

Preface

Welcome to my PhD dissertation created through and around my research on inclusive research and developing training for inclusive research teams.

My research focuses on the exploration of inclusive research and analysing what questions, themes and issues inclusive research teams are facing. Through this research project I had the opportunity to enter different inclusive ‘research kitchens’ and to join the meetings and roundtables within those kitchens (see Figure 1). From these experiences we created a training together with researchers with academic background, researchers with experiential knowledge, designers, experts from different disciplines.

In my own way I hope to have done justice to the stories and the trust that all people I have encountered in this research work gave me. I am truly grateful for all the connections, blockages, challenges and openings.

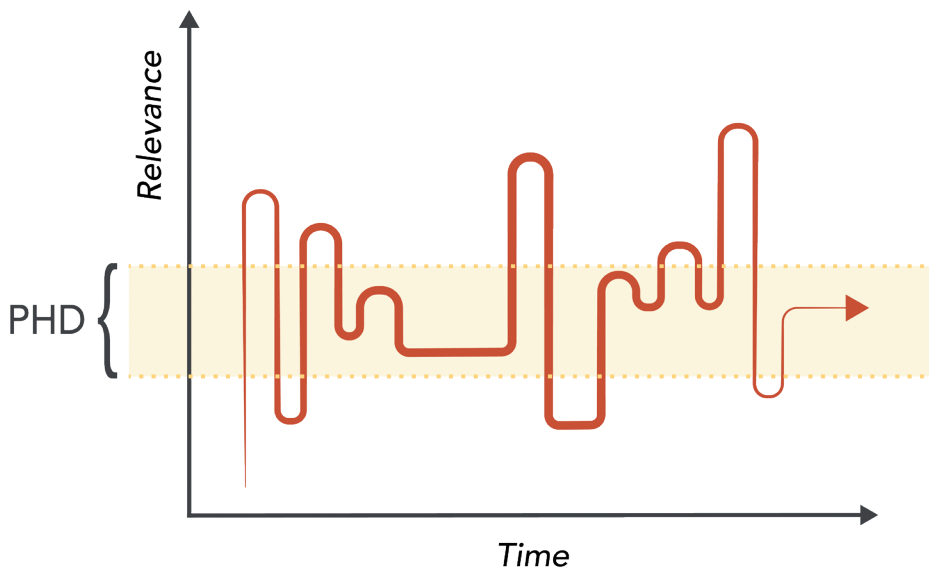


Figure 2: My PhD road over Time © René Krewinkel

In Figure 2 my PhD journey is expressed in a graphic made by one my ‘compagnons de route’ since years now, René Krewinkel. As you can see, some passages on the road were not relevant for inclusion in this manuscript. Other data, ideas that grow from this PhD seem very relevant, but I had to put the line somewhere: I decided to leave them out of this manuscript and to take them with me for exploration in future research.

I don't know where exactly my journey started but I think I have to go back to the time I worked for KONEKT, a Belgian network organisation that works for and with people with disabilities, towards an inclusive society. I developed and organised training sessions for people with disabilities and their allies. In that time, I created courses on social skills, dementia, mourning, palliative care, addiction and many other – abstract and delicate – themes, together with colleagues from many different fields. I discovered during these training sessions I needed very diverse training materials. So, I started working together with the artist Saar De Buysere. Prof. Dr. Geert Van Hove asked me to work on a PhD on these picture books. The problem was that I was enjoying the work of creating picture books so much that no scientific articles were written in that time.

Instead, we co-created the following materials:

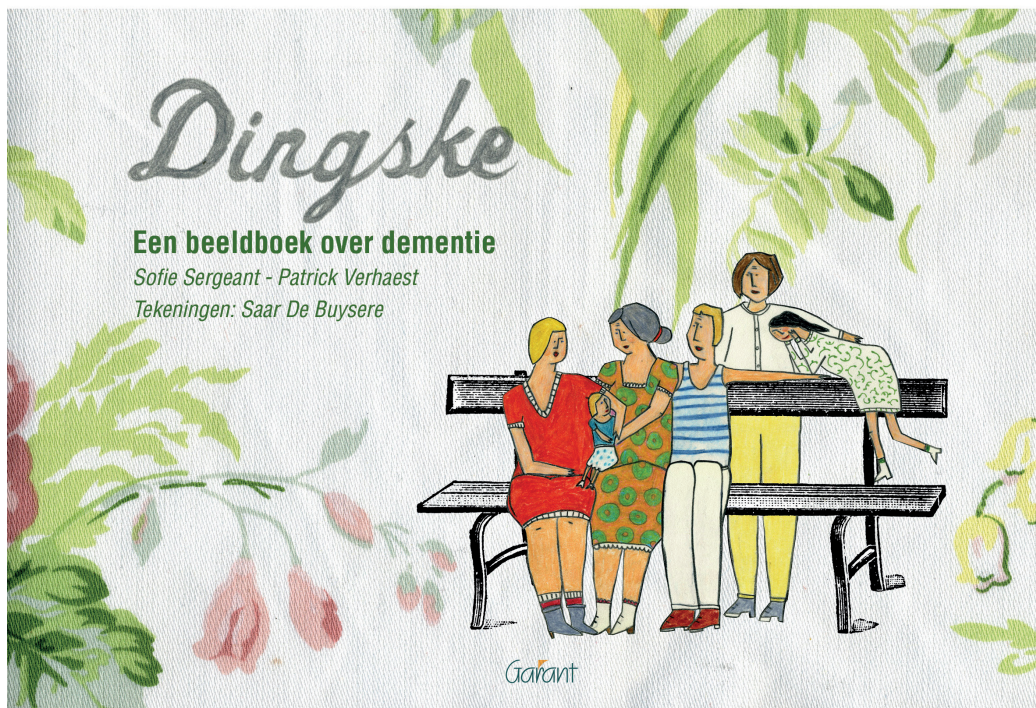


Figure 3: Dingske: a picture book on dementia (Sergeant, Verhaest & De Buysere, 2010) © Saar De Buysere



Figure 4: Nu en straks: a picture book on palliative care (Sergeant & De Buysere, 2013) © Saar De Buysere



Figure 5: Et maintenant: a picture book on palliative care, translated into French (Sergeant & De Buysere, 2014a) © Saar De Buysere

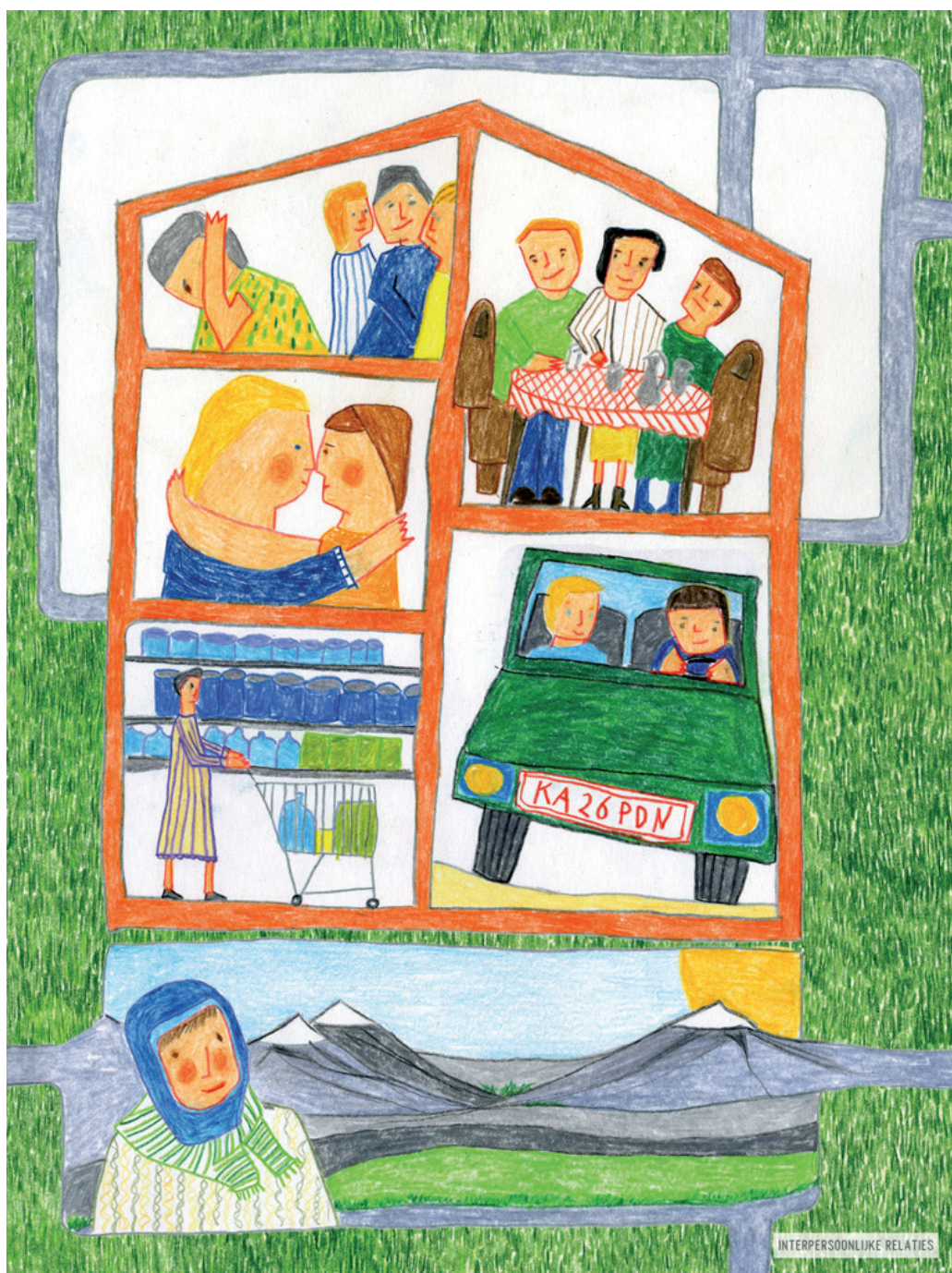


Figure 6: Achter de rouw: a package of 8 large puzzle pieces on mourning (Sergeant & De Buysere, 2014b) © Saar De Buysere

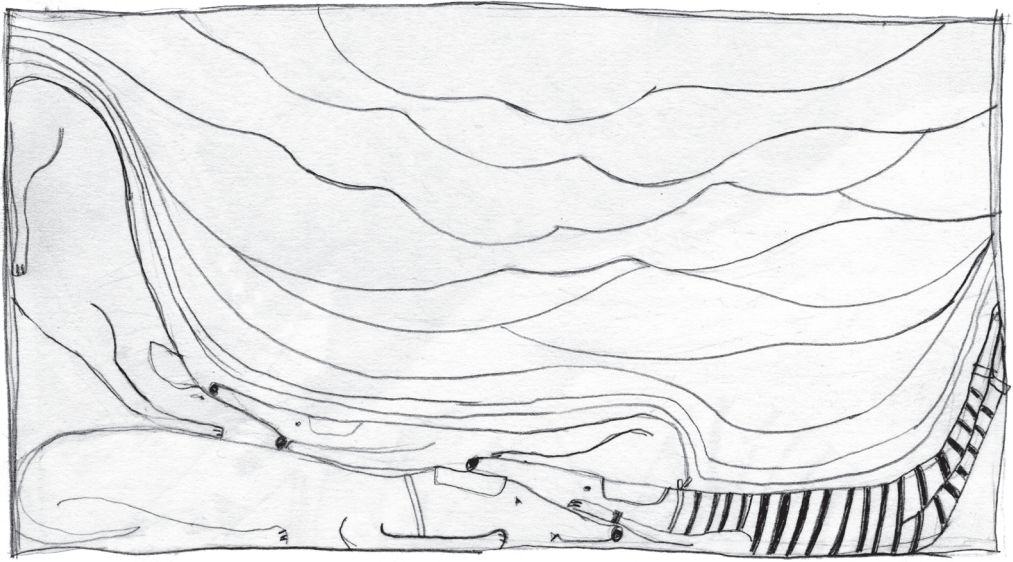


Figure 7: Young dogs: a graphic novel on fear (Sergeant & De Buysere, 2014c) © Saar De Buysere

In the process of creating picture books, I met Irene Tuffrey-Wijne in Ghent. She told me about her experiences in co-creating and co-researching with people with disabilities. This was an eye-opener for me, although I needed time to learn what this co-creation really implied...Until then, I shared our work: we organised testing sessions whether our drawings would ‘work’ or not. But to be honest, we organised this in the last phase of our research work: editing before printing.

Whilst living in Berlin, I was contacted by Prof. Dr. Geert Van Hove. If I could create education and training materials for Disability Studies in Nederland (DSiN). Subsequently, I was introduced Alice Schippers – the director of DSiN – and I started my engagement for the DSiN-foundation as education coordinator. In 2015, we moved from Berlin to Soestduinen, in The Netherlands. And in 2016 I was asked by Geert Van Hove and Alice Schippers to join the research project ‘Working Together, Learning Together’ (WTLT), a research project funded by ZonMW which aimed at researching the participation of people with disabilities within the National Programme ‘Gewoon Bijzonder’ research projects. The research work for WTLT comprised a deadline: finishing my PhD in 2020. Geert and Alice smiled: we had a deal and a deadline.

‘Working together, learning together’ is carried out by DSiN, Academische Werkplaats Leven met een verstandelijke beperking (AWVB) Tranzo and the LFB.

My research partners in this project were:

- Joint research partner Henriëtte Sandvoort (LFB)
- Dr. Kim van den Boogaard (postdoc researcher Tranzo)
- Prof.Dr. Alice Schippers, Disability Studies / VUmc Metamedica, co-supervisor of my PhD
- Prof. Dr. Petri Embregts, Tranzo, Tilburg University, co-supervisor of my PhD
- Prof. Geert Van Hove, VUmc Metamedica, supervisor of my PhD
- Joost Blommendaal (LFB)

Together with Henriëtte Sandvoort (trainer and researcher with experiential knowledge, LFB) we started our journey of four years (2016-2020) working closely together as ‘researcher duo’. The result of what we learned is described in my PhD dissertation. Of course, there is much more to tell beyond the chapters in this dissertation, but it is a carefully constructed beginning.

Working closely together was for both Henriëtte and myself a very exciting experience. We had hilarious moments; as well as breakdowns. But through the years, through all our encounters and ‘battles’, working together as a duo only got better and better, as depicted in Figure 8.

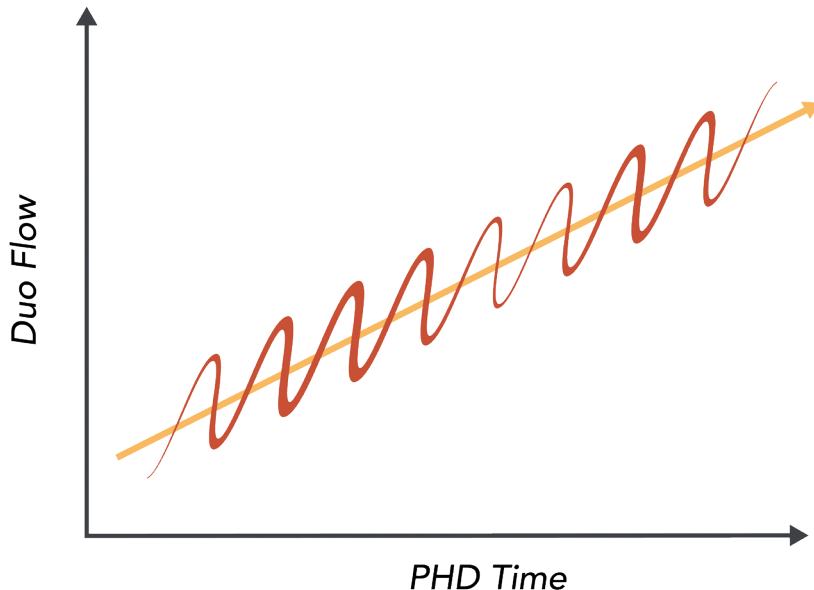


Figure 8: We had joy, we had fun, and we had our battles © René Krewinkel

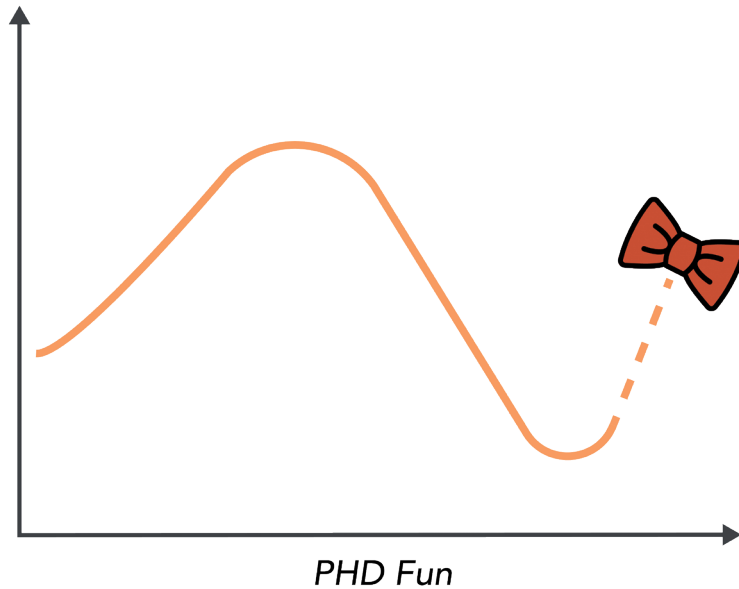


Figure 9: The funfactor during my PhD-time © René Krewinkel

As I am writing my PhD dissertation I look back at the whole process and also at the last period of feverish writing. In Figure 9 this overview is depicted.

It took me time to feel ‘at home’ in the WTLT-research project. Once I felt at home in my work with Henriëtte and other colleagues my work felt as an adventure with impact, a life-changing event.

ZonMw provided extra support for the implementation of our research work and the training we created. So, from January 2020, Henriëtte and I searched for more people to join our training-team.

I will introduce them shortly:

- Bernadette Wijnker-Holmes: researcher
- Andries Lever: trainer with experiential knowledge
- Sanneke Duijf: social designer
- Bob van den Berg: graphic designer with experiential knowledge
- Rosa Stalenberg: student researcher
- Marjolein Olde Heuvel: social scientist and mother with experiential knowledge
- René Krewinkel: app and website designer, cartoonist
- Remco Mostert: writer and trainer
- Irene van Helden: communication manager

- Angela Hanse: office manager
- Mitzi Waltz: researcher, English native speaker
- Ellis Merkelijn: trainer and coach with experiential knowledge
- Marja Steegenga: trainer and coach

We are very proud of our team; we celebrate the diversity and all the talents we assemble.

But then... I had to leave 'my playground' and write my articles and dissertation. COVID-19 times broke out which actually helped me to focus: to sit behind my desk and write my dissertation. Sometimes this process felt lonely, but at the same time it was an opportunity to carefully capture our research experiences in qualitative research articles. Creating the quantitative graphics with René Krewinkel for this preface helped me to smile and embrace the silent times of reflection and writing. Finishing the manuscript gives me a great boost and I am relieved to finally be able put a bow around this PhD time period.

In writing my dissertation I purposely chose for open access publications and for embedding non-academic publications that are accessible for a broad public. Within the scope of the forlating research work, social impact factor seemed to me more important than journal impact factor. Therefore you will also find photos, graphics, cartoons, films, blogs and vlogs in this dissertation. I will come back to this point in the discussion section on striving for a more accessible academic world, for more co-creation and for universal design for research.