

The art of belonging: about Dutch initiatives, limits and possibilities of belonging for people with a disability

1. **Good morning.** I am Coleta Platenkamp. I am the founder of a foundation CCC, Coleta's Chronic Circus, which want to let hear the voice of patients/disabled people to improve their way of life and health care. We have a website where one can find 2700 titles of books written by patients and disabled people and their family, with introducing stories, some quotes, themes. On the site we have links to blogs, short stories and documentaries, filmed ego documents.

We've only fifteen minutes and I want to show you a youtube movie of 4 minutes and give some examples told in stories of disabled people.

2. **I want to start** now by showing a short video, a song/ storie with a message that is very clear and important for all of us when we are talking about the art of belonging for people with and without a disability. After this song I want to illustrate two messages you can read and hear in the stories of disabled.

The introducing text of the movie says that the words of the song you are going to hear comes from a person who lived and died in a nursing home. The nurses found the text after the man died. After that **It starts with then with the words: Recognise... Acknowledge, Accept... Know..... Me, See Me**

I don't think I need not say more about the message. I am touched over and over again by the song.

3. **See Me**

4. **There are two messages** I want to illustrate here with just a few examples by talking about video's (on youtube) and ego documents.

The first is: There is not one way of showing the art of belonging, but many ways, there is diversity. You can read about it in many ego documents where disabled write about their lives. The ways of belonging differ not only because there are different diseases and handicaps, they vary in many contexts, with kind of people, networks, families, support etc.

5. **Examples: Different ways** of belonging while participating in the society are:

The way of belonging of Anne Mreijen.

A. Anne Mreijen makes the glossy lifestyle magazine 'Unlimmited' for disabled young people, with disabled young people in the city of Haarlem. She does it while laying on a couch in her house. After she was born she got a brain haemorrhage which makes that she must lay down a lot. Her mother and the Bart de Graaf foundation helped her starting the business. See:<http://www.youtube.com/watch?v=Bcx7X3Kal3g>

B. Of Joost Nauta is diagnosed with a severe, progressive muscular disease, called

SMA. He is the founder and president of the Border cross Foundation and the manager of a certified care enterprise called 'Joost Cares' (Joost Zorgt Nederland BV). He made a personal care model for people who need long term care which is spread by a franchise formula under care professionals in Curacao and Holland. Jan knows about personal care, because he needs help himself. Nowadays he offers inspiring workshops, training and lectures to various companies, schools and agencies.

http://www.youtube.com/watch?v=rXqIu_m6itw,

http://www.youtube.com/watch?v=Ac_Go8Lz6A8

<http://www.crohnjuwelen.nl/filmpjes.html>

C. Crohnjuwelry: A woman who works during the week must stay in bed during the weekend because of her fatigue. Otherwise she can't work. So her life is organized around her working life.

D. The Freud restaurant. A restaurant where people with a mental dysfunction work.

E. Different daytime activities: amongst other painting, ceramics pottery, park keeping, working on a farm.

6. These are just a few examples, but there are many stories and ego documents who show trying and arts of belonging in many ways and on different parts of life. For example : **Jacqueline Kool: Wrinkled Eros, Eros in the creases**, 'Eros in de kreukels.'(2010) **and Karin Spaink: : 'No lack of passion' 'Aan hartstocht geen gebrek' (1991)** about sexuality and being disabled, possibilities, examples and difficulties, art of belonging.

7. And on stage: Cabaret by Pelle Sandstrak a man with the syndrome Gilles de la Tourette, Sandstrak goes around the world with his show. <https://www.facebook.com/events/515972465125349/>. And in Holland we have amongst others Vincent Bijlo who is blind and Herman Finkers who has chronic lymphatic leukemie. <http://www.youtube.com/watch?v=3Ijz9W3xwD4>

8. The second message is: Each form of belonging asks different competences, necessary to make it possible that belonging will succeed. It is necessary to know limitations and own limits, you need to organize well, show what is possible etc.

9. Examples: We have limitations and once again I want to illustrate them with examples **Black Dog:**

First there is a stripmaker Mathew Johnstone who made a strip and a video on (youtube) about his depression called Black Dog. He tells his story and shows that the black dog can take possession of someone. He says: 'At its worst, depression can be a frightening, debilitating condition. Millions of people around the world live with depression. Many of these individuals and their families are afraid to talk about their

struggles, and don't know where to turn for help. However, depression is largely preventable and treatable. Recognizing depression and seeking help is the first and most critical towards recovery.'

So he knows his disability and can handle it know.

<http://www.youtube.com/watch?v=XiCrniLQGYc>

The advise on Twitter for persons with the syndrome of Gilles de la Tourette is another one: Don't fight your Tourette, embrace it!

10. And there are other aspects: The outside and the inside can differ and so are the(dis)abilities to belong. This is me: and I know that on the outside, 'what I used to be I am not, any more'. Because I worked as a sociologist on a High school before I got disabled for that. Now I am an Iron lady with a foundation since 2004 and a website www.patientveraringsverhalen.nl with patient experiences (2700 books, blogs, movies)

I haven't said a lot about other initiatives and way of belonging or about coping new problems like aging with a (congenital) disability or coping problems while living with a rare disease etcetera. So...

11. There is a world to explore for everyone, young and old, to learn about the unknown, not seen. I have given some examples, but you can find them on the internet, in ego documents , blogs, documentaries, films, youtube etc. It can help seeing other perspectives, diversity :

In stories for the Dutch people: www.patientveraringsverhalen.nl

For the not Dutch people: <http://www.healthtalkonline.org/> and

<http://www.patientslikeme.com/>Last examples: With music: Boys on wheels, Punk on wheels, The Zimmers (Talking about my generation)

http://www.youtube.com/watch?v=7gjWQmxu_tM&feature=results_video&playnext

<http://www.youtube.com/watch?v=DboztBIh8cU>

<http://www.youtube.com/watch?v=zqfFrCUrEbY>

12. The question is: Is there a solution for all limitations, can we cope them? And what do we need, what comes from our surrounding, society, our selves?

13. And what helps best is the question, we have work in progress:

- Abilities, Flexibility, Creativity, Humor, coping strategies etc...

- Knowledge of living with, Good life, Limits,

- Technology, Stories, Experiences, Disability studies –Examples (Best and worst),etc...

-Conditions in Society, Environment, Family, etc...

Necessary is:

-The old message: for, with, not without in different ways.

-And last but not least: See each other