

Talking about violence and abuse with women with intellectual disabilities

Research methodology from the Life after violence study



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[Life after violence](#). A study on how women with intellectual disabilities cope with violence they experienced in institutions

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Talking about violence and abuse with women with intellectual disabilities

Inclusion Europe

Selecting the interviewers: Who is asking the questions

Working with self-advocates

In the research in the Netherlands I had the lead. I worked together with self-advocates, so in this case women who themselves have an intellectual disability and who had experienced being in an institution.

I made clear to everyone I worked with that the self-advocates are the experts in this field, not me. They know first hand what it is like to experience these types of violence. They also know how difficult it is to talk about this topic. They helped me find ways to talk to the women. They defined violence, and they helped me make drawings (visual cards) about violence, which we could use to start the conversation. So, although I took the lead in the research, the self-advocates made most of the decisions in how we would work. They also played a large role in finding people for the research and interviewing people.

Before you start using the cards it is important to go through all of this information with the self-advocates who are working with you. It is also important to do the exercise with them. This allows you to find out whether you are the right person to do this research (do they trust you enough to talk) and to find out what topics might be particularly difficult for them.

Work with self-advocates:

- ✔ **Work alongside self-advocates as co-researchers/interviewers**
- ✔ **Recognize the expertise comes from the self-advocates**
- ✔ **Check the potential interviewers' suitability by doing the interview exercise with the self-advocates**

Finding the self-advocates

If you are doing this research, the first thing you want to do is find self-advocates who are willing to work with you. As I said, they are the experts. They are also the people with experiences of their own, making it easier to talk to them instead of yourself.

I have been working with a independent self-advocacy organisation for quite some time. There are people who are trained as trainers, some of whom were also good at leading these conversations. If you are not in that position, I still urge you to find a good self-advocate who can help you.

The self-advocates I worked with were:

- able to hear about all these experiences

- able to put the other person's experience before their own
- able to explain the drawings
- able to stay quiet and listen.

Find self-advocates willing to work with you in the research.

Ensure the self-advocates are :

- ✔ **able to hear about all these experiences**
- ✔ **able to put the other person's experience before their own**
- ✔ **able to explain the drawings**
- ✔ **able to stay quiet and listen.**
- ✔ **Tip: Look for self-advocates already working as trainers.**

The importance of the interviewer's ATTITUDE

Although the self-advocate can take a leading role in the conversation, you are always there too. For many people it is easier to talk to a self-advocate than to talk to a professional. It is hard for me to describe why people trusted me enough to talk about violence. I asked the self-advocates I worked with. This is what they said:

- You are always calm, that makes people you speak to calm
- You take people seriously
- You are honest and clear
- You are respectful
- "I know I can trust you" ("But why?" "I just sense that with people.")

The other factor which helped in the Netherlands is that I have been involved in the Dutch self-advocacy organisation for a number of years. This organisation, the LFB, has a reputation of taking people seriously, being respectful, honest and clear in its information. Being linked to this organisation helped people who did not know me at all to talk to me as well. Furthermore, I am not linked to any institutions and I do not introduce myself with any titles people are familiar with from the realm of 'care', such as psychologist. I also didn't use any other title that implies I am an expert in anything. Again, I made clear they were the experts and I wanted to learn from them.

On the importance of attitude:

- ✔ **Ensure you have the right attitude that can engage trust**
- ✔ **It helps if you have worked with self-advocates before**
- ✔ **What worked in this study: be calm – take people seriously – be honest – be respectful**
- ✔ **! Trust remains a subjective and personal assessment**

The importance of TAKING THE STORIES SERIOUSLY

The self-advocates and I made it a point to always take the people seriously, even though we did not have any way to check the stories. This does not mean that we used every story we heard in the final research. In fact, only stories that came back several times from several women made it to the final report of the research. However, it did mean that during the conversation we never gave any impression that we did not believe what someone was telling us. We just nodded in agreement and prompted people to carry on talking. At the same time, I do really believe that most of the experiences we heard about were real, so it was not hard to react in this way.

On the importance of taking stories seriously:

- ✔ **Always take people and their stories seriously – show you believe in their story**

The importance of NOT keeping a professional distance

Another important aspect, I think, is not keeping a professional distance. By this do not mean that I, or the self-advocates, became everyone's best friend. I told the women we spoke to they could ask me anything about me as well, and I would answer honestly. So did the self-advocates. Again, this separated me from care professionals in The Netherlands, who do keep a professional distance. Often the offer was enough. We got very few actual questions. But people liked the opportunity. I think this contributed to them trusting us.

On the importance of not having a professional distance:

- ✔ **Do not keep a professional distance: it helps build trust and differs from care professionals**
- ✔ **Tip! offer the interviewee to reciprocate questions**

The importance of leaving the women in charge of the conversation

Lastly, the women we talked to were in control of where and when the conversation was, with whom, and what they talked about. It was clear that they were in charge of what they would talk about and what they would not talk about. The cards helped them decide.

In short, I think it helped being seen as NOT being a care professional, and making sure people feel that they are believed and that they are in charge of the conversation.

On the importance of leaving the women in charge:

- ✔ **Leave women in charge of the conversation: They decide where, when and with whom it happens, and what they talk about**

Selecting the interviewees: Who do you ask?

The Interviewees' profile

The women we asked to participate were women with an intellectual disability who needed support in their lives and who had moved from a bigger care setting to a small care setting. Most of the women had been in big institutions and had moved through ever smaller care settings within the community, to end up living in their own apartment now.

In this research, we considered as institutions as 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' individualized needs.

Some of the women had not been in big institutional settings, but in small institutional settings more placed within the community, as this is becoming more normal in the Netherlands now. All of the places were run by care providers who own big institutional settings as well as smaller community settings. These places have in common that the 'clients' are not entirely in charge of their own life-choices.

We did not define intellectual disability further, or exclude women because they had multiple disabilities besides their intellectual disability. Also, people had different levels of intellectual disabilities. So, 'women' and 'intellectual disability' were really the only labels we looked at. Apart from that we spoke to women with all variety, differences and similarities which people generally have, which make life interesting.

In this research the women were:

- ✔ **all women with an intellectual disability, regardless of level or other disabilities**
- ✔ **who live(d) in care settings run by care providers where the 'clients' are not (entirely) in charge of their own-life choices**
- ✔ **who moved from bigger care settings to smaller care settings or on their own in the community**

Finding the interviewees

Once we had worked out the methodology, we had 2 ways of finding women we could interview:

- Through our own networks:
 - The self-advocates asked a few women they knew, some accepted.

- I asked my network of people working in the field of Inclusion in the Netherlands, again, some accepted.
- Through our presentations about violence, which we did for ‘clients’ of care providers, through the Self-Advocacy organisation. At these presentations we would ask at the end if any of the women wanted to talk to us some more.

Going through care providers to find the women has limitations. It can never be certain that the care provider will not fear that women speak up and inversely that the women will not speak up due to fears of repercussions. We had doubts in some cases with women we met and who reported they were happy about everything. Unfortunately, in such cases it will be difficult to find out more if the women do not wish to participate.

Find self advocates:

- ✔ **Through the researcher and self-advocates networks**
- ✔ **Through presentations about violence in care or other settings**

The importance of each interviewee’s consent

Not all the women we asked to participate said yes. Some of the women were scared their care-provider would not have a positive reaction to their participation. Mostly women said no because they had experienced so much, they were scared that talking about it would open up their wounds. People were well capable of telling us this themselves.

Respect each women choice to consent:

- ✔ **Always respect the choice of each woman whether to participate as interviewee in the research, regardless of the reasons**

Preliminary considerations for the interview

Introduction

We would not dive straight into the difficult questions. First, most (not all) of the women would have met us at a presentation, or through our networks. If they had not, we would first introduce ourselves.

Then we would talk about the research, what it was about, what it was for, what the purpose was, how talking about their experiences would make a difference.

We also made sure they understood that their experiences would not be recognizable by others. We would change names, dates and places. We would mix up their stories with other people's stories.

How to start the conversation:

- ✔ **Start easy - introduce the interviewers to the interviewee(s)**
- ✔ **Explain the research – aim and importance of hearing the interviewee's experience**
- ✔ **Ensure the anonymity of the testimony is understood**

Permission/Informed Consent

We talked for quite a while before a person would say yes to participating in the research. Not every person we spoke to wanted to participate, which is fine as well.

We talked about

- what we would do with the experiences we heard,

how we would write them down,

- that they would get to check what was written
- that they could decide at ANY time that their experiences were not to be used.

It had to be clear that they remained owners of their own experiences.

That in all that was written down, no individual would be recognisable.

And that no photographs or other recognisable things will be used from the conversation.

In appendix one is a consent form you can use.

When obtaining consent for the interview:

- ✔ **The interviewee remains in control of the information shared**
- ✔ **The interviewee is explained and understands what she consents to**

- ✔ **The interviewee gives formal written consent to the use of her testimony anonymously**

Ethical issues on collecting and using the information

Besides making very clear what the research was for and allowing women to give consent before talking about violence, it is important that they remain the owner of their experiences.

We would talk, I would take notes. I would write an elaborate version of events the same day, or at the latest the next day. I would take this back to the women and they would tell me if I got it right, if there was anything I needed to change, and whether I could use all of this material, anonymously.

The drawings I made were usually combinations of different stories. If one drawing related to the experience of a particular person they saw the drawing before anyone else did. So they remained the owner. They decided what was shared and what was not.

At the same time, we heard a lot of experiences during our workshops and in my daily work. Although some of those experiences strengthened our conclusions, none of them were written down or used in the research. Only the experiences of the women who had given specific consent were used.

Ensure ethical issues are respected:

- ✔ **The interviewee remains the owner of her experiences and stories**
- ✔ **The interviewee verifies and approves the reporting/drawing of her experience**
- ✔ **The interviewee decides what to share**
- ✔ **The interviewer heard more experiences, but where consent has not been given these are not used in the research**

I recorded everything by making written notes during our conversation. Taping the conversation would have had advantages and disadvantages. I felt it was strange to talk about their anonymity and then to record their voice or take pictures. This is why I did not. If that is your preferred way of working that is of course fine, but it must be very clear to the participating women that you are recording them.

To record the interview:

- ✔ **Make clear how you report on the information (in writing, voice recording, ...)**
- ✔ **Obtain consent for voice recording**
- ✔ **Tip! To be in line with anonymity, written record is preferred**

Questions before you start

If someone had given consent there were a number of questions I would ask before we started:

- Do you want to talk to us both (self-advocate and me) or just me?
- Do you prefer talking together with other women who have experienced violence, or just by yourself?
- Where would you feel most comfortable talking about your experiences?
- What is a good time/day for you?
- Would you like someone else to be there? If so, who do you trust to be there? Or do you need someone else to be there, if that makes communication easier? If so, who?

Before holding the interview:

- ✔ **The interviewee is asked and chooses, where, when, to whom and with whom to talk about her experiences**

Where do you ask the questions?

Some people choose to talk to us in a group. Usually these 'groups' consisted of 2 or at most 3 women, a self advocate and myself. Usually the women would at least know each other a little bit, and we would meet at the office of the organisation through which they knew each other.

Most of the 1:1 conversations took place in people's own home, apart from one, which was again at the office of an organisation the person was most involved with.

We would always go to the person. To the place where they felt most comfortable.

Where to ask the questions:

- ✔ **The interview can take place in group, 1:1, or with a person trusted by the interviewee**
- ✔ **The interviewee chooses a place he/she feels comfortable in for the interview**
- ✔ **The interviewers go to the interviewee for the interview and not the other way around**

Speaking with women not communicating in words

Two of the women we worked with could not communicate in words. Both choose their mother to be there with them to talk about violence. Of course there was no way of finding out what had happened exactly. But the pictures did give an idea. The mothers talked about what they had noticed, and their experiences, while their daughters communicated in their own way. Both could show whether they agreed with what was being said and whether they wanted to talk more about a specific topic. Off course these interviews took some time, but they were definitely worth that.

When speaking with women not communicating in words:

- ✔ **Ask the interviewee who she would like to be with for the interview**

- ✔ Often mothers support the interviewee
- ✔ Take the necessary extra time to conduct the interview

The importance of TIME

Time was an important factor in all interviews. We would always mention that we could stop whenever the individual wanted, and we could always continue or come back at a later date. By giving someone as much of your time as they need, you are telling them they as a person, and their experiences, really do matter to you.

Time is important to show the person and her experiences matter:

- ✔ Do not limit the time of the interview
 - ✔ each interviewee decides when to stop or if to continue at a later time
- Do not limit the time of the interview**

The importance of REALLY LISTENING

“Excuse me, I just want to check who sent me a message.”

Phone ringing.

[Looking at the clock, because you have another appointment.]

Having your own home life in the forefront of you mind while trying to listen.

These are all examples of barriers to really listening.

When you are having a conversation with someone, in this case about violence, try to switch everything else of. Try to really listen to what they are saying. Be there entirely!

Really listening is not always easy. If there is some reason why you feel it is difficult during a conversation, be honest about that. Say why you are finding it difficult at that time. You are human, that is fine. But make sure the reason is good. Do everything you can do to enable yourself to listen. Don't have your phone on. Don't plan something straight after your meeting.

Ensure you are fully really listening and present during the interview:

- ✔ Switch off you phone
- ✔ Be flexible with the length of the interview and reserve enough time for it
- ✔ Be honest if something prevents you from being fully focused on the conversation

Conducting the interview

How do you start?

The self-advocate usually started by laying all the pictures down on the table, one by one, asking the people present what they thought the picture was about. Everyone has their own interpretation of the pictures, and that is fine. If the interpretation was very different the self-advocate would also mention her opinion on the meaning of the picture. Sometimes we had a little conversation about one picture, but not too long. We tried not to steer people into any certain direction.

We would allow whatever happened to happen. Some people started talking about a picture while not all the pictures were on the table yet. That is fine. They are just meant to get people talking anyway. Usually we would find some time later to continue putting the pictures on the table.

Once all the pictures were on the table we simply asked if the individual(s) present had experiences any of this. Some people would point out a few, and then start talking. Some launched into telling us about their experiences straight away. Some would first tell us about something that was missing in the pictures. Whichever way it went, the conversation had started.

When starting the conversation:

- ✔ Lay first the pictures on the table one by one
- ✔ Ask what each picture represents to the person interviewed
- ✔ Shortly talk about one picture if it needs explaining – but not too much
- ✔ Try to stay neutral and not influence the person interviewed
- ✔ Each person responds differently – allow this to happen

The importance of SILENCE

Once we had put the pictures down and we had asked if the individual(s) present had experiences anything like this we would basically shut up. The people had already consented to having this conversation. All that was needed now was patience and silence. We gave people all the time they needed to just think. Once the conversation started, sometimes people just needed some quiet time to think about something. Don't panic when this happens. Staying quiet is great! Besides, it gives you time to think or make notes as well.

During the interview:

- ✔ Be comfortable with silence as it gives opportunities of persons to think

✔ **Be patient**

How do you ask GOOD questions?

If you ask questions it is best to ask open questions, but also questions that are not leading or emotional. Examples:

- What happened next?
- How did you cope?
- What did this mean for you?
- When did this happen?

Or if a 'closed' question slips out:

- Did you get help? - yes – Who?

When asking questions during the interview:

- ✔ **Ask open questions**
- ✔ **Do not ask leading questions – try to stay as neutral as possible**

A place for empathy

Not being emotional, does not mean not having any empathy. It is fine to say things like: "That must have been hard".

✔ **It is good to show empathy**

How do you prompt people to tell you more?

- Showing people you are listening.
- Acknowledging you heard them by making affirmative noises.
- Repeat or summarise what they told you to check if you got it right.

You can prompt people to say more by :

- ✔ **Showing people you are listening.**
- ✔ **Acknowledging you heard them by making affirmative noises.**
- ✔ **Repeat or summarise what they told you to check if you got it right.**

Managing group discussions

Working with a group, even a small group, can be challenging. During the research we had some women who overpowered the others in all they wanted to tell us. It was not uncommon to meet up again with the people who did not have enough opportunity to speak about their own experiences.

It helped, when someone had told one experience, to really listen, and once they were finished thank them for telling about that experience. Then we would turn back to the others and talk about other experiences.

When managing a group discussion:

- ✔ **Ensure each person has opportunities to speak**
- ✔ **Tip! When a women overpowers others: listen until the end the person, thank her for sharing her experience, and turn to others.**

What if people tell you something horrible?

Hearing someone talk about horrible things happening to them can be hard. How do you react? One thing people have told me is that it made it easier to talk about their experiences, because I stayed calm, no matter what they told me. So that is step one. Try to stay calm. Remember you are not the one hurting them by opening up the conversation. The hurt is already there, you are allowing someone to talk about it.

There are people who feel that opening up this conversation opens up wounds that were forgotten. It is VERY important that nobody is forced into telling you anything. That even when a person participates, you make clear that the person decides what they want to talk about and what they do not want to talk about.

We have never directly asked a person to tell us about their experiences with a specific form of violence. They looked at ALL the pictures and decided what they wanted to tell us.

You may hear things that make you angry, or sad. But do try to stay calm, focused, and just listen.

If you hear a horrible experience:

- ✔ **Stay calm.**
- ✔ **Remember: You are not the source of the trauma, you just allow the person to speak about it**
- ✔ **Make clear that the person controls what she wants to share or not**
- ✔ **Never directly ask the interviewee about a specific form of violence – just lay the cards and let her decide**

Following up on the interview

Evaluate

Once a conversation was at its end, and at the end of each session if the conversation was not finished, we always asked how they felt the conversation was going, whether they wanted to ask us any questions about the research or personal questions. We would ask if they wanted to meet up again, or whether they had told us all they wanted to tell us. Whether they were still okay with us writing down all their experiences.

Later I would also evaluate with the self advocate, usually on the way home. There were two things to consider. One, did the interview go okay? Two, is the self advocate was okay after hearing all the experiences.

The self advocate and I are able to give each other feedback. If she talked too much I could tell her. If I used difficult words, she would tell me. We would discuss these things after the interview when we were together. Never during the interview.

During the interview we heard about shocking experiences. It is important to make sure they are okay too.

Evaluate the interview in the end:

- ✔ **Discuss with the interviewee if they are good or want to meet again and say more.**
- ✔ **Verify with the interviewee that they are ok with reporting about their experiences**
- ✔ **Evaluate the interview with self-advocate, giving each other feedback and making sure we are both okay with what we heard.**

After care

The women who participated in the Netherlands were each very different. We learned that it is important that a person does not have to be alone once we finished. Some women preferred to be alone. Some women just went about their business as usual after we finished. But for some women the conversation did stay with them for a night. Then it can be nice not to be alone.

What we did always do is phone up the next day just to see how someone spend their time after we left and if all was okay.

Ensure after care following the interview:

- ✔ **Follow-up with a call to ensure the women interviewed are okay**

When and how to support women through the told experiences

There may be experiences you hear about, which you feel should be reported to the police. Or which you feel a person needs a help for from a professional. We did only with one women. From what she told us she also had bad experiences with professionals and she did not trust the police. She felt talking about it to either professionals or police was a one way ticket back to the institution. And with what she had told me, I think she might be right.

We made a protocol about dealing with these situations, which was basically:

- listen and stay calm
- tell a person you think there are people who could help
- ask if there is anyone close to them they trust to talk to
- support them to talk to this one person
- talk to both of them about all the options for getting help, using the information in Appendix 2.

We knew we could not be the ones to support a person through a trauma. We could however support them to get help. So that is what we also did with the women who certainly did not want police or psychologists involved.

However, had there been a chance of acute danger to the person at the moment of our conversation we would have talked to them about this but we would have explained the need for us to take action now.

Luckily, we did not encounter this situation.

When and how to support women through the told experiences:

- ✔ **listen and stay calm**
- ✔ **tell the person you think there are people who could help**
- ✔ **ask if there is anyone close that they trust to talk to**
- ✔ **support them to talk to this one person**
- ✔ **talk to both of them about all the options for getting help, using the information in Appendix 2 modified with information from your country/region.**
- ✔ **In extreme cases of danger to the person, explain the need to take action/report**

Taking care of yourselves as interviewers

Find a way to deal with the stories you heard. For me this was writing them down as soon as possible. This got them 'out of my system' as it were. Also, ckeck if the self-

advocate who is doing the research with you is also able to get the stories out of her system, or if they are bothering her. Talking and evaluating helped in our case.

Take care of yourselves as interviewers:

- ✔ **Find a way to deal with the stories heard**
- ✔ **Ensure the self-advocate co-interviewing also has a way to cope with the stories**

Reporting on the interview: the results





I took notes while the person was talking. I typed everything up as soon as possible after the conversation had finished. Usually the same day. This helped me to get as much right as I could. Every time though, I found out I had missed things, or not asked about something I now had a question about. Usually I phoned people the next day to see how they were and if they were okay with it I would ask a few more things. I sent the notes to them as soon as possible. Some people read through them themselves, others needed help. We usually ended up meeting again, just to make sure I got everything right, and I could use everything. Some people just made me change their fictional name into something nicer, but most of the time I got details wrong.


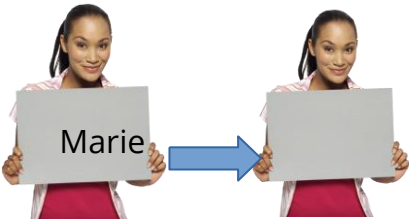



Only if we were both happy with the story I would use quotes from it in the long text. The drawings came a little bit later. Again, people saw what I used. There was always a chance to stop the text from going out.

Report on the interview:

- ✔ **Finalise the interview report as soon as possible to have the discussion clear**
- ✔ **Ask clarifications when calling them the next day for checking-in**
- ✔ **Ask the person interviewed to read and correct your report**

Appendix 1 : Consent Form

<h3><u>Consent form</u></h3>			
	<p>My name is:</p> <p>.....</p>		
	<h3>Tick your choice</h3>		
	<p>I have received enough information about the project</p>	<div style="border: 1px solid green; padding: 5px; display: inline-block; margin-bottom: 5px;">?</div> Yes	<div style="border: 1px solid red; padding: 5px; display: inline-block; margin-bottom: 5px;">?</div> No

	<p>I understand what I say is written down.</p>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<p>Anne</p> 	<p>I understand my name is not used.</p> <p>This is anonymous.</p>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<p>I understand I can read what is written before it is used.</p>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<p>My experience can be used in a report.</p>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<p>I participate in this research!</p>	<input type="checkbox"/> Yes	<input type="checkbox"/> No



Date

.....



Signature

.....

Please give this form to:

Add address to send the form to by post:

Appendix 2: Have you experienced violence?

Remark: Organisations available for support /reporting need to be adapted to each country/region. The ones presented in this document are relevant for people in the Netherlands only.

Dare to talk about it!

A lot of people are scared to talk about violence.

They do not dare to ask for help.

Even when something bad has happened.

Sometimes a person is ashamed.

Sometimes a person thinks it is their own fault.

Sometimes a person thinks no one will understand.

It does no good not to talk about it.

Don't be ashamed.

It is not your fault.

There are people who understand.

For example because they have similar experiences.

Trust

Find someone you trust.

This can be family, a friend, or a support worker.

You can tell that person what happened.

Just say you want to talk about something.

You can say this is hard to talk about,

if you want to.

Sometimes it helps to talk about your experiences more than once.

You can always tell people you want to talk.

General Practitioner (GP)

Family Doctor

Your GP can be a good person to talk to.

He or she can find help with you.

You can choose what you want.

Police

Phone the police when you want to report a crime.

This can be rape, assault, robbery, or physical violence.

The police will explain how you can report the crime.

They will also explain what this means for you.

If you are in danger now: phone 112

Getting help from organisations

You can also find help with organisations.

This means talking to people you don't know yet.

Some people prefer this.

There are many organisations.

These are just the main ones:

Victim Support

Victim support helps people after:

- a crime, like theft, sexual abuse, and physical violence
- a traffic accident
- unexpected, horrible experiences

- missing persons.

You can tell them what happened.

They can help you to cope.

They can help you find peer support.

The number of victim support is 0900-0101

The website is: www.slachtofferhulp.nl

Safe Home

Safe Home wants everyone to feel safe at home.

They are there for everyone who does not live with a care provider.

You can contact them when you do not feel safe at home.

You can also phone about others, when you think they are not safe at home.

Even if you are not sure.

Share your worries with Safe Home on: 0800-2000

The website is: www.vooreenveiligthuis.nl

And also:

Every Council has neighbourhood teams.

Every Council has their own name for these teams.

Often they have a consultancy you can visit for free.

They will help you contact:

- Victim Support or Safe Home
- the Police
- Find support with local organisations

PLEASE NOTE THESE CONTACTS ARE RELEVANT FOR PEOPLE IN THE NETHERLANDS