

Presentation Disability Studies in the Netherlands Conference, Friday 1st November 2013

Toon Maillard - A self-advocate's right to belong as a form of resistance in higher education and disability studies (0-59)

Slide 1

Hi, I am **Toon**. I'm from Ghent in Belgium and not so long ago I was a student at the university there.

I studied at the **department of Special Education and Disability Studies**. And thanks to my education I met **some extraordinary people**, from all over the world.

Thanks to my education I also got into contact with Disability Studies, otherwise I probably wouldn't have been here for you today.

And also thanks to my education I had the privilege to do a research project for my dissertation, because, if I didn't. My entire training wouldn't count. So there's that...

Today I would like to guide you through some of the **concepts** my comrades and I used and developed during this research process. And we are still working with today. So we're **always happy to get new (or old) insights from others**.

As TinTin would say:

It all started with... this particular situation I found myself in a couple of years ago.

All my fellow students were busy doing what good, albeit somewhat stereotypical, academics do, and that's finding out what problem they can research, hypothesize about and then offer a plausible solution to their question.

The main problem I tried to solve was that I didn't have a problem...

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Luckily, like I said, I got to know a few extraordinary people along the way of my education.

Some of them form a group called **Our New Future**, which is a movement of, by and for people with the label of an intellectual disability.

As it turned out, the research department at our faculty had structural ties with the group that went all the way back to its foundation in 1997.

I found it **intriguing that a research department collaborated with people who, according to standardised testing, all had IQ's way below academic standards**. And somehow it wasn't just the researchers' playground...

These people turned out to be very self-conscious, and had a thing for stirring up debate about **their rights as humans**. They even made an accessible version of the universal declaration of human rights, and their accessible version of the UN convention on the rights of people with disabilities is even up on the UN website.

So I set out to meet them, and ask them if they had any use for me as a researcher. I saw myself building **bridges between practice and theory**, and was glad that after 4 years, I'd be able to escape Higher Education for a bit...

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So I went over to their monthly meeting and told them about my problem of not having a problem...

And that I would like to contribute to theory and to practice with the future research.

Basically my question was: **"do you guys have any use for me?"**

And so they gave me a question: **"Are people with the label of an intellectual disability able to study in higher education in Flanders?"**

Even more than that, they gave me **a methodology**. It was made clear that I wasn't expected to just go out and do some researching and report back to them (in an accessible way), no, we'd take on this project together from start to ending...

Soon enough it turned out that it wasn't just a personal question from Ludo, the president of our new future. But also Marc and Didier joined the team.

Each of them with their own take on how to participate in Higher Education, based on their experiences with the research department.

So by the end of the meeting I had a question, a methodology and a team.

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So we started a **cooperative research process**. We did **several interviews** with students, educators, researchers, policy makers and self-advocates.

We represent our process with this cycle. In which **thinking and doing alternate**, as well as **working individually and working in group**.

It's a **continuous process in which reflection on the cooperation is at the heart**. That's why it says at the bottom that the more you get to know, the more new insights it brings, so the deeper you know, the deeper you learn. Also the **reflective process** helped to **keep our focus and guard the ownership** of the material. As well as ethical issues which are bound to come up when cooperating.

We met up multiple times and exchanged what we thought of, or had done, or read since the last meeting. We worked through the interviews and literature and afterwards we each went home with

new inspiration and new questions so we could bring something new to the table the next time we met up.

Or **someone brought new insights and ideas, or new questions**, like one a crazy professor asked us: “waddaya think. This intellectual disability... Does it really exist?” We’re still working on that last one...

I also got to know the **Partnership Steering Group at Manchester University**. A group of self-advocates, educators and researchers, who organise the BA and MSC program on Learning Disability Studies in a cooperative way. We found that they had worked on a similar question: ‘is there room at the academy for people with intellectual disabilities?’, and they did it in a similar way. They’d even written a brilliant article about it. So we were happy to learn there were different people on the same track in different parts of the world.

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During this **process** we redefined our question into: **“In what ways are people with the label of an intellectual disability able to participate in higher education?”**

Ludo for one saw the **university as a place of learning**. Concepts as disability, accessibility and interaction can be learned and studied there.

At a university information event, one of the employees told him that he wouldn’t learn a job if he just took a course on communication.

Ludo told him that he **didn’t want a job**. He **already** had **one**, he **just wanted to learn**.

The employee, who was **really quite concerned**, told him his label would work against him. **“You know, it’s already in your label what you can’t do.”** to which Ludo replied: **“It’s not because I have a label that I can’t learn. I’m an intellectual person, with a disability.”**

Marc on the other hand was focused on **research**. He had done a couple of research project together with students, where they had asked him to participate in their research. He told us at one point that he cunningly **always took more from it than he gave**.

He felt the way academic research was done just wasn’t right... There was **a lot of research about people, but not accessible to the people**. Also a lot of the research was on **topics nobody but academics cared about**. He dreamed of a position as a researcher so people with an intellectual disability could be in charge of the research topics and process.

Our third partner in crime, Didier, had **years of experience giving lectures and co-teaching students**. His talents lie in speaking and storytelling. The **idea of teaching brought the self-advocate to the fore**. If the people who were to become caregivers, medics, teachers ... **Should know anything about disabled people, it should come from the people themselves**.

So we **mapped it all out** and came up with this: [slide 6]

Slide 6

Don't worry if you're feeling a bit dizzy or stressed out when seeing this. It crashed the computers at the copy centre.

We've been working on this for nearly two years and still there is something that didn't feel quite right... And it wasn't just our lack of focus...

When presenting, or rather **defending**, our work, a professor reassured us that **the door to his lectures was always open.**

For anyone, because even his **grandmother** would love to see him in action, so she could come, and we could come and we all could attend the lecture.

He even had **special Youtube clips to keep us entertained**, while he was doing the serious work with the real students...

So we had already adapted our initial question from: are people able to study in higher education, to in what ways are people able to participate, but **still participation didn't really quite cut it...**

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Something we always came back to was a **connectedness with others and also with the structures and environment** of higher education. Students, researchers and teachers are **all connected**, or at least **should connect**. They had quite an innovative view on as to how higher education could function if educators and learners connected more, so there's an exchange of knowledge. Not just an unidirectional transfer.

Belonging was also conceptualised as **to be part of the community of academia**. In one of the interviews the diversity coordinator was doing her best to find ways to participate in higher education if you went through special education and you didn't have a diploma. She was guiding us through **procedures** and pointing out all the **loop holes and back doors**. Ludo stopped her at one point and said: "enough with the back doors. **I want to come in through the front door**. Like anyone else."

It's something Ann **Turnbull** touched on last night, that it's **not just about being there**. It's about **knowing the secret handshake**. '**Belonging**' expresses the need to **connect as a person with others**.

Feeling and being welcomed, being part of it, belonging is what our conceptualisation of participation had lacked up to that point.

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So we set out to conceptualise belonging and found it in something called the **Circle of Courage**.

This is a **strengths based model** developed in the US during the early 90's by **Larry Brendtro, Martin Brokenleg** en **Steve Van Bockern**.

It offers a framework of **four basic values** that any person needs to **develop** him or herself. These values are **connected** and **interact**.

Other than Belonging; Mastery, Independence and Generosity complete the Circle.

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'**Mastery**' is explained as the way in which people learn. It focusses on the **connection with others by investing in their talents** and the **development** of their **competences** and **abilities** which support the putting into practice of their talents. In this way inspiration, motivation and self-esteem grow.

As said, **each member** of our research team had his **own focus on belonging** in higher education.

Ludo, Marc, Didier and I started from the question: 'Who am I?' and searched for **talents, interests, dreams, strengths, weaknesses and motivation** to belong in higher education. The answers to these questions **fed the basis for the search of desires** with the question: "What do I want?". **Lifelong learning, having your voice heard, gaining experience** and **equal opportunities** were things that were wanted. The eruption symbolises het **strength** of people and the necessity to dare to **dream**, dare to **think** and **dare** to do. And of course the **courage** and **perseverance** required.

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You might now wonder why there are so many people on a slide that says '**Independence**'?

In the COC 'independence' represents **taking action starting from your own strenght, connecting with others**.

It doesn't represent taking individual actions disconnected from all others.

People need **encouragement** and **a supporting environment** to make their own choices, to make decisions, to solve problems and to show responsibility. **It's important that those who have the means and responsibility create the possibility to make choices**.

We find there's a contrast with our exclusionary, elitist, modernist, neoliberal, bureaucratic and hierarchical educational systems where usually possibilities aren't maximized, but minimized on the basis of prejudices.

Or where people with special needs are welcomed as test objects for researchers who want to validate their next standardised test.

That's why our preference goes to the right of the spectrum of the slide. **Too often the researcher is on the left side and the flow of information only goes in one direction**, for the sake of reliability.

The other side is a side of **equals**, of co-creation of knowledge. Where you can ask questions to one another, but also can question one another. This is real cooperation, and this a situation in which you can independently take actions which connect you with others.

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Last in the circle is '**Generosity**', the giving, the need one has to make a contribution. We've found the giving and reciprocal in our student, our researcher and our teacher.

Ludo's ambition to share everything he learned with others might be the best example. By sharing your talents and by aiding others in discovering theirs, **without expecting anything in return**, you get a feeling of pride and joy.

Ludo asked me once why I worked with him, and he with me? I started with my story about how I didn't have a problem but he hushed me. He told me: "I work with you, because I can learn from you. And you learn from me. Different things, but by working together we learn from each other, right? And everything we've learned, we can share with others: with the people from Our New Future, with your fellow students, with others in higher education. So they can learn from us, and we can learn from them."

This is what we wanted to share with you. We don't expect anything in return, but we're open to anything that comes.

Before I finish, just one more thing...

Just one more thing...

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I told you how I basically just asked a group I didn't know, whether I was of use to them.

I didn't know where it would lead, I didn't know where it would go, but **I took the leap** and as a student I've found a mentor.

Maybe the most important thing is that I've found a sense of belonging in our team as well.

We had **planned a different presentation**. Ludo and I made short movie clips, in which he did parts of the presentation. But as you probably all know, technology has its own will.

So I would like to end by reading out a short transcript from one of the films:

"By showing others that we as self-advocates think about our talent, about what our interests are, and work on that personally, ourselves. In our personal layer.

By standing up for our rights, the right to education, even more important: the right to learn. As self-advocates.

By sharing this with others in the same boat, and cooperating with them. As musketeers.

By bringing this into practice and by doing research together, thus showing that we can learn and want to learn. That it is not too difficult for us... Because often we, people with an intellectual disability are forgotten in research, because they think we wouldn't understand anyway. By organising a workshop, we people who with all due respect have nothing to gain from higher education only more disappointments, and in that workshop we stimulate students, policy makers, professors, trainers and researchers to reflect. It is by doing these things in higher education that we and others can break through barriers, labels and prejudices."

And thus bring about a form of resistance in the fortress of academia.