responsible for their support and living arrangements. The status makes them so dependent on the institutions that they find it extremely difficult to stand up to any misbehaviour or violent acts by caregivers or other 'patients'.³⁸

Violence can be non-ethical behaviour or misbehaviour, sometimes on the edge of what is considered acceptable, such as humiliation, denying or withholding care, freedom restricting measures, applying force during care, denying choice etc. Such misbehaviour can come from care workers, family members, or people living in the same institution or group home.

The cultural perspective is useful when it comes to determining what kind of behaviour and which actions are regarded as common and acceptable, within regular limits, and which are regarded as out-of-bounds, abusive, and violent. Cultural attitudes affect whether it is seen as important that someone makes their own choices, and indeed whether it is judged that they are able to. It also makes a major difference whether a culture accepts the autonomy of women with intellectual disabilities. Whether women with intellectual disabilities are listened to, have legal control, and are allowed to make their own life choices, are important to consider from a cultural perspective.

The influence of different cultural perspectives can be shown in the example of a sexual relationship between two people, one with an intellectual disability and one without a disability. Those who consider the person with an intellectual disability to be incapable of freely choosing a sexual partner may conclude that the relationship is abusive. The person without a disability might be seen as dominant, manipulative, or coercive, and it might be considered that the sex in that relationship is not freely chosen by both people. Those that acknowledge the capability of the person with intellectual disabilities to enjoy sexual relations, to choose a partner and to make decisions, would be quicker to accept their relationship as freely chosen and non-abusive.³⁹

The legal perspective is also relevant in this example of a sexual relationship. If one of the persons in the relationship is a professional providing care to the other person in the relationship, then the professional may face prosecution, at least in the

³⁸ Achter de façade II, Zwartboek over misstanden in de verstandelijk gehandicapten zorg. Het zwartboek van stichting KlokkenluidersVG beschrijft met voorbeelden hoe geweld en seksueel misbruik in zorginstellingen ongemeld en onbestreden blijven als gevolg van de financiële structuur en zeggenschapsverhoudingen in instellingen. <http://www.klokkenluidersvg.nl/images/klvgzwartboek28112014.pdf>

³⁹ Gill, 2010

Netherlands. In Dutch criminal law, any sexual relationship between a professional caregiver and someone dependent on the professional care is punishable, even if the person receiving care freely consents to the sex. Dutch criminal law supposes that the dominance of the professional over the care receiver makes it impossible for the care receiver to choose freely.⁴⁰

International definitions and analyses of violence

In research and policy reports on violence at national level, emphasis is usually placed on physical and sexual violence, with prevalence measured by the number of reported incidents. Incidents are defined as cases of violence between persons, and usually concern acts that are punishable by law, such as rape, abuse, maltreatment, beating etc. Violence is less often measured and analysed as a phenomenon that occurs as an outcome of societal structures or unbalanced power relations between individuals and/or groups (such as the imbalance in power between men and women).

However, in the set of norms, rights, and values laid down by the international community, and in covenants, recommendations, reports and comments by the United Nations and its organisations and representatives, much more emphasis is placed on these societal structures and imbalances of power. Here, violence receives a broader definition than the strict legal definition. Violence against women is acknowledged to include discrimination against women, which hinders them in the exercise of their human rights and their ability to develop themselves on an equal footing with men.

In a number of UN Conventions, General Recommendations, General Comments, and Reports by UN rapporteurs, the international community has studied violence against women, and more specifically violence against women with disabilities. It describes and analyses this violence as something interpersonal, and an outcome of the subordinate position in society of women in general, and of women with disabilities in particular.

Discrimination against women is defined in Article 1 of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), adopted 1979 by the General Assembly of the UN.⁴¹ The definition of discrimination in CEDAW includes gender-based violence as: “violence that is directed against a woman because she is a woman or that affects women disproportionately. It includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty”.⁴²

⁴⁰ Article 249, second paragraph, preamble and under 3, Criminal law. Wetboek van Strafrecht,

⁴¹ <http://www.un.org/womenwatch/daw/cedaw/>

⁴² General recommendation No. 19 by the Committee On The Elimination Of Discrimination Against Women 1992: http://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/1_Global/INT_CEDAW_GEC_3731_E.pdf

The UN Committee on the Elimination of Discrimination Against Women explains in General Recommendation No. 19 of the Convention that “such violence impairs or nullifies the enjoyment by women of human rights and fundamental freedoms under general international law or under human rights conventions.”⁴³

The UN Committee on CEDAW describes the effect of traditional attitudes in society on the subordinate position of women, in General Recommendation No.19:

“Traditional attitudes by which women are regarded as subordinate to men or as having stereotyped roles perpetuate widespread practices involving violence or coercion, such as family violence and abuse, forced marriage, dowry deaths, acid attacks and female circumcision. Such prejudices and practices may justify gender-based violence as a form of protection or control of women. The effect of such violence on the physical and mental integrity of women is to deprive them of the equal enjoyment, exercise and knowledge of human rights and fundamental freedoms.”⁴⁴

In 2002, the Council of Europe adopted the Convention on preventing and combating violence against women and domestic violence. The convention describes violence against women as “a form of gender-based violence that is committed against women because they are women.”⁴⁵ The Council of Europe further explains: “Stalking, sexual harassment, sexual violence (including rape), physical, and psychological abuse at the hands of intimate partners, forced marriage, and forced sterilisation are deeply traumatising acts of violence. The overwhelming majority of victims are women. Adding female genital mutilation and forced abortion as forms of violence that only women can be subjected to, shows the shocking level of diversity in cruel and degrading behaviour that women experience. If we consider the fact that most violence is carried out by men, it is just a small step to understanding that violence against women is structural violence – violence that is used to sustain male power and control.”⁴⁶

⁴³ Quoted from the Report of the Special Rapporteur on violence against women, its causes and consequences. Human Rights Council, Thirty-fifth session, 6-23 June 2017 <http://www.ohchr.org/EN/Issues/Women/SRWomen/Pages/AnnualReports.aspx>

⁴⁴ Ibid. General Recommendation No. 19, point 11

⁴⁵ Council of Europe Convention on preventing and combating violence against women and domestic violence <https://rm.coe.int/168046031c>

⁴⁶ <http://www.coe.int/en/web/istanbul-convention/about-the-convention>

In General Comment No.3 of the UN CRPD, the UN Committee on the Rights of Persons with Disabilities emphasises the effect of societal structures, imbalance in power, cultural attitudes, and family structures on the enjoyment of human rights and freedom from violence: “Women with disabilities are at a heightened risk of violence, exploitation and abuse compared to other women. Violence may be interpersonal or institutional and/or structural. Institutional and/or structural violence is any form of structural inequality or institutional discrimination that keeps a woman in a subordinate position, whether physically or ideologically, compared with other people in her family, household or community.”⁴⁷

According to the UN Committee on the Rights of Persons with Disabilities, women and girls who are deaf, deafblind, or have intellectual disabilities may be “at an even greater risk of violence and abuse because of their isolation, dependency or oppression.”

General Comment No. 3 on Article 6 of the UN CRPD describes the effect of stereotypes regarding woman with disabilities:

“Enjoyment by women with disabilities of the right to freedom from exploitation, violence and abuse can be hindered by harmful stereotypes that heighten the risk of experiencing violence. Harmful stereotypes that infantilize women with disabilities and call into question their ability to make judgments, perceptions of women with disabilities as being asexual or hypersexual and erroneous beliefs and myths heavily influenced by superstition that increase the risk of sexual violence against women with albinism, all stop women with disabilities from exercising their rights as set out in article 16.”⁴⁸

The UN Committee on the Rights Of Persons With Disabilities explicitly describes many forms of violence and abuse. “Certain forms of violence, exploitation and abuse may be considered as cruel, inhuman or degrading treatment or punishment and as breaching a number of international human rights treaties. Among them are: forced, coerced and otherwise involuntary pregnancy or sterilisation; any medical procedure or intervention performed without free and informed consent, including procedures and interventions related to contraception and abortion; invasive and irreversible surgical practices such as psychosurgery, female genital mutilation and surgery or treatment performed on intersex children without their informed consent; the administration of electroshock treatment and the use of chemical, physical or mechanical restraints; and isolation or seclusion.”⁴⁹

⁴⁷ CRPD, General Comment No 3 Article 6: Women and girls with disabilities (Adopted 26 August 2016), para 29. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

⁴⁸ CRPD, General Comment No 3, para 30

⁴⁹ CRPD, General Comment No 3, para 32

Other forms of violence against women and girls with disabilities that are explicitly described by the UN CRPD Committee include: “the acquisition of a disability as a consequence of violence, physical force; economic coercion; trafficking and deception; misinformation; abandonment; the absence of free and informed consent and legal compulsion; neglect, including the withholding or denial of access to medication; the removal or control of communication aids and the refusal to assist in communicating; the denial of personal mobility and accessibility by, for example, removing or destroying accessibility features such as ramps, assistive devices such as white canes or mobility devices such as wheelchairs; the refusal by caregivers to assist with daily activities such as bathing, menstrual and/or sanitation management, dressing and eating, which hinders enjoyment of the right to live independently and to freedom from degrading treatment; the withholding of food or water, or the threat of doing so; the infliction of fear by intimidation through bullying, verbal abuse and ridicule on the grounds of disability; the harming or threat of harming, removing or killing pets or assistance dogs or destroying objects; psychological manipulation; and the exercise of control, for example by restricting face-to-face or virtual access to family, friends or others.”⁵⁰ The UN CRPD Committee also states:

“Sexual violence against women with disabilities includes rape. Sexual abuse occurs in all scenarios, within State and non-State institutions and within the family or the community.”⁵¹

Use of the term violence in Dutch policies and legislation

Since the beginning of this century, there has been increasing attention in the Netherlands to the fact that people with a disability are more often victims of violence than people without a disability. This growing awareness led the Dutch Government to commission research on sexual violence among people with intellectual disabilities, resulting in an influential report published in 2011, titled “Beperkt Weerbaar”, which can be translated as “Disabled Resilient”.⁵²

⁵⁰ CRPD, General Comment No 3, para 31, 33, 36, 53.

⁵¹ CRPD, General Comment No 3, para 33.

⁵² W. van Berlo e.a.: Beperkt weerbaar, een onderzoek naar seksueel geweld bij mensen met een lichamelijke, zintuiglijke of verstandelijke beperking. Rutgers WPF/MOVISIE, Utrecht, 2011. ISBN 978-90-77289-04-4 https://www.rutgers.nl/sites/rutgersnl/files/PDF-Onderzoek/Rapport_Beperkt_Weerbaar_Rutgers-WPF_Movisie1.19mb.pdf

As a result of the report and growing awareness, new policies have been formulated to prevent “violence in dependency relations”. The phrase “violence in dependency relations” refers to violence within families (against children or violence between partners), violence against elderly people, and violence against people who are dependent on long-term care. In policies and legislation, the term ‘violence’ is interpreted broadly, not restricted to the legal definition of acts punishable by criminal law. One of the elements in the policy to prevent ‘violence in dependency relations’ was to make municipalities responsible for prevention policies. The Dutch Social Support Act 2015⁵³ governs the right to support and care for people with a disability who live independently. The act makes municipalities responsible for preventing and combatting violence in “dependency relations”. The definition of violence used in this Social Support Act distinguishes between physical, psychological, and sexual violence. It highlights:

“– violence while providing support, sexual penetration of the body, sexual intercourse with coercion, as well as physical and psychological violence against a client, by a professional or by another client with whom the client resides in accommodation provided through the care organisation.

– violence in the private home: physical, psychological or sexual violence or threat by someone from the household.”

Together with care provider organisations, the Dutch Government discussed and wrote further policy plans to prevent and combat ‘violence in private homes’.⁵⁴ These policy plans⁵⁵ used the phrase “unacceptable behaviour”⁵⁶ instead of the term “violence”. All behaviour leading to a feeling of social insecurity is considered off-limits. People can feel unsafe either because they are actually a victim of violent acts perpetrated by someone, or because they fear becoming a victim of such acts.

⁵³ Wet Maatschappelijke Ondersteuning 2015 (Social Support Act 2015) <http://wetten.overheid.nl/BWBR0035362/2016-08-01>

⁵⁴ in Dutch: huiselijk geweld

⁵⁵ Veilige zorgrelatie. Handvatten voor bewustwording, preventie en interventie bij grensoverschrijdend gedrag en mishandeling in de professionele zorgrelatie. Uitgewerkte versie. Vastgesteld juli 2014, geactualiseerd april 2016. Antoinette Bolscher en Marie-Josée Smits. [http://www.veiligezorgrelatie.nl/downloads/Leidraad%20Veilige%20zorgrelatie,%20uitgewerkt%20\(april%202016\).pdf](http://www.veiligezorgrelatie.nl/downloads/Leidraad%20Veilige%20zorgrelatie,%20uitgewerkt%20(april%202016).pdf)

Toolkit Werken aan sociale veiligheid, Janssens, K.; Lammers, M.; Hartog, Z.; Goes, A.; Heeringa, N. Movisie en Vilans, mei 2012. <https://www.movisie.nl/publicaties/toolkit-werken-aan-sociale-veiligheid>

⁵⁶ In Dutch: grensoverschrijdend gedrag.

Behaviour that is considered unacceptable according to these policies includes:

- neglect and withholding of care;
- psychological misbehaviour, including emotional abuse;
- physical misbehaviour, including maltreatment and abuse;
- sexual misbehaviour, including sexual abuse;
- financial and material exploitation;
- discrimination;
- violation of rights.

According to this policy by the Dutch government and care providers, what may be considered off limits is to a large extent subject to the interpretation of the victim.

The research report “Beperkt Weerbaar” bases its own definition of violence on several international research reports and formulates it as:

- Any form of sexual behaviour or sexual proposal, verbally, non-verbally or physically, intentionally or unintentionally, which is perceived by the person who is made subject to this behaviour as unwanted or forced;⁵⁷
- which takes place within an unbalanced power relation (adult-child, teacher-pupil, trainer-pupil, coach-youth etc.);
- and/or other acts or kinds of behaviour that are punishable by criminal law.

⁵⁷ McCarthy en Thompson (1996) summarise the different efforts to define as: sexual abuse happens ‘where sexual acts are performed on or with someone who is unwilling or unable to consent to those acts’, where ‘any sexual contact which is unwanted and/or unenjoyed by one partner and is for the sexual gratification of the other’, and where ‘that person’s apparent willingness is unacceptably exploited.’ (cited from Gill, 2010).

The researchers offer the following explanation of this definition⁵⁸:

“Sexual violence may include many forms of misbehaviour, either physical or otherwise. With physical off limits behaviour, the victim is subjected to or must perform sexual acts by force. The term force should be interpreted broadly. Whether force is being used is mainly a matter of interpretation by the victim or, in the case of minors, also interpretation by parents. It concerns situations in which the victim feels she cannot refuse or cannot withdraw, for instance because emotional pressure is applied (such as psychological pressure or blackmail), physical force is exerted, or economic dependency is used. Examples of non-physical sexual misbehaviour include the unsolicited sending of pornographic pictures or of sexually tinted text messages or email.”⁵⁹

With violence other than sexual violence, it is sometimes difficult to make clear when behaviour is unacceptable and to recognise such behaviour as a form of violence. Commissioned and used by the Dutch Ministry of Health, Welfare and Sports, and with advice from care providers and care professionals organisations, a set of ‘guidelines to safe relations’⁶⁰ was developed and published in 2014. These guideline aims to raise awareness among care professionals about forms of violence that could harm people who are long-term dependent on support and care. It also aims to provide instructions on what to do when violence occurs. The extended version of these guidelines⁶¹ offers an extensive list of situations that could be interpreted as misbehaviour (behaviour that crosses ethical boundaries) but which are not always recognised as such.

The guidelines explain that mostly physical and psychological violence, such as beating, pinching, and theft is characterised as violence. However, in day-to-day routines, behaviour might creep into care relations (whether care is provided by family or a professional,) which is harmful to the person with a disability but which is not recognised as violence:

“When it comes to misbehaviour (“off-limits” behaviour), one thinks first of obvious, clear cases such as theft, beating of a client, extortion. The first reaction is usually, “that” (unacceptable behaviour) doesn’t happen here with us. If, however, the conversation about various forms of violence continues, examples start to arise of behaviour that actually does happen in the daily reality of work, and not just with “that one nasty client”.”

⁵⁸ The definition and explanation as used in the report Beperkt Weerbaar.

⁵⁹ Beperkt Weerbaar, page 4.

⁶⁰ Leidraad veilige zorgrelatie. <http://www.veiligezorgrelatie.nl/>

⁶¹ Leidraad Veilige Zorgrelatie, pag. 27 e.v. [http://www.veiligezorgrelatie.nl/downloads/Leidraad%20Veilige%20zorgrelatie,%20uitgewerkt%20\(april%202016\).pdf](http://www.veiligezorgrelatie.nl/downloads/Leidraad%20Veilige%20zorgrelatie,%20uitgewerkt%20(april%202016).pdf)

The guidelines describe many examples of behaviour that is not always recognised as violence.

“For instance: situations in which a care provider ignores a call for help by a client because the client is known to call for help too often; letting a client sit for too long on a toilet; making jokes about tics or behaviour of a client; speaking very loud to someone with an intellectual disability such that this frightens the person.”

Psychological misbehaviour could also be acts that are intentionally meant by the carer to ‘correct’ or modify the behaviour of a client. This could be incidental or part of a behaviour modification program that hands out rewards for a client’s ‘good’ actions or punishments for ‘bad’ actions. The guidelines give the following examples:

“Threatening a client with an intellectual disability that he cannot go out that day if he does not sit quietly at the table. Threatening a client with a psychosocial disability that he may not get weekend leave if he does not clean his room immediately. Placing a client in a wheelchair in a way that he cannot see the television screen.”

The administration of small electric shocks to modify behaviour is also mentioned in the guidelines as psychological unacceptable behaviour by carers. Rough handling of persons, or manipulating clients to pay expenses such as drinks and meals for their carers, or to have clients pay for ‘presents’ for the carers, are more examples of misbehaviour. Other examples of psychological misbehaviour are neglecting pain and discomfort during washing, or leaving someone lying naked on a bed while the carer goes off to help someone else.

10.2 Prevalence of violence

The UN CRPD Committee worries about “the persistence of violence against women and girls with disabilities, including sexual violence and abuse; forced sterilisation; female genital mutilation; sexual and economic exploitation.”⁶² The UN CRPD Committee highlights that according to its research, women with a disability are at a greater risk of becoming a victim of violence compared to women without disabilities.⁶³

⁶² CRPD, General Comment No 3, para 10. “the persistence of violence against women and girls with disabilities, including sexual violence and abuse; forced sterilisation; female genital mutilation; sexual and economic exploitation;”

⁶³ CRPD, General Comment No 3, para 29, reference to A/67/227, para 13.

An English study from 1999⁶⁴ shows that physical and psychological violence is more prevalent than sexual violence among people with an intellectual disability. It also reveals that physical violence often is often part of sexual abuse, if the latter occurs. The same study found that people with an intellectual disability often report that others demonstrate degrading and negative attitudes towards them.

A 2005 study from the USA⁶⁵ showed that children with an intellectual disability are three to four times more likely to experience violent behaviour against them compared to children without disabilities. Another American study⁶⁶ and a Unicef report⁶⁷, also both published in 2005, mention the same high prevalence of violence against children with intellectual disabilities.

“Stop the Violence”, a project conducted in 2012-2013 by Women with Disabilities Australia, People with Disabilities Australia, and the University of New South Wales, found that violence intensified in frequency, extent, and nature when gender and disability intersect.⁶⁸

To establish the prevalence of violence against people with an intellectual disability in the Netherlands, the “Beperkt Weerbaar”⁶⁹ research report involved interviews of Dutch people with intellectual disabilities, staff workers in institutions, and family members. The results of those interviews were as follows: 61% of women with an intellectual disability and 23% of men with an intellectual disability reported experiences with sexual violence. 23% of the women in this study reported rape. The experiences were fairly recent: 13% of the women reported the violence had occurred in the year before the interview took place. The self-reported sexual abuse varied

⁶⁴ Brown, H. (1999). Abuse of people with learning disabilities. Layers of concern and analysis. In: N. Stanley, J. Manthorp & B. Penhale. (Eds.), *Institutional Abuse: Perspectives Across Life Course*. (pp. 89-109). London: Routledge.

⁶⁵ O.M. Sobsey, D. (2005). Violence & Disability. In: W. M. Nehring (Ed.), *Health promotion for persons with intellectual/developmental disabilities: The state of scientific evidence*. Washington, DC: American Association on Mental Retardation.

⁶⁶ The abuse of individuals with developmental disabilities, Catherine Thornberry and Karin Olson, University of Alberta. *Developmental Disabilities Bulletin*, 2005, Vol. 33, No. 1 & 2, pp. 1-19 <http://files.eric.ed.gov/fulltext/EJ844468.pdf>

⁶⁷ Violence against Disabled Children. UN Secretary Generals Report on Violence against Children. Thematic Group on Violence against Disabled Children. Findings and Recommendations. Convened by UNICEF at the United Nations, New York, July 28, 2005. https://www.unicef.org/videoaudio/PDFs/UNICEF_Violence_Against_Disabled_Children_Report_Distributed_Version.pdf

⁶⁸ Stop the Violence Project (STVP), background paper. October 2013. http://wwda.org.au/wp-content/uploads/2013/12/STV_Background_Paper_FINAL.pdf

⁶⁹ Beperkt weerbaar, een onderzoek naar seksueel geweld bij mensen met een lichamelijke, zintuiglijke of verstandelijke beperking. Utrecht, 2011. http://www.rutgers.nl/sites/rutgersnl/files/PDF-Onderzoek/Rapport_Beperkt_Weerbaar_Rutgers-WPF_Movisie1.19mb.pdf

from unsolicited harmful touching to rape.

The researchers of the “Beperkt Weerbaar” report also analysed international studies on the prevalence of violence against people with intellectual disabilities. These were the results:

“Regarding violence against children with an intellectual disability, Sullivan and Knutson (2000) found a prevalence of 31% (including both physical and sexual abuse). In a Dutch study (Spanjaard, Haspels and Roos, 2000), the prevalence of experiencing violence was found to be 65% for girls with an intellectual disability and 26% for boys with an intellectual disability.”

The “Beperkt Weerbaar” report also mentions a study (Hershkowitz, Lamb and Horowitz, 2007), in which it was found that 12% of a group of abused children had an intellectual disability. In another study (Kvam, 2000), the proportion of intellectually disabled children in a group of abused children turned out to be 6.4 %.

According to the “Beperkt Weerbaar” report, several studies have come up with varying but high percentages regarding the prevalence of violence against people with intellectual disabilities. These vary from 8% of men and women with intellectual disabilities, up to 83% among women with intellectual disabilities and 32% among men with intellectual disabilities.⁷⁰

Prevalence per year of violence against people with intellectual disabilities

Measured in incidents per given year, prevalence of sexual abuse is, according to some studies, between 2,88 per 1,000 people with disabilities up to 0.5% per year.⁷¹ A longitudinal study showed that over a period of 15 years, 6% of children and adults with intellectual disabilities had been victims of (confirmed, not only self-reported) sexual abuse.⁷²

The prevalence of sexual abuse against people with intellectual disabilities in the Netherlands was, according to a study dating from 1995⁷³, 1.2% confirmed cases and 1.3 % suspected cases over a period of 2 years. The majority of the victims in this study (both adults and children) had a minor to moderate intellectual disability.

⁷⁰ Referenced in Beperkt Weerbaar: Douma, Van den Bergh & Hoekman, 1998; Hassouneh-Phillips & Curry, 2002. McCarthy & Thompson, 1997.

⁷¹ Referenced in Beperkt Weerbaar: McCarthy: 2,88 per 1.000 per year (published in Dunne & Power, 1990), and 0,5% per year (Brown, Stein & Turk, 1995, in McCarthy, 1999).

⁷² Referenced in Beperkt Weerbaar: McCormack, Kavanagh, Caffrey en Power (2005)

⁷³ Referenced in Beperkt Weerbaar: Van Berlo, 1999.

This study found that a third of the perpetrators turned out to be someone else with a disability (such as a fellow resident in an institution, group home, day-care centre or school). Another third of the perpetrators were people who shared a household with the victim. 16% of perpetrators turned out to be a staff member in a care-providing organisation.

In a small-scale Dutch study in which adolescents between 14-19 years old and who lived in a residential institute were interviewed,⁷⁴ 26% of the boys and 65% of the girls reported to have been victims of sexual abuse. Care professionals working in that institution reported lower percentages of incidents of sexual abuse, suggesting that not all incidents experienced by the boys and girls were known to the supporting professionals.

In another study of adolescents with an intellectual disability,⁷⁵ 41% of girls reported sexual intimidation, 38% reported unwanted touching, and 4 % reported to have been forced to touch another person. None of them reported rape.

One Dutch study titled “Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010” (Prevalence of Sexual Abuse in Youth Care)⁷⁶ examined the prevalence of sexual abuse among young people in youth care institutions. This study found a prevalence of 9.7 per 1,000 sexual abuse incidents among young people with an intellectual disability.

Prevalence of violence against people with intellectual disabilities compared to the general population

Sexual abuse does not only happen to people with a disability. The prevalence of sexual abuse among the general population in the Netherlands is, according to the “Beperkt Weerbaar” report, 33% for women and 5% for men. Compared to the percentages of self-reported violence among people with intellectual disabilities in the same research project – 61% for women and 23% for men – we can see that the prevalence is approximately twice as much among women with intellectual disabilities and 5 times higher among men with intellectual disabilities.

The “Beperkt Weerbaar” report cites some studies⁷⁷ in which the experiences of people with intellectual disabilities regarding sexual abuse were compared to the

⁷⁴ Referenced in Beperkt Weerbaar: Spanjaard et al. (2000)

⁷⁵ Referenced in Beperkt Weerbaar: Reiter, Bryen and Shachar (2007)

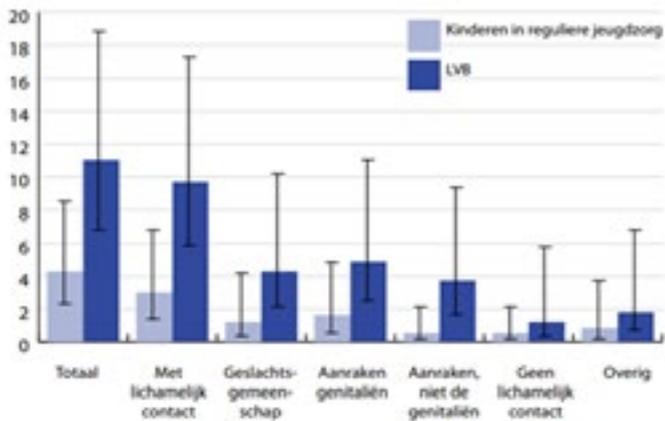
⁷⁶ Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010: Een Kwantitatieve Studie. <http://www.leidenattachementresearchprogram.eu/wordpress/content/prevalentie-seksueel-misbruik-in-de-nederlandse-jeugdzorg.pdf>

⁷⁷ Beperkt Weerbaar, reference to Casteel, Martin, Smith, Gurka & Kupper, 2007; Powers et al., 2002; Reiter et al. 2009.

experiences of people without a disability. The general outcome was that violence and abuse is far more prevalent among children and adults with a disability, and up to four times higher among women with a disability than the general population.

The “Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010” study⁷⁸ compared the prevalence of sexual abuse among young people in youth care institutions with that of the general population. This study found that sexual abuse of people in youth care institutions was three to four times higher than in the general population. According to the study, the risk of sexual abuse among young people with an intellectual disability is even higher than among young people without a disability in youth care. The researchers remarked:

“This shows an enormous number of victims [of sexual violence] in youth care. We know from hundreds of other studies that professionals give a much lower estimation of the number of victims than young people themselves. The prevalence of sexual abuse being 9.7 per 1,000 people, as reported by young people with intellectual disabilities, is a minimum estimate. This means there is a high risk of abuse among one of the most vulnerable groups within youth care.”



Figuur 8.2. Prevalentie seksueel misbruik in 2010 (%), totaal en per categorie

⁷⁸ Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010: Een Kwantitatieve Studie. <http://www.leidenattachmentresearchprogram.eu/wordpress/content/prevalentie-seksueel-misbruik-in-de-nederlandse-jeugdzorg.pdf>

This graphic⁷⁹ shows the difference in prevalence of sexual abuse among young people between 1 and 20 years old in youth care. The figures for children without disabilities are shown in light blue, while darker blue represents the figures for children with an intellectual disability who are in youth care. From the left, the first column indicates the total levels of abuse. Then towards the right, in order, the columns indicate levels of abuse with physical contact, intercourse, touching of genitals, touching without touching genitals, no physical contact, and all other kinds of sexual abuse.

10.3 General data gathering Netherlands

There is no general data on the prevalence of violence (sexual, physical, or psychological) against people with disabilities. Care providers in the Netherlands are legally obliged⁸⁰ to report “serious incidents concerning quality of care that lead to death or serious harm” to the Inspectorate of Health. The condition that incidents should be related to the quality of care provided suggests that incidents caused by care providers, or incidents that occur because of staff negligence, should be reported only when serious harm or death is caused. It is unclear whether these conditions are strictly applied.

The Inspectorate of Health’s 2016 annual report⁸¹ states that over 2016, 940 mentions of incidents were received. Of those 940 mentions, 180 incidents were labelled as the obligatory reports on incidents causing serious harm or death. According to the same report, there were 160 cases of sexual abuse reported (of which in 40 cases, a member of staff was involved, and 100 were abuse incidents between people with a disability living in the same group home or sharing a day-care activity).

⁷⁹ Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010: Een Kwantitatieve Studie. <http://www.leidenattachmentresearchprogram.eu/wordpress/content/prevalentie-seksueel-misbruik-in-de-nederlandse-jeugdzorg.pdf>

⁸⁰ Wet kwaliteit, klachten en geschillen zorg (WKKGZ) in artikel 11, 1e lid, onder b.

⁸¹ Jaarbeeld 2016, page 51 and 52. http://igz.nl/Images/IGZ%20Jaarbeeld%202016-def-IA_tcm294-383131.pdf

10.4 Under-reporting: by families and professionals, and in the gathering of formal data

The “Beperkt Weerbaar” researchers interviewed women and men with intellectual disabilities, as well as their family members and support professionals. While 61% of the women reported violence (13% of which had occurred in the past year), 29% of their support professionals reported such incidents. The researchers concluded that professionals and family members are often poorly informed about the abuse being experienced inside an institution, and that it should be taken into account in any study where professionals and family members are interviewed on this matter that under-reporting is a possibility.

The number of incidents in care homes that was reported to the Inspectorate of Health can be put into perspective when we know the number of people with an intellectual disability living in care institutions (residential settings, various size group homes) in the country. In the Netherlands, statistical data is obtained through surveys executed by the Central Bureau of Statistics (CBS).⁸² People with intellectual disabilities are excluded from these surveys. It is therefore not known exactly how many inhabitants of the Netherlands have an intellectual disability, nor how many of them live in an institution or are independent. Only estimates are available.

An estimation made by Dutch National Disability Care, a care providers’ organisation,⁸³ states that around 78,000 people with a disability live in a residential care home (small or large), of which around 75% are labelled as intellectually disabled. If we figure that around half of them are female, it would mean that an estimated 29,250 women with intellectual disabilities live in residential care homes in the Netherlands.

⁸² The method used in the surveys by the Central Bureau of Statistics (CBS) exclude many people with disabilities. The surveys by CBS are based on samples of people who are requested to fill in online forms. The surveys exclude explicitly all people living in residential settings. They will not receive requests to fill in online forms. People with intellectual disabilities or mental health problems who live independently can participate in the survey as people are requested through mail to fill in online forms. If they do not respond, they can be interviewed by phone or in person. Interviewers who meet with persons who have difficulty understanding the standard questions are not allowed to adapt the questioning but must exclude these persons (according to a description by a spokesperson for CBS). See: http://www.disability-europe.net/dotcom/?l%5B%5D=25&t%5B%5D=43&t%5B%5D=44&t%5B%5D=45&t%5B%5D=46&view_type=list

⁸³ Factsheet VGN: file:///C:/Users/grooff/Downloads/Factsheet%20-%20Cli%C3%ABnten%20die%20gebruikmaken%20van%20AWBZ%20Gehandicaptenzorg.pdf

If we would extrapolate from the “Beperkt Weerbaar” report that 13% of women with intellectual disabilities experience a form of sexual violence in a given year,⁸⁴ this would mean that around 3,800 women with intellectual disabilities experience some form of sexual violence annually.

It should be taken into account that the Dutch Inspectorate of Health only seeks to have “serious incidents” reported, so cases viewed as “less serious” by staff may not have been reported. It seems that cases of abuse and other violence within residential care are under-reported.

There is another important indication of under-reporting, when we look at registers of discrimination with the anti-discrimination office⁸⁵ in the Netherlands. People who experience discrimination may report incidents at municipal anti-discrimination facilities. According to a factsheet by the anti-discrimination office,⁸⁶ there were 391 complaints in 2016 about experiencing discrimination on the grounds of a disability or chronic illness. Of those 391 incidents, 59 talked about being handled in a hostile manner, 335 cited controversial treatment, and only one concerned a threat and only one concerned violence. These figures indicate that women who experience violence may not interpret this as discrimination and/or may not know they can report the incidents to the anti-discrimination office.

We asked the Dutch Ministry of Justice and Security and the Dutch national police to provide statistics on violence against people with disabilities, for our research. Neither the Ministry nor the national police were able to provide this information because in no crime statistics is it registered whether the victim or perpetrator has a disability or not.

10.5 The influence of having a disability

In interviews made for the “Beperkt Weerbaar” report, family members and care professionals were asked whether the fact that victims have an intellectual disability had anything to do with them becoming victim of sexual abuse. Most of the respondents said yes, the disability had made the victims more vulnerable.

⁸⁴ The prevalence % per year from the interviews with Dutch women in residential care from the study Beperkt Weerbaar.

⁸⁵ See for the national website in which these offices work together: <http://www.discriminatie.nl/#/home>

⁸⁶ http://discriminatie.nl/files/2017-03/1490021884_factsheet-discriminatie-2016-adv-s-lvtd-def-mrt-2017.pdf

Parents reported that their children are less resilient, and are also less aware of the cause and effect of their actions, because of their intellectual disability. Some parents said that their children were not able to refuse another person's attempt to engage them in an activity or interaction that leads to abuse, especially if the other person was able to prey on their vulnerability. In such cases, it is not easy to say no to proposals because they fear or admire the other person, or they simply would not know how to react to improper proposals. A few respondents were of the opinion that the disability did not play any role if the perpetrator also had a disability.

The professionals who responded in the “Beperkt Weerbaar” report also said that having an intellectual disability plays a role in becoming a victim of violence. They pointed out that people with an intellectual disability are more vulnerable, and are not able to protect themselves against improper proposals. They could be afraid to say no to another person, or feel too dependent on the other person to refuse them. Professionals interviewed also emphasised that people with an intellectual disability may not be able to express themselves verbally. Furthermore, the professionals said that women with intellectual disabilities tend to place much trust in others, and are not always capable of understanding the cause and effect of their own actions. This sometimes led to situations where their signals were misunderstood by others, to others, culminating in the other person abusing them. According to these professionals, this kind of situation appears to happen more quickly if the perpetrator also has an intellectual disability. They also remarked that sometimes women with intellectual disabilities are not capable of recognising abuse as abuse. They may seem to accept sexual abuse as “something that just is part of the game” or something “one just does for another”.

The “Beperkt Weerbaar” report found that most perpetrators were men and most were acquaintances of the victim. A minority of perpetrators were working as professionals in a care home.

The researchers of the study, “Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010”,⁸⁷ remarked that given the high prevalence of sexual abuse in youth care institutions, there is a strong need for scientific research on the causes and effects of sexual abuse, and yet this is currently almost non-existent. They refer to a study by Stalker and McArthur, 2012, stating:

“Little is known about the effects on children of experiencing abuse, why they may become easier victims than children without disabilities, and what the consequences are for their mental health and welfare in comparison with other children.”

⁸⁷ Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010: Een Kwantitatieve Studie. <http://www.leidenattachmentresearchprogram.eu/wordpress/content/prevalentie-seksueel-misbruik-in-de-nederlandse-jeugdzorg.pdf>

“These experiences have made us who we are.”

Lucy, 32 years old

Inclusion Europe.

Equal rights and full inclusion

of people with intellectual disabilities
and their families.

More than 70 members in 39 European countries.



@InclusionEurope



facebook.com/inclusion europe



youtube.com/user/inclusion europe

Rue d'Arlon 55

B-1040 Brussels Belgium

Telephone: +32-2-502 28 15

secretariat@inclusion-europe.org

www.inclusion-europe.org