

This is how you collaborate in research!

Our experiences as co-researchers with an intellectual disability

Easy read dissertation



Anneke van der Cruisen

Henk Jansen

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intellectual disability*

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By Anneke van der Crujsen and Henk Jansen

Welcome!

Hello everybody,

We are Anneke and Henk.

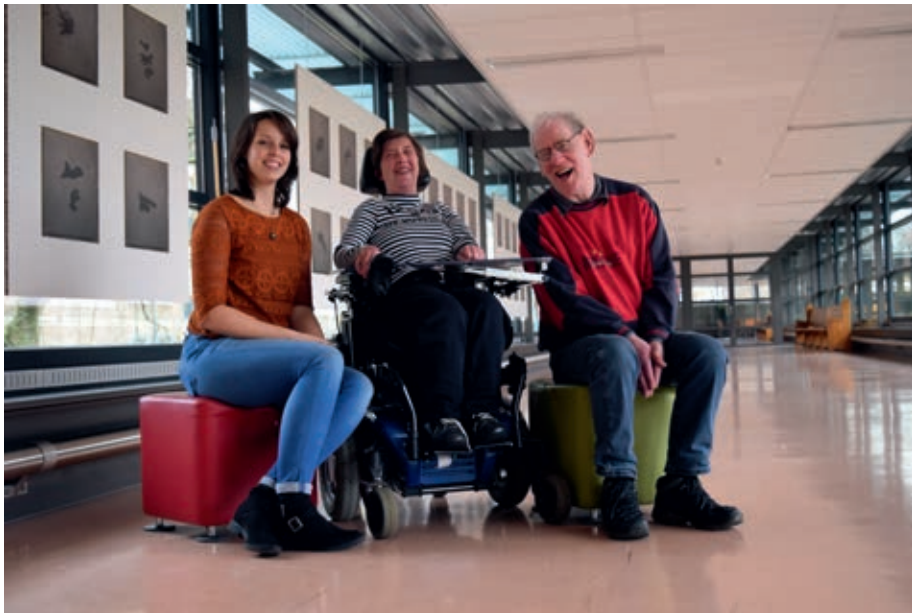
From 2014 until 2018 we did research together with Tessa.

For you this might not be very special.

But if we tell you that we are a group of researchers with and without an intellectual disability?

Than it is very special!

When we started in 2014, this was unknown territory.



Tessa, Anneke and Henk

Tessa started on the 1st of August 2013 as researcher in training.

Anneke started on the 1st of April 2014 as co-researcher.

Henk started on the 1st of May 2015 as co-researcher.

Together we have done lots of things:

- Writing a research plan
- Making interview questions
- Doing interviews
- Studying interviews
- Writing reports

Most of the time it was very fun to work together.

But sometimes it was difficult too.

We had to be very patient.

Luckily we pushed through.

Now we have an appointment at the university.

We also have our own workplace adapted to our needs.

In this book we will show you what we have learned.

Tessa wrote about this in her dissertation.

We felt there had to be an easy read version of her dissertation.

That is why we wrote this book.

We also tell you what it was like for us to do research.

We hope you enjoy reading our book!

Anneke & Henk

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We are researchers

We tell you what it was like for us to be co-researchers.

Anneke van der Cruijssen



What was it like to be a co-researcher?

In the beginning I found it a difficult choice to apply for the job.

But I did want to take on a new challenge.

It suited my other work as an expert-by-experience.

In the beginning it took a lot of searching together, because we had never worked together.

We were used to it quickly.

Now it is really good!

What do I like about doing research?

I like thinking along with other researchers.

I like that I was asked for the research.

The research yields more because my experiences are to be included.

I like it that I can also provide education and presentations since I work as a researcher.



What do I dislike about research?

What I find difficult is to know what the research is really about.
At the beginning I did not know what to think about Tessa's project.

We have talked a lot about it together.

We have thought about it a lot.

That helped!

What are my wishes for the future?

My wish is to continue to do research.

I would like to do a little more research.

Henk Jansen



What is it like to be a co-researcher?

In the beginning I found it quite exciting to work as a co-researcher. I did not know what to expect. I like to take on new challenges. Research was a great new experience for me. I am happy with my colleagues. We connect and they are very involved.

What do I like about doing research?

I like to research new subjects.
I like to give presentations, although I did not like that at first.

What do I dislike about research?

Actually nothing, but if I should choose something:
It is difficult to explain to others what I do.

What are my wishes for the future?

I would like to continue doing research.
For now, I still work for Kristel's project.
Soon I will retire at my other job.
I hope to continue to do research during my retirement.



What is inclusive health research?

This book is about our experiences as co-researchers.
We were co-researchers in inclusive health research.
We explain here what inclusive health research is.



Inclusive research = when people with intellectual disabilities and university researchers work together.

Inclusive health research = inclusive research about the health of people with intellectual disabilities. For example about people's mental, physical and emotional health.

Inclusive health research says people with intellectual disabilities are involved in every step of the research.

For example, we wrote a research plan together with Tessa:



On the way to research

During our collaboration we made a timeline.

We called this timeline "On the way to the research"

In this timeline we have put all the important moments.

Every important moment was a flower.

The timeline looked like this:



This way, we could celebrate together when something went well.

For example, when we won a prize:



This way we could also see what we had already done.
For example, make a research plan, hold an advisory board meeting and do interviews:



We are very proud of "our way".
We advise everyone who does research to make a timeline.
It does not matter how.

Be creative!

Inclusive mindset

We have learned in our research that your way of thinking is very important when you do research together. If you think in the right way, you can work well together. We call this the "inclusive mindset".



Ten things are important in your way of thinking:

1. Respecting human rights
2. Working as a team
3. Hearing everybody's voice
4. Respecting differences
5. Building a relationship
6. Having accessible information
7. Contributing in your own way
8. Knowing it can be difficult
9. Feeling safe and supported
10. Making decisions together

It is important that you talk about these 10 things in your research team.

This is also stated in the statement on inclusive health research.



Roles in inclusive health research

We have studied our own collaboration.

We wanted to know which roles are played in including health research.

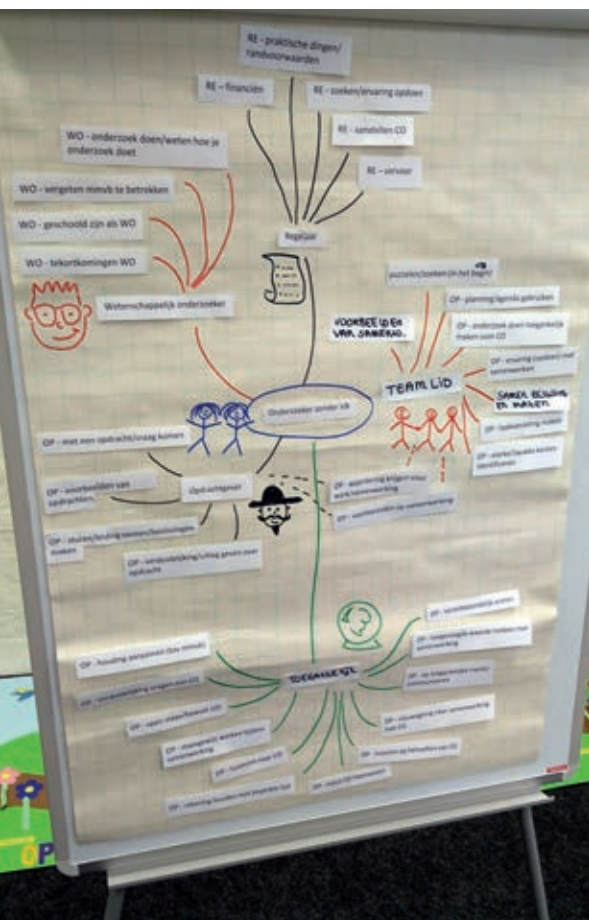
We wanted to know who has which role.

We have done interviews with colleagues.

And someone interviewed us.

We discussed this extensively.

We have made a “mind-map” about this:

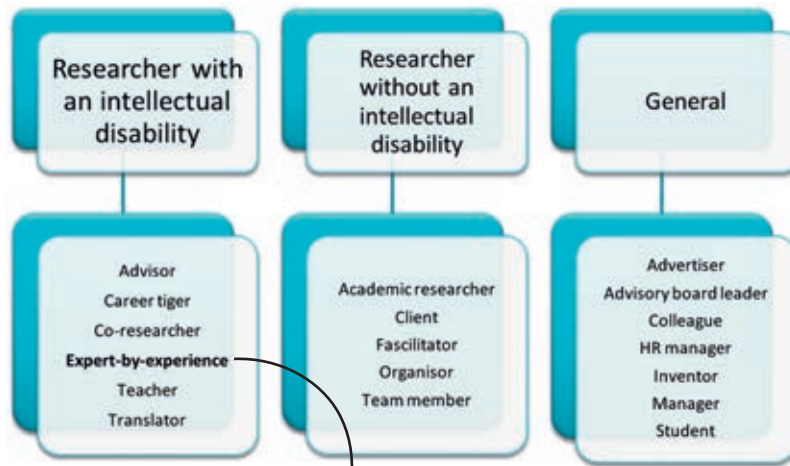


We have divided the roles of inclusive health research into 3 groups:

1. Researcher with an intellectual disability
2. Researcher without an intellectual disability
3. General

Each group exists of several roles.
Each role exists of several activities.

We now show you the roles in each group:



For example, in the "expert-by-experience" role, the activities are:

- Telling what you experience
- Knowing what people with intellectual disabilities need
- Putting people with an intellectual disability at the center
- Placing yourself in people with intellectual disabilities' shoes
- Following training as an experience expert
- Knowing that you cannot talk to everyone

This way, we have found a list of activities for each role. This helps to get insight into inclusive health research. And it helps if you discuss these roles and activities before working together.



The statement

We have written a statement about inclusive health research.

This advice is officially called a Consensus Statement.

A lot of inclusive health research is done.

But there are no agreements on how this can best be done.

This statement is written with experts on inclusive health research.

The statement is the most important report we have made during our collaboration.

We would like to share this with you!

We hope that it helps other researchers with inclusive health research.

Here is the statement:

Researchers with and without intellectual disabilities who work together



Heather Allan, Fionn Angus, Joan Body, Margaret Collins, Anneke van der Cruisen, Gary Cunningham, Derek, Marie Dillon, Martin Dooher, Nathan Gray, Craig Hart, Kevin Head, Tyler Henderson, Brian Hogan, Karrissa Horan-LaRoche, Henk Jansen, Rex Marchi, Donna McCormick, Kevin McGrath, Lisa McHugh, Kathleen McMeal, Claire Mitchell, Murphy, Laura Murray, D. Noone, Donovan O'Neil Allen, Helen O'Regan, Wolfgang Orehounig, Carol-Ann O'Toole, Sean Rowley, Jaspreet Kaur Sekhon, Kyla Stewart, Michael Sullivan, Lisa Woelfl, and Members of the CDS Inclusive Research Network.

Content

Chapter 1: What is this document about?

Chapter 2: What is important for doing inclusive health research?

Chapter 3: What comes out of inclusive health?

Chapter 4: What should be shared when you are doing inclusive health research?

Chapter 5: What do we need to know about inclusive health research?

Chapter 1:

What is this document about?

This document is about inclusive health research.

What is inclusive health research?



Inclusive research = when people with intellectual disabilities and university researchers work together.

Inclusive health research = inclusive research about the health of people with intellectual disabilities. For example about people's mental, physical and emotional health. Inclusive health research says people with intellectual disabilities are involved in every step of the research.

Why do we need this document?



A lot of inclusive health research is done.

People want to learn about the best way to do inclusive health research. But there is not a lot of information about how inclusive health research should be done.



What is this document about?



We think that these 4 questions are important:

1. What is important when you are doing inclusive health research?
2. What comes out of inclusive health research?
3. What should be shared when you are doing inclusive health research?
4. What do we need to know about inclusive health research?

How did we write this document?



This document was written with experts on inclusive health research. These experts are researchers with and without intellectual disabilities who have done inclusive research. Experts without intellectual disabilities wrote this easy read document. Experts with intellectual disabilities said what was good and bad about it. Forty experts with intellectual disabilities from all over the world helped us.

Chapter 2:

What is important for doing inclusive health research?

8 important topics



Experts say that researchers need to think about 8 important topics when they are doing inclusive health research:

1. The **mindset** of the research team
2. How to **recruit researchers**
3. How to make the **research plan**
4. How to making the research **accessible**
5. How to deal with **practical things**
6. How to **collect data** for the research
7. How to **analyse data**
8. How to **share results**



We will talk about each of the 8 topics in more detail:

Mindset



These things are important in the mindset:

- Respecting human rights
- Working as a team
- Hearing everybody's voice
- Respecting differences
- Building a relationship
- Having accessible information
- Contributing in your own way
- Knowing it can be difficult
- Feeling safe and supported
- Making decisions together

Recruiting researchers



These things are important when researchers are being recruited:

- Asking people in different places
- Supporting service providers
- Knowing what skills team members need
- Providing training
- Finding out how researchers will be paid for their work
- Making goals clear
- Allowing people to stop at any time

Research plan



These things are important when you are making the research plan:

- Talking about each team member's role
- Having an accessible meeting place
- Knowing each team member's skills
- Providing training
- Deciding together on the research topic, research questions and methods
- Being creative

Accessibility



These things are important for making the research accessible:

- Talking about everybody's needs
- Finding an accessible place to meet
- Developing easy read information
- Adapting communication
- Talking about structure and flexibility
- Planning team meetings
- Talking about how problems will be handled
- Using tools



Practical things



These practical things are important:

- Transport
- Extra time
- Breaks
- Easy-read information
- Other formats, for example audio
- Support

Collecting data



These things are important for collecting data:

- Talking about what is needed to collect data
- Training on collecting data
- Being creative

Analysing data



These things are important for analysing data:

- Talking about how information will be analysed and who will analyse it
- Training on data analysis
- Comparing and discussing the analysis

Sharing results



These things are important when you are sharing results:

- Talking about how results can be shared
- Deciding together how results will be shared
- Organising meetings for the public
- Talking about who will write the report
- Making sure everybody is happy with the sharing of results



Chapter 3:

What comes out of inclusive health research?

This is what experts say comes out of inclusive health research:

Personal outcomes



- Enjoying the research
- Getting new experiences
- Learning how to do research better
- Learning to talk up
- Learning about your rights
- Meeting new people
- Being listened to
- Getting insight into the experiences of other people

Professional



- Contract and (sometimes) salary
- Feeling responsible
- Getting recognition
- Learning how the university works
- Having a more equal working relationship
- Hearing and including the voices of people with intellectual disabilities
- Meeting other researchers
- Learning new and creative ways of communicating
- Getting new information
- Seeing the bigger picture

Research



- Better ways of collecting data
- Researching what people with intellectual disabilities find important
- Research outcomes suit people's lives better
- Learning what it means to do inclusive health research
- Research that takes people with intellectual disabilities into account

Healthcare



- Learning the most important healthcare issues for people with intellectual disabilities
- Reducing healthcare issues for people with intellectual disabilities
- Better fitting healthcare to the needs of people with intellectual disabilities
- Improving the quality and accessibility of healthcare for people with intellectual disabilities
- Improving the quality of life of people with intellectual disabilities



Community



- Reducing health differences between people with and without intellectual disabilities
- Raising awareness of problems faced by people with intellectual disabilities
- Raising awareness of the rights of people with intellectual disabilities
- Knowing how to support people with intellectual disabilities in their rights
- Suiting research findings to community needs
- Starting a change in the community

Chapter 4:

What should be shared when you are doing inclusive health research?



Researchers usually write a report. Experts have identified a top 10 list of things that need to be written in this report.

This top 10 should help share experiences of inclusive health research. Experts say that research teams should share these 10 things:

1. Who chose to do inclusive health research, and why.
2. How decisions were made during the inclusive health research.
3. How all team members experienced the inclusive health research.
4. How information was shared with people with intellectual disabilities.
5. How team members with and without intellectual disabilities communicated.
6. How team members were supported.
7. The role of all the team members.
8. How researchers with intellectual disabilities were paid. And, if not, why not.
9. How the research was made accessible.
10. Easy-read abstract and report, shared with people with intellectual disabilities and service providers.



Chapter 5:

What do we need to know about inclusive health research?



Experts in this document talked about what we don't know about inclusive health research.

They made a list of things that we need to know about inclusive health research.

This is the list they made:

- Experiences from researchers with intellectual disabilities: we need personal stories!
- Sharing experiences and knowledge on inclusive health research
- Relationships between researchers with and without intellectual disabilities
- Ethical issues in inclusive health research
- Similarities between inclusive health research and advocacy
- Different ways of doing inclusive health research
- Sharing inclusive health research results with people with intellectual disabilities
- Training for researchers with and without intellectual disabilities
- Research ideas coming from people with intellectual disabilities.

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