

Life after violence



Easy-to-read version

A study on violence against women with intellectual disabilities 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

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For full version of the research report please visit www.inclusion-europe.eu.

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Introduction by Senada Halilčević

I spent a lot of time in an institution myself. That is why the topic of this publication is important for me. I am proud to present you this research.

At the beginning of this research we had a question: "What happens to women with intellectual disabilities after they experienced violence in an institution?"

We spoke with the women themselves. We found women with a lot of courage, who shared their stories with us.

This is what we found out:

Violence happens to women with intellectual disabilities everywhere.

It happens to them in institutions, in families,

in the community.

This is also what I personally experienced.

Sometimes it is difficult to read about all these experiences. But we must listen to the women who shared their experiences, and to all other women with intellectual disabilities.



Senada Halilčević Vice-President of Inclusion Europe Chair of the European Platform of Self-Advocates



Introduction

Women with intellectual disabilities experience a lot of violence.

Someone who has an intellectual disability has more difficulties in understanding information and learning new skills than other people. This makes some parts of their life harder.

There are a lot of studies about violence. Most of these studies are about sexual violence. We know that many women experience sexual violence.

But women with intellectual disabilities experience sexual violence even more often.



Sexual violence is when a woman is touched in her private parts when she does not want this. Or when she is told she will be touched. This makes her feel afraid.

Care staff often don't know about this.

Many women don't talk about violence.

They are scared that:

- they will not be believed,
- they will get hurt if they speak,
- they will lose the care they get.



What you need to know is:

- Violence happens everywhere.
- Violence happens a lot to women with intellectual disabilities.
- There are many types of violence.

We did a study about violence against women with intellectual disabilities in institutions.

Institutions are places where people with intellectual disabilities live with other people with intellectual disabilities. They often live there apart from other people. They often have little choice who they live with or who supports them.

What we wanted to know was:

- What happens to women with intellectual disabilities after they experienced violence in an institution?
- How does their experience shape their lives once they leave the institution to live in the community?

Self-advocates about violence

First, we wanted self-advocates to teach us about violence.

Self-advocates are people with intellectual disabilities who speak up for themselves.



They said there are different types of violence:

• Physical Violence:



Some women were physically hurt. For example, when someone punched, hit, pushed or kicked them.

Sexual Violence



Some women were touched in their private parts but they did not want this.

Some were told that they would be touched. This made them feel afraid. Psychological Violence



Some women had people shouting at them. Some women were bullied.

Bullying is when someone threatens you or tells you that you are a bad person. This can make you feel afraid and alone.

Not being looked after



Some women did not get the care or support they needed. For example, they did not get medication. They did not get to see a doctor. They did not get enough food or water. • Too much medication



Some women were forced to take medication they didn't want. Some got medication, but

- they didn't know why they should take that medication.
- they didn't know what the medication would do to them.

Not being free



You are not free if there are rules that do not let you do the things you want to do.

For example, eat what you want, meet your friends when you want to, going out when you want to. Or if people do not listen to what you say you want to do.

Money problems



Some women said that some people stole their money. Or that they did not get the money they earned.

Keeping you quiet



Some women were not allowed to speak up. They were told to shut up. They were told not to be difficult.

Some people use speech computers to talk. It is violence when someone turns off their computers, because they cannot speak anymore. This happened to some of the women.

Taking advantage of you



Someone is taking advantage of you when you work hard but don't get anything in return. Or when you need to do all the bad jobs. This happened to some of the women.

Less chances



It's not fair when you get less chances than other people.

For example,

if you are not educated to get a diploma. Or if you are not getting a job. of if you told: "You can't do that anyway." Some women experienced this.

• Violence on social media



Some women were stalked on social media. This means that people did not leave them alone and they kept sending them messages.

Violence is also when someone uses your data or photographs against you. Or when someone threatens you when you're online. This also happened to some of the women.

Not allowed to have a family



Some women were not allowed to start a love relationship with another person.

Some were forced to take medication so they could not have children.

Sometimes, they took this medication but they did not know what it was for.

Sterilisation is when a doctor does an operation so you cannot have children anymore.

Forced sterilisation is when this happens even though you don't want it. Or even though you don't know what the operation is about.

Some women experienced this. Not being taken seriously



This means that people don't listen to you. Or that

people think that your experiences are just made up stories.

If you feel emotions like anger, fear, disappointment, you are not allowed to show them. This happened to all of the women. It is important to know that there are many forms of violence. All of these have an effect on people. Sometimes when a woman experiences violence, support workers don't agree that this is violence.

When we did our study, we took a decision:

- We believe someone who says they experienced violence.
- We want to hear what women had experienced themselves.

Types of violence

1. Direct Violence



Direct violence is directly against someone.

It can happen once or many times.

It can make you feel bad for a long time.

Others most of the time agree that this is violence.

There is help available. We heard about direct violence that took place outside of the institution.

We also heard about workers from an institution who abused two different women.

Unfortunately, women in institutions often do not dare to talk about direct violence.

They are scared.

Often this is because of the structural violence they have experienced.

2. Structural violence

The women in our study experienced a lot of structural violence in institutions.

This violence happens because of how our society works.



In our society,

women are sometimes seen as less important than men because they are less strong.

People with intellectual disabilities can also be seen as less important because they need support. This is not fair. We are all important. It is difficult to see when structural violence happens.

People who have power over someone can hurt that person. The things they do seem small to them.

But to the person who has less power, these things can be very painful.

Often people do not understand how much hurt they can do to another person.

Most of the experiences women told us about in institutions were about structural violence.

A lot of this violence happened when:

- women needed other people for support.
 So they were not allowed to make their own choices,
- Strict rules did not allow people to live how they wanted.
- women were kept away from others. So they felt alone;
- the people in the institutions did not care about the women's talents and interests. They only looked at their disability.

Here are some examples: Not making your own choices:



Rules making your life hard:



Not being allowed contact:



When people look just at your disability, nothing else:



These are all examples of structural violence.

3. Not receiving the right help

There is a difference between

- caring for somebody,
- caring about somebody.



When people care for you they make sure you have:

- a roof over your head,
- food,
- a toilet,
- medication,
- safety,
- etc.

You need all these things. Institutions try to provide these things. When people care about you:

- they want to know how you feel,
- they want to know if you are happy,
- they want to get to know all about you,
- they want to know what your choices are.

When nobody cares about you your life is very lonely. Then you are more likely to experience violence.

This means you're not receiving the right kind of help. Here are some examples of ways in which caring for people can go wrong.

Not receiving good care: If you need a lot of support,



you have a bigger risk of not receiving good care.

When care is violent:

Sometimes the way people are cared for is violent.



Women we spoke had some bad experiences.

When caregivers don't support you: When caregivers see something as your own problem:



When caregivers don't share information with each other:



It is very important for every person to have people in their lives who care about them.



The women we spoke to could get out of the institutions only because they had people who cared about them.

Having people in your life who care about you is important. They can support you so you don't suffer from violence.

Effects of violence

Violence had a big effect on the women we spoke to.

After sexual abuse or physical violence often help was available.

Help came from the institution or from organisations.

Getting help is very important. The women who did not get help had a very hard time.

The women who did not get help did not get if for different reasons. For example:

- they had nobody to talk to;
- they were afraid they would lose their support;
- they were afraid nobody would believe them;
- they were afraid they would get hurt again;
- they did not want to be sent to a doctor they did not know;
- they thought what happened was normal.

Many of these reasons are linked to structural violence. No help was available for structural violence.

Every women dealt with the violence in a different way. For example:

• They became sad

The women we spoke to experienced a lot of violence.

Some had experienced so much it made them sad for a long time.

Often they were stressed and scared as well.



They changed the way they look at the world

The womens' experiences of violence had changed the way they look at the world around them.

And also the way they looked at themselves.

After these experiences, many women had a very low self-esteem. They did not feel important to other people. Many women did not trust the people who wanted to help them.



For example:

One woman was threatened a lot by her support workers. The support workers said they would send her to a psychologist if she did not do what they wanted.

The psychologist became a punishment in her mind.



Later, she experienced sexual violence.

The support workers sent her to the psychologist.

For her, this was a punishment.

Because before, the psychologist had always been used as a threat.

She went to the psychologist. She did not speak to her.

She was not open to the help she needed.

This was because of the threats she had received before.

The women we spoke to also thought the world was against them.

Many of them could not believe that they will be happy for long.

They were always scared of losing the good things in their life.

Not getting hurt again

All of the women who experienced violence tried not to get hurt again.



The women did 3 things:

1. Adapt:

Many of the women we spoke to adapted their behavior. It means they changed their behavior to make it fit better with the situation.


2. Avoid:

The women who had experienced violence would avoid many situations.



3. Communicate:

The women who experienced violence communicated about it. But they did not always do it with words.

Sometimes their experiences became too much and they got very agitated or angry.



Support workers sometimes would then say that this was a 'problem in their behaviour'.

Other women were so bored they just slept all the time.

Communication only worked if someone who cared about a woman understood what she was trying to communicate.

Some of the ways to deal with the violence worked very well in the institution. This means they helped the women to not get hurt again.

1. Life After Violence

We showed to the women a set of cards. The cards helped to talk about inclusion. Inclusion means being part of your community.



We wanted to know what got in their way of inclusion. And if this had anything to do with the violence they experienced.

The women we spoke to already got out of residential institutions. They had taken their sadness, their world view and their ways to get hurt less with them. Some of these ways now got in their way of inclusion.

For example:

- The women did not trust people.
- They did not dare to meet new people,
- They did not feel important at all.
- They had a low self-esteem.
- They were afraid that they would be treated badly in new places,
- They were afraid of doing something wrong and having to go back to the institution,
- The did not know how to introduce themselves to someone else.

The women who had lived in bigger institutions had experienced more violence. And then it was more difficult to become a member of the community.

2. Support after violence in an institution

The women told us what they need. Each woman knew what she needed herself. If people listen to you, it is easier to get the right support. It is important to feel safe.

It is important to have someone who cares about you. It is important to talk about yourself,

to let someone know why you react a certain way.

3. How to support women so they can be included

Some of the women we spoke to now live very inclusive lives.

They received good support from people who care about them.

Others did not have this support.

We wanted to know what the good support did and why it was so important.

We found 4 main things that made the support so important:



1. Listening and understanding

2. Helping the women experience less violence



3. Making sure not to be hurt again



4. Finding connections in the community



Summary

A lot of violence in institutions is structural violence. Women were also hurt because they did not have people who cared about them.

Because of this the women we interviewed were having a hard time.

The way they look at the world changed.

They came up with ways to avoid pain.

They took these ways with them when they moved into the community.

These ways stopped them from being included in their community.

Women need support to overcome their experiences with violence. This means that they need someone who listens to them and understands them. Someone who they feel safe with.

Getting support can lead to many good things. It helps being stronger. It helps not getting harmed again. It helps to have a better life in the community.

What needs to be done now?

Education

It is important that women with intellectual disabilities:

- are not separated into special education schools,
- are given the chance to develop friendships from an early age,
- have the chance to have love relationships if they want to,
- are given good education about sexuality and relationships,
- are taught to talk about what they like or don't like,
- are supported to make their own rules,
- are taught to respect the rules of others. It is important that men also learn, that when a women says 'no', she means no.

Inclusion

It is important that we all work on:

- including all people with intellectual disabilities in society,
- making all people with intellectual disabilities part of our communities,
- making sure people with intellectual disabilities know a lot of people who care about them.
- giving people with intellectual disabilities the chance to choose
 - who to live with,
 - where to live,
 - who supports them and with what.

Preventing violence in institutions

Institutions will always have structural violence. People in institutions will always be at risk of having no one who really cares about them. But many people don't have anywhere else to go yet.

So people who work in institutions should be able to notice violence. And they should be able to fight against all types of violence. We think they should:

- talk about violence,
- take women's (and men's) experiences seriously,
- provide easy-to-read information about what to do when you experience violence,
- invite people from outside to come to the institution to see if there is violence going on,
- ask self-advocates and family members to give an opinion on how they work
- make sure the rules in the institution let the staff work with the people they care about most,
- work together with the people who live in the institution so they can live in the community.

Understanding

Persons supporting people with intellectual disabilities need to:

- understand why structural violence happens,
- understand the effect it can have on people,
- understand that sometimes people react differently than you expect them to, because of their past experiences.

We need to talk about violence. To do this, people need to feel safe. It helps to work with independent self-advocates. Listen to their experiences.

It helps to work with the cards about violence we used.

You can get them on the Inclusion Europe website.

Support

People need support.

Not only when they have experienced direct violence. Also to deal with structural violence. Also to find people who care about them.

European level

The European Union (in short, EU) is a group of 28 countries. We call these countries "member states". They have joined together to be stronger politically and economically.

The European Parliament is a place where important decisions of the European Union are made. For example: laws. We think that people in the European Parliament should:

Make sure to do studies about

women with intellectual disabilities in institutions. Introduce rules to make sure women with intellectual disabilities have more power over their own lives.

• Push to change support for people with intellectual disabilities.

Support should:

- concentrate on the person,
- enable people to live as part of the community,
- organise groups of support persons,
- allow people to choose where they want to live and who they want to live with,
- make sure people know everyone is important.
- Make sure everyone can choose to live outside of institutions.
- Make sure people get the support they need for having a good life in the community.
- Listen carefully and check what progress has been made.
- Make rules to push every country to make sure that institutions: fight against every kind of violence, listen to and look at what people who live in institutions experience.

"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.

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