

Intro

A Patchwork

A Patchwork of Entanglements

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This doctoral thesis is about the *entangled* lived experiences of family members of people with a label. The search for and the (re-)creation of entanglements around families and disability from a common thread. Entanglement is a concept from quantum mechanics, which states that two spatially separate objects always remain connected—one can never be fully described without also naming the other (Oxford University Press, 2021). It is based on the idea that people with a label are entangled with their family context. The reverse is equally true—a family member of a person with a disability cannot ignore or distance themselves from that family member’s disability. Karen Barad (2007, p. 33) invites us to see our being as “mutual constitution of entangled agencies”. This doctoral research therefore does not work with chapters but is a patchwork that is made up of different patches that are/become strongly intertwined. The word ‘patch’ refers to a piece of fabric and patchwork to the interplay of the different patches. Each patch has its uniqueness/history, but by bringing them together, a (new/different) story is created again and again. The patches in this doctoral thesis do not only consist of textile. For example, one patch is a short film. Another of the patches is a conversation conducted by letter and yet another takes the form of a written conversation. Some patches are printed drawings, stitched drawings created using a sewing machine, while some of the patches bring out the experiences of families with a label while writing/reading.

The patchwork is not stitched together in a linear fashion or in the form of categories, but it has grown organically in an affective way, from a succession of encounters between humans and matter (Springgay, 2019). The patchwork is in book form, which means patches are not next to each other but on top of each other... If you open one patch, another patch is more out of sight but never completely gone. In an invisible way, it lives on in another layer. In this research, entanglements are allowed to persist. Academic research about families of people with labels has a habit of disentangling and unravelling everyday encounters, of rendering them transparent by means of clear and delineated research question(s) in order to be able to explore them in greater depth by means of a grounded and transparent research plan (Nolas & Varvantakis, 2018).

Throughout my doctoral research, I was regularly presented with the following questions: “Now tell me: what is Lode’s code?” In most cases, this implicitly meant: what syndrome does your brother actually ‘suffer’ from? “Surely it must be difficult for your family to deal with your brother’s disability. What are your coping strategies for dealing with this situation as a family member?”

These questions seek clear, universal answers regarding the way in which families with a family member with a label fit together. People with labels are often reduced to their DSM criteria and/or their medical syndrome. Ideas of individualism and progress, combined with the belief that positivist measurable science is the key to improving human beings, provides fuel to attribute very high value to linear medical expert terms (Ezzy, 2000). This medical-psychiatric knowledge certainly has its value, but it can never fully capture the complexity in which families of people with labels find themselves. It says nothing about the complex sociocultural context in which disability is embedded or about the way in which normative power structures help shape family experiences around disability (Lalvani & Polvere, 2013).

It is not medical labelling in itself that is problematic, rather the way in which it is deployed. In many cases, the label is presented as definitive and all-encompassing (Fisher & Goodley, 2007; Goodley, 2007; Goodley & Runswick-Cole, 2012). The all-encompassing character of labelling fails to recognise all of the other entanglements that are present. Deleuze & Guattari (1987) conceptualise these all-encompassing ways of thinking as an “overcoded machine.” As a machine that leaves no room to engage in connection with other machines. In this research, we chose to bring a medical-psychiatric approach into dialogue with other approaches. We ask how, within their context, families go about working with the given label and what the consequences are for their cohabitation and participation in the family and in society. This knowledge is much less straightforward and measurable and therefore risks being dismissed as “too unscientific” (McKeever & Miller, 2004, McLaughlin, 2005). Barad (2007) argues that families can provide what she calls “agential cuts”. Discursive and material power structures are not immutable. Sometimes, small deviations/agential cuts in discursive and material habits can succeed in reshaping pattern structures in the long run (Barad, 2007, p. 178). Our aim, in this research, is

to lay bare how families can contribute to this by highlighting encounters. Encounters are understood as follows:

An encounter is an intensity, a becoming that takes you outside the habitual practices of the already-known; it is intra-active, and corresponds to the power to affect and be affected (Deleuze & Guattari, 1987). Being open, and being vulnerable to being affected by the other, is how we accomplish our humanity; it is how the communities of which we are part, create and re-create themselves. We are not separate from the encounters that make up the community but, rather, emergent with them. (Davies, 2014, p. 10)

The starting point for my research involved encounters within my own parental nest. At a very early age, my oldest brother Lode was given numerous labels. From the encounter with my own family, I made jumps to the entanglements of other brothers or sisters who grew up in a family with someone with a label. Each encounter had its specific uniqueness and called for its own specific form within this patchwork. Each of the encounters arose from a common being touched in which we found each other as family members. Without having to explain anything, we connected, and a common search emerged. “How matter comes to matter,” was our starting point (Barad, 2003). The emphasis was always on the subject in the making that took shape through the intra-action with his/her non/human environment (Warfield, 2019). Karen Barad speaks of intra-action rather than interaction to describe such moments of encounter. Interaction, for Karen Barad, is too heavily based on detached decontextualised individuals, who do not transform with each other. Barad generates the neologism intra-action to examine the ongoing “mutual constitution of entangled agencies” (Barad, 2007, p. 33). Intra-action, on the other hand, emphasises how in each encounter individuals appear through the relationship with humans and matter and are reinvented each time. “Relata do not pre-exist relations; rather, relata within-phenomena emerge through specific intra-actions” (Barad, 2003, p. 815). The concept of intra-action breaks through the idea that humans are in complete control of life. As humans, we are one small cog in a very much larger whole that is so fantastically complex (Davies, 2021). As a researcher, you are not in the world but of the world (Davies, 2021). As

a human/researcher, you are always ethically involved in the research you conduct.

Each action we engage in and each interpretation is, therefore, an ethical matter and mattering. When something comes to matter, when it actively changes the way things are and are perceived to be, both the ontology of bodies (our own and others), and the meaning made of what happens, are affected. (Davies, 2014, p. 4)

At some point, I was asked why I wanted to make the film Lode's Code. That is a question I could not answer immediately. This doctoral research gave me the opportunity to investigate this in greater depth. This involved seeking to identify my position in the family and was a search that brought me to new questions (Adams et al., 2017). Do I really have the right to consider my brother and my family members and everyone else, including the material world, as research material? I did not want to become stranded in a colonialising, dualising attitude, in which I, as a sister without disability, am writing about families where someone lives with a disability, and am using my brother or the voices of other family members to convey my own desires or wishes (van. Dienderen, 2006; Rutten et al, 2013; Khader, 2011, Kittay, 2019). An ethical search was constantly present, and I discovered how important it is not to gloss over this search, but rather to see it as the core of my research. I noticed how strongly the intra-action was working. The questions of family members I was working with sometimes became my questions and my questions also became their questions. "We became-with each other" (Davies, 2021, p. 141). The researcher-ness, the sister-ness of Lode, the love of art and creating, the special needs educator-ness, the white woman-ness, the motherhood of two children, etc. All these elements played a role in the entanglements throughout the stories of families of people with labels. "How then shall we understand our role in helping constitute who and what come to matter?" (Barad 2007, preface). Karen Barad (2007) speaks of "ethico-onto-epistemology" to make clear that a researcher is never free of response-ability. Not the liberal individual responsibility we would first think of. The concept of 'entanglement' brings with it an entirely different response-ability. Barad (2007) talks about the connection of ethics, ontology, and epistemology to indicate that that a researcher's ethics

are very much connected to his/her view of knowledge and existence in the world. Within a research ontology that puts entanglement first, the ethics of the research is always shaped through what appears in the research. It is not procedurally fixed, but always appears from a process of becoming.

The concept of entanglement brings with it an entirely different conception of ethics. In place of the institutional ethics that tie down the research event to controlled and predictable practices and outcomes, new materialist ethics, in its unpredictability, never lets the researcher off the hook of considering how their emergent thoughts and actions matter. (Davies, 2021, p. 9)

Entangled thinking does not work according to causal-linear relationships, but arise from multiplicities that make us stop, turn back, with an emphasis on turning, pivoting and transforming. Sometimes, certain layers work against each other, whereas at other times, they work with each other. Multiplicities refer to assemblages that constantly transform themselves and merge into each other (Deleuze & Guattari, 1987). Researchers are produced by intra-actions: multiplicities, always in a process of becoming different to what they were before.

The-family-disability-entangled-patchwork



The-family-disability-entangled-patchwork includes many secret layers that sometimes surface, before disappearing again under another patch. Invariably, hidden layers remain present. This doctoral thesis has been written from a Disability Studies framework. Disability Studies scholars are developing critiques of, and responses to dominant and exclusionary discourses and, from a curious open stance, giving space to the hidden complex family layers that are not often heard (Macartney, 2011).

From a historical point of view, research into the families of children with disabilities has been framed by the medical model. This model considers disability as a biological/individual deficit, necessarily associated with *burden* and *grief*. Having a child with a label and growing up with a person with a disability has been seen as a *personal tragedy* that burdens the entire family. Members of the family are seen as *co-victims* of the disability (Oliver, 1990; Yuan, 2003). You instantly become a *disabled family* in which family members must learn to cope with the disability of brother/sister/son or daughter (Ferguson, 2001). The mourning model of Kubler-Ross and/or the ABC-X model that views the child with a disability mainly as source of stress/pain in its family still leaves behind heavy traces in the dominant image of families with a label (Van Hove, et al., 2009).

Interpreting parental/family realities solely from an individual-pathological point of view ignores the very complex ways in which parents and families negotiate and understand their situation. Many Disability Studies scholars have themselves experienced being a family member of someone with a label (see Ferguson & Ferguson, 1993; Gabel, 2018; Bjarnason, 2003; Ware, 2009; Runswick-Cole, 2007; Kittay, 2019) and write from their own personal position as a mother, father, brother, brother-in-law, sister, etc. (Sauer & Ferguson, 2013). Over the years, they have been building a collection of narratives in which disability is located within a family context (Berglund, 2007). They present labelled people and their family's perspectives to lay bare experiences and lived effects of being viewed and labelled as disabled or impaired.

When presenting the stories of families with family members with a label we must be very conscious of the danger that exists when situating families and disability within an epistemology of being and the associated meaning making of the constructed (almost finished and complete) family. Together with Goodley (2007), we learn that families consistently defy

categorisation. In this doctoral thesis, family experiences are approached as complex, temporal and relational. Contradictions are allowed to exist (Bagnoli, 2009; Davies & Davies, 2007; Mason, 2006; Polkinghorne, 2007). Family members experience life within many different dimensions: physical, sensory, emotional, aesthetic, etc. (Bruner, 1986; Clandinin & Connelly 1994; Mason, 2006). Each family has its own story, context, and history. Each family appears to form a small society unto itself with a lot of diversity. You have the mother's story and the father's story. You also have the brother(s) and/or sister(s), the grandmas and the grandpas, the neighbours and uncles and aunts, nieces, and nephews and so on, as a result of which the stories become even different when all of them come together. You have big families, small families, poor families, and rich families. People who are very docile, people who are very contrarian. Families are no longer limited to the nuclear family consisting of a mother, father and two children. You have newly formed families, families with two mothers or two fathers, foster families, you have single-parent families, you have intentionally unmarried mothers, families who are fleeing, ... It is important to recognise that the experiences of people with disabilities and their families are just as diverse as other groups in society. This is an important insight when it comes to developing a critique of universalistic, "expert"-based systems of knowledge and interventions (Macartney, 2011).

If we neglect the family perspective, we lose a lot of valuable information regarding the support of the labelled family member (Goodley & Tregaskis, 2006). It would be wrong to pretend that everything that happens in families is "right" and everything that happens anywhere else is "wrong", but by not listening to or including the family's story, we miss out on so much contextual information that is important when getting to know and possibly supporting someone. We cannot simply isolate an individual from his/her family context. This is also what Ferguson (2001, p. 87) advocates:

We must start to approach disability as relational, not essential. (...) Everything that tells us who we are—how we are the same and how we are different—is suspended in the webs of, relationships that construct our culture. To interpret disability as relational simply shows us where to look not what we should see. It only begins our search.

Can we look in a humble way at how families of people with labels organise their family life (Kittay, 2019) and be careful not to adopt or condemn from an expert position? Can we listen to families from a ‘not-knowing’ position and therefore learn from them? Having a child is a quest in which you do not know where you are going to end up. Most parents can barely imagine the life they are stepping into the moment their child is born. That unknown world is only magnified when disability comes into play (Isarin, 2004). Parents of children with a disability label face the challenge of having to let go of expectations they themselves did not even know they had (Isarin, 2004). This is no different for parents of children without a label, although it does seem to be (sometimes) magnified in the case of the parents of a child with a disability (Salomon, 2016, Kittay, 2019). The approach adopted by most family members is based on an emotional involvement, always trying to give the child as many opportunities in life as possible (Kittay, 2019) Parents are often concerned about the future of their child with a label. As children with labels start to grow up, it can feel like an ambivalent process for their family members (Isarin, 2004). A lot of members of the family will ask themselves similar questions: what will happen if we, as a family member, are no longer around? How will the family be organised going forward? How can we seek to achieve a tailor-made pathway for the family member with a label and his/her context? What role can his/her brothers and sisters without a label play?

Family members sometimes encounter structural walls in support organisations, and this can bring about a significant break with the home situation (Hodge & Runswick-Cole, 2008). For example, family members are expected to conform to the facility’s rules for visitors. People with a label and their families must adapt to the existing offerings for people with labels. Existing support offerings for people with a more severe intellectual disability are mostly group-organised where dialogue with the family does not seem possible in all cases (Ferguson & Ferguson, 1993). Unequal power relationships come into play between family members and the professional caregiver (Macartney, 2011). In this regard, Azzopardi (2000) emphasises that families feel significant pressure to go along with the already prevailing ‘care facility logic’ because they fear being pinned down themselves as difficult or inadequate parents. Todd and Jones (2003) also describe that family

members often feel vulnerable and inferior to the language of experts and therefore do not always dare to engage in dialogue.

Yet we certainly do not want to reduce family members of people with labels to passive beings within the family-disability-entangled patchwork. We learned how creative family members can be. For example, Goodley (2007, p. 156) describes: “Disabled people and their families create, resist, and negotiate meanings about disability and difference within a web of competing discourses.” Many families with labels are aware of the presence of the normalising practices in healthcare contexts. Sometimes, families use the medical discourse skilfully, while at other times they turn it down completely and try to find or follow their own path (Van Hove et al, 2009). These two flows, going along with the norm and questioning the norm, always go hand in hand. In this patchwork, we consider families of people with a label as “assemblages”, as a collection of a multitude of possibilities in thought and action with sometimes opposing lines of forces with multiple entries and multiple exits, of various, separately assembled elements that are continually shaped by processes of de- and reterritorialization (Deleuze & Guattari, 1987). Stratification lines confine themselves to the known. Lines of flight, on the other hand, create the possibility of breaking open the known path and, by doing so, bringing in new ways of thinking and acting that set the assemblage in motion (Allan, 2008). Both movements are always present. Sometimes the stratification line gets the upper hand, while at other times, the line of flight becomes the dominant factor. Each line of flight is re-embedded and incorporated into the assemblage and is re-territorialised.

With the arrival of disability in a family, a reinvention of the family becomes necessary. This is often a confusing quest that requires regular reverting to “a safe plot of land” (Davies, 2021, p. 97) or to stratification lines that enable family members find footholds by drawing on what is known, such as medical discourse. This can provide recognition and clarity to enter into communication with friends, school or other caregivers. Sometimes, the family members of people with labels resist the deterministic medical language that very strongly locks their family member with a label into a deficit. Linda Ware (2009) testifies as follows: “It is difficult to explain the feelings that accompany the loss of possibility—to explain how one is robbed of flourishing (...) Upon whose authority does one diminish the

hope of another?” (Ware, 2009, pp. 147-148). The advent of disability can give family members a special drive to try new things, creating lines of flight (Fisher and Goodley, 2007; Goodley, 2007). Isarin talks about “eigen-wijs ouderschap”, freely translated as “parentship-with-wisdom-of-their-own”. I suggest broadening it to “familyhood-with-a-wisdom-of-their-own”. From wisdom gathered through living in a family machine, they know to transform the experts’ diagnosis into a lived reality (Isarin, 2004). New forms of communication between their brother/sister/mother/father can be tried out. Family members travel both literally and figuratively, taking unexpected steps for their family member with a label and for themselves in the process (Van Hove et al., 2009). From their position of living closely together, family members sometimes discover hidden paths. Sometimes they curse when they are lost, sometimes they are surprised by the interesting detours that come their way. “My child is my voyage around the world, so I am a world traveller...” is a quote from a parent of a child with a label (Van Hove et al., 2009, p. 191). Eva Kittay (2019, p. 104) also uses travelling to an unknown destination as a metaphor to describe the birth of her daughter:

We fell in love immediately and madly with this sweet child. But we did not yet know that our love was in fact grounded not in our dreams, but in the reality of the small person who was entrusted to our care. This concrete individual, the love we bore her, the care she inspired, was our trip, and the destination was far less significant than we imagined it ever could be.

Along with Macartney (2011), as Disability Studies researchers, we see it as our task to expose more fully the complex narratives of people with disabilities and their families so that they can enter into dialogue with the dominant discourse surrounding disability and in order to allow for a greater divergence in approach (Clandinin & Connelly, 1997). In this doctoral thesis, I have abandoned the idea of the linear narrative as much as possible and have made space to enable families with labels to be approached based on the concept of an ongoing becoming. Goodley articulates as follows: “It is all about a complex interplay of enjoying the present, being hopeful for the future and considering that a lot is uncertain” (Goodley, 2007, p. 156).

Bringing Creation into Academia

Entanglements call for a paradoxical form of agency from the researcher. On the one hand, the researcher is called on to go beyond categorisation and interpretation: it is a form of agency that assumes and necessitates invention as the researcher is “called on to fill in the gaps in the image, engage with the traces the image leaves” (Marks, 2002). (...) Simultaneously it asks the researcher to give up their own sense of distinctiveness from an image and to relinquish control. (Nolas & Varvantakis, 2018, p. 3)

Nolas and Varvantakis (2018) cite Laura Marks (2002) to describe the complex position of a researcher taking entanglement as a starting point. He/she would appear to have few points of reference when determining what to do. He/she seems to follow the tracks where intuition leads. My intuition always took me somewhere. Usually I did not know where, but that very fact actually made the search much more fascinating. Creation was my thread. Both in terms of content and form. In terms of content, for example, a dedicated search to identify the creative processes that existed in the families of people with a label came forward. As far as the collaboration with creative siblings was concerned, every patch was an experiment. Each time, it involved searching for a suitable form that could tell something that, until then, it had not been possible to convey... In what follows, I provide a more in-depth account of how research-creation formed a foundation of my way of working and how that way of working took shape from the meetings with other family members of people with a label.

Research-Creation as an “Encounter”

I collect, draw, redraw, print, cut, rearrange, paste and stitch. I tie in what I read, write, hear, see, feel and re-touch. New layers emerge and old ones sometimes become visible, or, in some case, hidden. While creating, I am researching... The collection and creation of visual narratives is invariably the angle of approach of this doctoral thesis. The concept of research-creation arose at the beginning of the 21st century in Canada as a funding

category¹ that provides a wording by means of which visual thinking can be given an equal place in an academic context. Quite a few artists brought new forms of knowledge into universities as a result (Manning & Massumi, 2014; Truman et al., 2019). Research-creation is described by Sarah Truman (2021) as a meeting place of art, theory and science. The interaction between art and science in academia is not limited to Canada but reaches worldwide and across disciplines. Already since the early 1990s, there has been a very strong and growing interest in experimenting with hybrid forms between art and science (Coemans & Hannes, 2017). Besides research-creation as a term, many other terms are used to describe creative methods in academia (Chilton, 2013): including art(s)-based research (in education), arts-informed research, arts-informed education, visual ethnography, practice-based research, practice-led research, a/r/tography, image-based research, performative research, poetic inquiry, photovoice, photo-elicitation, photo-novella, theatre of the oppressed, popular theatre, playback theatre, image theatre, found poetry, reader's theatre, participatory video... (Coemans & Hannes, 2017; Gerber et al., 2020).

The terms are highly discipline-dependent and geographically determined. The umbrella term 'arts-based research' (ABR) is mainly found in America and was first introduced by the educational scientist Elliot Eisner (Chapman & Sawchuk, 2012, Coemans & Hannes, 2017) and later elaborated upon by a considerable number of other researchers from various disciplines. Especially because of its participatory and emancipatory character, arts-based research became very popular in socially engaged research (Coemans & Hannes, 2017). Coemans & Hannes (2017, p. 43) define arts-based methods in community-based inquiry as:

The use of artistically inspired methods by researchers and participants in a collaborative research environment where members of the commu-

1. In 2003 a Canadian governing agency, implemented research-creation as a funding category. Erin Manning (2016), in "A Minor Gesture," describes the dual benefits of this funding category. On the one hand, it is useful for artists who would not have the opportunity to work at the University (because they do not have publications for example). On the other hand, it does entail that research-creation separates itself from other research so that research and creation are still approached as two separate things. Also, like other researchers, research-creation face the same neoliberal pressure to think strongly output-oriented (Manning, 2016, p. 240).

nity are actively involved either in creating art in the search for meaning or in providing a critical, situated response to artistically inspired formats of research dissemination from others.

Many approaches exist within the creative research domain. In some cases, the focus is more on creating for the researcher, while in others it is more about stimulating creation in the participants and sometimes it is about both, as was the case in my research. In some cases, the artistic process forms only a small part of the research and is not the main focus. For this, the term ‘arts-informed research’ is more commonly used (Cole and Knowles, 2008). A frequently used example is in research using ‘photo elicitation’ or ‘photovoice’, in which the photographs are used primarily to gather information in a different way than by means of interviews or focus groups. In this type of research, the emphasis is less on the aesthetic of the photographs (Gerber et al., 2020).

It was via the South-African artist-visual researcher Leora Farber (2010), that I became familiar with the term ‘practice-based research’. Practice-based research and practice-led research are terms more commonly used in the UK and Australia (Chapman & Sawchuk, 2012) and are strongly situated in Art and Design world (Frayling et al., 1997). In both forms, the researcher is performing a creative practice. Candy (2006, p. 1) defines the difference as follows: “If a creative artefact is the basis of the contribution to knowledge, the research is practice-based. If the research leads primarily to new understandings about practice, it is practice-led.”

Visual ethnography is defined by Sarah Pink (2020) as a research methodology informed by the theories, methods, and vocabulary of the discipline of anthropology. It brings theory and visual approaches (like photography, film, and many others visual media) to learning and knowing about the world and communicating this knowledge. Visual ethnography asks for a constant questioning on the part of the researcher, the visual medium and the participants’ view of reality in the representation of the other (van Dienderen, 2006).

‘A/r/tography’ is a poststructuralist term that strongly emphasises the entanglement between art-research-education and is firmly linked to the concept of research-creation, which is also interpreted from a posthumanist framework. A/r/tography does focus more strongly on education. A/r/

tography is described as a type of living research. Springgay et al. (2005, p. 899) describe it as follows:

A/r/tography is not intended to discredit other forms of art-based research, nor is it separate from all previous discourse. Rather, it is one of many research methodologies involving art and education. It is a tangential thread; perhaps a thread that has become disconnected and is unravelling its own existence into a new beginning. A/r/tography as such is a methodology of embodiment, never isolated in its activity but always involved in the world.

Current work by Erin Manning, Stephanie Springgay, Sarah Truman, and David Shannon mostly have recourse to the term ‘research-creation’. The research-creation ethics was very much in line with my way of working and I consequently chose to use this concept in order to describe my research trajectory.

Research-creation is a way of doing theory/thinking that is bodily, experimental, and considers research (knowledge making) as a (speculative) event emerging from a practice, rather than preformed or predetermined. (Springgay, 2020, p. 226)

Research-creation does not consist of nicely delineated research phases. Rather, research is seen as “a messy practice, as an affective, emergent, relational and more-than-representational approach to doing-research” (Thrift, 2007; McCormack, 2008; Truman & Springgay, 2016 cited by Truman & Shannon, 2018, p. 62). Stephanie Springgay (2020) brings the metaphor of “felting” into research. By rubbing longer and longer, threads literally and figuratively intertwine. Personally, I see the search for materials, the drawing, the printing, the stitching, the reading of literature, the attentive listening to other family members of persons with labels and to everything that surrounds me as the “rubbing”, as a result of which certain concepts slowly intertwine. To this way of working a form of rigour is attached, an ethical position that I adopted and helped me to make choices each time.

Making-thinking-doing

My visual creating and my thinking go hand in hand. It is a creating of layers. Springgay & Truman (2017) speak of “making-thinking-doing”. Chapman and Sawchuck (2015) speak of “creation-as-research”. They regard knowledge acquisition as a creative work, not only when analysing or interpreting data. They actually see the entire research process as a creative process in which making and doing have an equal place. Erin Manning (2016) describes research-creation as “a practice that thinks” (p. 27). The sewing machine, the scissors, the glue, the ink, the paper, the fabric, the keys on my computer, the place where I am, the animation & graphics studio, the landscape agency,... all play a part in that which emerges during the research-creation process. I see data in a broad sense. It does not only refer to words. It is about everything you have consciously or unconsciously absorbed so far in function of your research question (smells, tactile materials, what was not said, etc.). As a researcher, you cannot disconnect yourself from your data. This is also what Maggy MacLure (2013a, p. 660) describes in connection with the process of data collection.

Data cannot be seen as an inert and indifferent mass waiting to be informed and calibrated by our analytic acumen or our coding systems. We are no longer autonomous agents, choosing and disposing. Rather, we are obliged to acknowledge that data have their ways of making themselves intelligible to us.

Sometimes, it seems that data choose us and not the other way around. Maggie MacLure (2003b, p. 229) also talks about the wonder of data.

Wonder is relational. It is not clear where it originates and to whom it belongs. It seems to be “out there,” emanating from a particular object, image, or fragment of text; but it is also “in” the person that is affected. A passion: the capacity to affect and to be affected.

My visual work influences my academic writing and vice versa. I find it difficult to discern where one begins and the other ends. Drawing, cutting and working with wire and textiles help me to let my thoughts run free. For example, I often work with one image that continues to haunt me from the

many encounters. I try to make that image more abstract, either by cutting/drawing or by printing graphically. The making enables me to connect with the here-and-now, in motion, beyond a linear thinking.

It is a question of moving experience beyond the way it has a habit of taking, of discovering how the edges of lifeliving commingle with the force of that which cannot yet be perceived but is nonetheless felt. (Manning, 2016, p. 52)

In such a moment, something new can emerge. This certainly does not happen in every case, but sometimes it does. Sometimes something appears that you never could have imagined in advance. A form that appears or a situation in which it suddenly becomes clear which direction you can go because all the threads intertwine....

Matter plays a major role in what follows. The time-consuming process of animation and free graphics forces me to slow down. It prompts me to sometimes reuse the same images but add a slight variation with each repetition. It is a good exercise in learning to look at things differently. Each “try” leaves traces that then lead to new traces. It reminds me a bit of the working method of South African artist William Kentridge. He draws with charcoal, erasing parts of it each time and then continuing to draw on them again. After erasing, charcoal traces always remain on the paper. These traces also determine the drawing that follows. Kentridge (Pompidou, Klara, 2021) describes it as “thinking in the material”.

However hard I tried to erase, there is a trace of the charcoal in the paper, so what the drawing and the technique does by itself, not through any meaning that I give it. It keeps a trace of the passage of time of the making of the drawing. It is there in the paper, it is what the process itself does...

Touching & being touched

Sometimes you have no words for what you are doing. If there is another thread within my doctoral thesis, it is this one. What touched me so much in my family story? It became a quest that I was unable to run away from. Animated film became my first entry point to work with it. I worked with

what affected me physically. Affect as a “becoming sensation, a force or intensity manifested at the surface of the body” (Springgay and Zaliwska, 2017, pp. 276-277). Springgay talks about thinking-in-movement as “a thinking saturated with rhythm and affect” (Springgay and Truman, 2016). In creative inquiry, a researcher allows herself to be emotionally and intuitively immersed in life, attentive to the felt, the unsaid, and the tactile as an “embodied way of knowing” (Springgay & et al., 2005).

When I showed my short film ‘Lode’s Code’ (see patch one), I often got a deafening silence in response and a little later the message from the audience that the film hits to the core, but finding words for what exactly hit them, was difficult. Somehow, finding a place for the things that always elude you is important... I like to look for what lies between the folds, for the holes, for what does not or does not yet allow itself to be grasped in a narrative but which, because of that, is perhaps all the more present. Erin Manning (2016) talks in her book ‘A Minor Gesture’ about the more-than or the outdoing of an artistic research process. Research only becomes research when it can make something emerge/appear that was not there before. “A work outdoes itself when it begins to participate with its conditions for emergence in a way that exceeds expectations, becoming a work in motion” (Manning, 2016, p. 62). Research is seen as an “enacted living inquiry” (Merleau-Ponty, 1962, p. 899. cited in Springgay & et al., 2005).

Cutting up and recreating through imagination

In my cupboard, I always have strange objects/paper/fabrics lying around. I am not quite sure why I leave them there or collect them, but suddenly, when the time comes, they come in handy. Perhaps the best way to describe my way of working is as a ‘bricoleur’, a concept introduced by Levi Strauss (1962), which involves starting out from the available materials and tools and setting out to make something. A bricoleur works primarily with “des objets trouvés”. He does not plan, he discovers... The material comes to him. He does not invent new concepts but reorders the existing and adapts it to the new circumstances. Using my imagination, I therefore assemble the bricolage in a certain order that can capture a certain atmosphere, in a composition that feels right.

I find strong common ground in the art form “collage”. In a collage, one works with cut-out pieces, which are brought together on a different

medium with different elements, and therefore acquire a different meaning (Chilton & Scotti, 2014). By bringing them in their new context, they can make you look back in a different way, is what particularly attracts me to working with collages. It is fascinating to see “what comes alive in each encounter” (Davies, 2021, p. 110), what new forms of looking (human and non-human) appear in the flow in-between. In other words, there is an ontological dimension to working from research-creation practices “in terms of expanding what is in the world by revealing new layers, permutations of reality, or experiences to be experienced” (Chapman & Sawchuk, 2012, p. 21).

Research-Creation with families of people with labels

“Looking at and collaborating with families of people with labels: what do research-creation practices open up for engaging with families in research and social support?” became my research question that emerged throughout this patchwork.

“Looking at” refers to looking for creative views and incorporating it into research about families of people with labels; creative views can complement purely linear/medical ways of looking at families that include a person with a label. Along the way, I encountered many family members who had undertaken creative work with their labelled family member as part of a search for relationship. For example, I discovered family members who made interesting podcasts with a collection of accurate records of phrases/sounds made by their family member with a label who used words infrequently or in a different way (cf. Dillen, 2019, Mulier; 2015). One mother who was an opera singer created an opera performance using the sounds of her child with a disability (cf. van Beek, 2016). Some fathers/mothers who were cameramen or documentary makers, decided to make a film about their son/daughter that deviated from the norm (see. Boland, 2005; Hiddinga & Blume, 2012, Habib, 2007). Some sisters of people with disabilities started a website with instructional videos around smog gestures (see <https://smogjemee.be/>). When I started paying attention to it, I discovered more and more creations born out of family bonding and disability.

“Collaborating with” refers to literally getting creative together and how this can be incorporated into social practices. In this study, in addition to my own family, I worked with three other family members of people

with labels who incorporated this into their creative approach as artists. Invariably, my entry point during these encounters was the common search underlying creative activities undertaken within our “special” families. At the meetings with the family members, a special energy was in the air. We both felt the urge to make something together and to reflect on our family nest and our creations. Using each other’s artistic work as an entry point, we engaged in conversation, not only through words but also by creating together. What this creation would look like, took shape differently each time we met.

The making processes tell something about a relational search of the family members of people with a label. It tells something about the relationship with their family without locking their family member with a disability into one particular discourse. Growing up, disability, families, ... these themes can be difficult to talk about. Using fantasy and creation as a point of entry makes it possible to provide scope for affective knowledge that goes beyond words. “It was a knotting and twisting of different modes of knowledge generation” as Nolas & Varvantakis (2018, p. 1) put it. The creation processes illustrate the complexity of the “family assemblage” at that moment in time. It is a different way of approaching the topic than if you were to ask the family members to tell you who they were or what growing up/creating together is/was like in their parental family. “What else can artistic practice become when the object is not the goal, but the activator, the conduit towards new modes of existence?” states Manning (2016, p. 46). I was very careful not to overanalyse their artistic work into fixed meanings. It was very important to walk through a process of creating together, searching together for new modes of existence. The search is more interesting than the finding or result: “It is not about representing a final structure, but rather it is about constructing a map as a field of play to experiment on” (Kinchin & Gravett, 2020, p. 39).

It is fascinating to be able to follow the different processes, each of which has its own rhythm, and to search together for a suitable form, not to lay down the form beforehand but to let it appear from the encounter. Such encounters require a different approach to time than we are used to. They require an experimental attitude. They require enduring a slowness that provides scope with which to follow the rhythm of what emerges relationally. Sometimes you do not know where it will lead you and it seems like

it is going nowhere. Yet this different rhythm can offer openings to the unknown (Manning, 2009). Truman & Shannon (2018, p. 62) talk about “‘queering chronological time’ as temporality that disrupts the regular space-time delineations”. I and my fellow research-creation researcher Inge Blockmans, call this process “turtle time” or “becoming a turtle”, due to the fact that as a researcher, you have to dare to slow down in order to look closely and listen to what emerges from the encounter (see patch nine). “To enjoy the processual force of time, it is necessary to take time, and to give time” (Manning, 2016, pp. 57-58).

Patchwork outline

Patch 1 LODE'S CODE. My dissertation began with experimenting with animated film. When I graduated as a special needs educator, I started a course in animation film with one goal: I wanted to make a film about my brother Lode. Supported by a Vocatio scholarship, I got started. By using my father's letters and family images that he collected over the years; my mother's and brother Lode's sound fragments; my brother Toon's music jams; Lode's drawings and movements, a hybrid animation-documentary titled ‘De Code van Lode’ emerged. Finally, I chose to have the film end on a “line of flight” (Deleuze & Guattari, 1987), at the moment I myself leave my parental nest. At a point of uncertainty, a point of searching for a new relationship with my family and my oldest brother Lode. No explanations or solutions, but subjective experiences are at the foreground. The film has been shown in many places and occasions: from conferences on qualitative research, to students of Educational Sciences, at study days for parents of children with labels, at short film festivals and at a poetry festival. The screening venue and the audience ensured that the film was always transforming, and new encounters emerged that further propelled my research.

Patch 2 FAMILY MACHINE. The second patch of my patchwork rightly returns to the film ‘Lode’s Code’. Not in order to enclose it with fixed meanings, but to discover new layers. This time, we zoom in on the film-making process itself. What can the shooting and editing process of the film tell us? Can we see this as a form of qualitative research? What contribution can an animated film make as a research medium? What happens to the film when

we apply Deleuze & Guattari's concepts of 'rhizome' and 'machine' (Deleuze & Guattari, 1998)? What layered codes emerge, how do the different family codes intrude into the family machine, and how are they set in motion?

Patch 3 FIRST FOLDS. The third patch consists of a collage on paper titled "First Folds". The graphic work was shown at the exhibition "Ongehoord, over kleine interacties wanneer woorden niet vanzelfsprekend zijn" (Van Goidsenhoven, 2021) at Museum Dr. Guislain. The image is accompanied by a short text based on the chapter 'Re-touche' (Vandecasteele, 2021) from the accompanying book of the exhibition. "How are we folded throughout our culture and how does something always remain unfolded" is a question that appears throughout the work.

Patch 4 RE-TOUCHE. The fourth patch departs from meeting the theatre/television actor and screenwriter Mathias Sercu. He created the television series 'Marsman' (Sercu, 2014). The series is about a man over fifty who decides to take care of his adult brother with autism when their mother is no longer there. The question arises: is this situation going to be able to continue? Between 2014 and 2017, I engaged in conversation with Mathias about Marsman and the link to Mathias' family nest. The series is inspired by the screenwriter's own family experiences. Mathias Sercu comes from a nest of seven children and has a brother himself who was once diagnosed with autism. We met each other at a pre-screening of Lode's Code. Sercu came to talk about Marsman, and I about my film, which was still in production at that time. We immediately had a common ground. We both created something from our 'special' brothers and this is how our collaboration started.

In this patch, the dual thinking in terms of abled/disabled was ignored by taking 'affect' and 'creation' as entry point. The world of etching and stitching was used to bring together different layers: the scriptwriter's biographical story, the making process of Marsman, Marsman's script, this in combination with my own associations, without lapsing into explanatory logic. By literally working with layers, while drawing, etching and stitching with a stitching machine, the concept of re-touch was explored. About touching and being touched, always returning to family fissures from which something new is created.

Patch 5 FAMILY NEST. The fifth patch consists of monotypes based on conversations with brother/scriptwriter/actor Mathias Sercu (2014) and

fragments from Marsman, in which the concept of family nest forms a common thread.

Patch 6 A VISITOR IN YOUR HOUSE. The sixth patch starts from the encounter with sister & visual artist Ted Oonk. Oonk makes photographs and video installations of and with her youngest sister who was diagnosed with Down's Syndrome. We met at a social-artistic project that revolved around the existence of the NIP test (non-invasive prenatal test) that can detect conditions such as Down's Syndrome). We both became just mothers ourselves. Ted had a son and I a daughter. Meanwhile, my oldest daughter can already talk. "Mommy, are you going to grow?" she asks me. This question brings me back to Ted's family photo collection 'This is not about you'. Ted started this collection in 2005 and is still adding to it (Oonk, 2005-present). Pim, Ted's sister, lives in the Netherlands, Ted herself lives in Belgium. Ted invariably has her photo camera in her pocket when she is with her sister Pim, "so I can hold the moments of being together a little longer," she confides to me. The photographic work consists of images taken through three different lenses. The lens of Ted Oonk herself, the lens of Pim Oonk taking selfies and the lens of their mother, as Ted selects photos from the family album that their mother once took. Our collaboration started in 2016 and continued until 2021. From the search as 'the sister of' and 'becoming a new mother', a correspondence by letter emerged, in which we shared memories from our childhood, including small events and small creations around our mother/sister/daughterhood. Each time, we began by asking each other a question. Soon we noticed that motherhood does not exist in isolation but is entangled with the position of being a sister and daughter and the intergenerational entanglement of the present, past and future in looking at difference/disability and care comes out very strongly.

Patch 7 AMONG SISTERS. The seventh piece consists of monotypes based on conversations with Ted and on her creative work. The monotypes were turned into a dialogue with photographs from Ted Oonk's family photo collection 'This is not about you' (Oonk, 2005-present).

Patch 8 ENTANGLED. Patch eight is about the encounters with Terre Mulier, a word artist who made the podcast 'Geduld Californië'(2015) about Bram, his brother who communicates through Walt Disney stories. Bram waited a long time to speak. In the Disney stories, he found the words to express himself. Terre was given the assignment to create a podcast as part

of his education in Drama. He saw this as an opportunity to participate in his brother's big dream: to become a voice artist like Mr. Walt Disney. However, Terre was left with a lot of ethical questions after making the podcast. We experimented together with images and words in looking for what is going on within a family with a label. The word 'entangled' arose. The entanglement of siblings, the entanglement of Terre's family with Mr Walt Disney, etc. The question of what we leave behind when the research ends also continued to reverberate.

Patch 9 TURTLE TIME. My ninth patch is a dialogue with my fellow researcher Inge Blockmans who also embarked on a research-creation path. For five years we shared a "landscape island" at the Department of Special Needs Education at Ghent University. We both started out from a different approach, but we grew closer. Without realizing it, each other's presence was very inspiring to break through linear ways of research. Intuition and creativity were resolutely at the forefront of our approach. In both our studies disability is a component, but it is never in the foreground. Rather, disability was seen as a relational concept. We explored together through a playful conversation concerning the consequences of this in our research.

Patch 10 IN MOTION. Finally, the discussion continues by means of a lively conversation with colleagues, students, art teachers and people involved in socio-artistic practices. Together, we looked back at the research process, at the threads that emerged and discussed the opportunities that such research can offer for further qualitative research and when working with families of people with disabilities in various special needs practices.

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