RE-TOUCHE: RE-STITCHING FISSURES THROUGH AFFECT IN FAMILIES WITH A FAMILY MEMBER WHO IS LABELLED AS DISABLED

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Abstract: Creativity and affect in families with a family member, who is labelled as disabled, is central in this article. These families are often pinned down to individual, closed categories where everything revolves around the label "disability." Our research goes beyond binary thinking in terms of abled/disabled and other linear explanations by using artistic processes as ethnography. We start from encounters between two people who both created something about their "non-ordinary" brothers. One (first author) made a shortfilm/documentary about her own family, the other (research participant) wrote a TV series about a man who takes care of his brother after their mother's death, which was not autobiographical yet inspired by his own experiences. The first author distilled etchings from their encounters, which piece together different layers: the scenarist's biographical story, the story of creating the series, the series' script and the first author's thoughts and readings. The concept of *re-touche*—of touching and being touched, and in this way returning to family fissures and creating something new from them—runs through this art-based project.

Keywords: arts-based research; siblings; disability label; family fissures; creating; affect

"I want to recreate, recreate the past. To be active instead of passive."
(Bourgeois, (n.d), as cited in Gorovoy, 2015, p. 6)

Disability and Families

Family stories. They touch me… or do they re-touch me? Touching—being touched—retouching—and never being the same again because of it. *Re-touche* offers an angle to the fascinating journey of families whose lives somehow do not fit within what is considered "normal" due to the presence of a sibling who is labelled as disabled. Disability is present and has a place within the family. It brings doubts, tensions, fissures. Fissures, however, are rarely static. They rotate in the Deleuzian family machine and drive the machine to start or continue moving. This constant search for movement fascinates me. What do brothers and sisters create from and around potential family fissures, not just once but continuously, as an everlasting nomadic process that can touch people and invites us to create?

Brothers and sisters of people with disabilities are often described as "the invisible children" (Naylor & Prescott, 2004). They have their very own, wise stories about growing up with their sibling with a disability label, and yet they tend to be overlooked within Disability Studies. When I introduce my research about siblings of people with disabilities, the most frequent response is a whistling sound of effort: "That must be a tremendously heavy burden for a family, having such a family member." And immediately afterwards: "What is wrong with your brother?" This is the dominant tone of research around family and the disability label: the focus on *labelling*, *family stress*, *family burden,* and *coping strategies* as popular key words (Blancher et al., 2005; Damiani, 1999; Hassall et al., 2005; Nixon & Cummings, 1999; Roper et al., 2014; Sharpe & Rossiter, 2002; Smith & Elder, 2010). The *ABCX-family stress-coping model*, originally developed by Reuben Hill (1949), has had an impact on the Family and Disability field. The model facilitates mapping the stress factors of families with a family member with a disability label, indicating how family members cope with the extra stress triggered by the disability label of their brother/ sister/father/mother/… (Salviita et al., 2003).

The linear way of thinking about families and disability labels that seeps in through the use of this model has been criticized by Philip Ferguson, Disability Studies author and parent of a child labelled as disabled (Ferguson et al., 2000; Ferguson, 2002). The ABCX model is argued to depart from a deficit/ableist viewpoint. Siblings without disabilities are approached unilaterally as victims because of the presence of a disability label in their family, which is often associated with deficit and treated as something individual and static. The concept of *coping*

creates the illusion that family members can learn to give the disability label a fixed, stable place, or solve a *problem* and accept their family member "as who he/she is." A disability label does sometimes bring extra family challenges, but that is not the only possible story line.

From a Disability Studies angle, we plead for thinking beyond binaries in terms of abled/disabled. We consider many more threads running through and affecting a family, including the thread of the disability label potentially creating openings within a family (Connor & Berman, 2019; Cavendish & Connor, 2017; De Schauwer & Davies, 2015; De Schauwer et al., 2021; Ferguson & Ferguson, 1993; Murray, 2000, Ryan & Runswick-Cole, 2008, Van Hove et al., 2009). This also connects with Goodley's approach of describing families with a member labelled as disability as rhizomatic, viewing them not as definitive subjects but as people who defy categorization challenge boundaries, and are always becoming (Goodley, 2007). In line with Margaret Gibson, we want to make room for different stories, stories that resist the rigid narratives imposed by the institution of being a family, the institution of normalcy, and the institution of expertise (Gibson, 2014).

Re-touche as an Arts-Based Affective Patchwork

The TV-series *Marsman*,[1] written by Mathias Sercu, was broadcast on the Flemish public television channel *Een* in 2014.

Marsman tells the story of 40-year-old Nico Marsman, who takes care of his autistic [*sic*] brother Rudy after the death of their mother. We step into the story at the point where, on top of everything he loses his job and his wife tells him she needs a break. From now on he's on his own. Nico wants to get back on track as soon as possible, but where to start? Luckily he can count on his friends Marc, Peter and Ludovic with whom he plays in a band called "De Mannen Van Mars" (which translates loosely to "The Martians") and his 20-year-old daughter Femke. Step by step, Nico tries to climb up the hill and find a lasting solution for his brother. Marsman is a tragic but also funny story about choices and relationships, loyalty and friendship, about unconditionality and doubt. (Verbeeck, n.d.).

This creation touched me deeply. Rudy repairs old bras in his mother's lingerie boutique. He lovingly calls these repairs "retouchkes." Rudy was a "retoucheur." RETOUCHE: French for repairing clothes and works of art. The word spoke to me. RE-TOUCH(E). The first scene Sercu imagined is the start of a puzzle journey. Brothers Rudy and Nico Marsman are facing each other around a table.

"Shall we play cards?" Who are these brothers? Why are they together? Why do they live there? Is one of them married and the other one single, and is one of them labelled as autistic and the other one not? *Marsman* has, at its foundation, the death of a mother, a turning point in Nico's life. He decides to return to his parents' home to take care of his brother Rudy. They reopen the lingerie shop so that "Uncle" Rudy can continue doing what he was used to doing: retouchkes. Nico has a special gift: he continues to see his mother (despite her passing) and she remains his interlocutor with whom to share his doubts. Unfortunately, there is also a real estate agent who covets the premises of the lingerie shop. The real estate agent wants to build a new, modern complex. Rudy is not keen on this. He is very attached to this house; however, Nico feels that he cannot look after his brother permanently.

In real life, Mathias Sercu grew up with a brother labelled with autism. His story about "being the brother of" reflects my own story, and offers me a glimpse of a possible future 20 years from now. I, too, have a brother labelled with an intellectual disability, which inspired me to make the film "De Code van Lode" in 2016. It was the result of an intense four-year journey searching for the story I longed to tell, and for my positioning as a researcher/sister.

It was intriguing to see the various effects my film had when screened: it moved and touched people (and myself) or invigorated them, depending on the screening place and the audience. The film stayed the same, and yet it became something different every time it was shown in another place. One of the most peculiar locations was an old hayloft at the Watou Art Festival in a remote little town in West-Flanders, Belgium. The cracking sound of the wooden floor and the shape of the rooftop invited the audience literally into the film. Lode's Code was shown in a loop, so the audience could decide when to step in and when to leave the room. I noticed that many people remained seated after the film had ended and watched it several times. The looping of the film and the movements of the people disrupted the linearity that often comes with a film screening. A totally different experience was created during a screening at the International Congress of Qualitative Inquiry (ICQI), where the audience asked me about my arts-based research methods. Yet another was created at a study day for parents with children labelled as disabled. Remarkably, people were always eager to share stories about their own experiences involving a family member who deviates from the norm.

This is how I met Mathias Sercu. He told me after such a screening moment about his own "remarkable brother." Even though he did not know me at all at that point, he had recognised himself in the story. Sercu is a versatile artist himself. As a theatre and television actor, musician, and scriptwriter he cannot be forced into one

box. I became curious about his incentive to write the *Marsman* series. What touches him, being "the brother of?"

From November 2014 to December 2016, I had the opportunity to build up a long-term dialogue with Sercu about growing up with his brother labelled as disabled, and his artistic work. He was first inspired to write a piece about autism when his brother went to live on his own in the care facility that their parents had founded. Sercu challenged himself to write a piece about autism without explicitly referring to autism. He, being "brother of," was often asked (by people including his classmates): "What is autism, actually?" He was never able to reply, and this might have fuelled his interest in writing a story about it. The television series aims to offer the audience encounters with Rudy and his autism label in a casual way, without explaining.

Marsman is not Sercu's only artistic work that touches upon autism. It grew out of his theatre piece *Frederik*, in which the two main characters were labelled as autistic. The seeds for his artistic work are very often the things that he encounters in his daily life and which touch him. He emphasises that his work is not literally about his labelled brother and himself: it is based on his experiences, but his imagination roams freely. Moreover, *Marsman* is not solely about someone with an autism label. The series is much more about relationships between people, one of whom happens to have the label.

How can I handle the stories given to me as respectfully as Mathias Sercu handles stories and people? Cautious about being trapped into explanation, I am hesitant to devote an academic paper to the topic. How can we develop methodologies that enable researchers to study the affective processes in relation to what they are studying? This question has already been raised within Cultural Studies in discussions about the affective turn within qualitative research (Clough, 2007; Knudsen & Stage, 2015). These authors engage with the following question: "How do you identify affective processes and discuss their social consequences through qualitative research strategies if affect is bodily, fleeting and immaterial and always in between entities or nods" (Knudsen & Stage, 2015, p. 2)? How can new kinds of embodied knowledges find their place within academia? Descartian dualism is still remarkably dominant within academic research.

In line with post-feminist directions (Ahmed, 2004; Blackman, 2012; Leys, 2011; Wetherell, 2012;), I search for ways to disrupt and by-pass the dichotomies between "mind and matter, body and cognition, biology and culture, the physical and psychological" (Law, 2004, p. 3). In this way, new forms of research can be found which allow embodied knowledges "to grasp the messiness, ephemerality and unpredictability of social life" (Knudsen & Stage, 2015, p. 2). One field of research

that can offer methodological tools and guidance is *Arts-Based Research*, described by Patricia Leavy (2015) as follows:

> Arts-Based Research practices (ABR) are a set of methodological tools used by researchers across the disciplines during all phases of social research, including data generation, analysis, interpretation, and representation. These emerging tools adapt the tenets of the creative arts in order to address social research questions in holistic and engaged ways in which theory and practice are intertwined. (p. 4)

Arts-Based Research is meant to enhance perspectives pertaining to certain human activities (Barone & Eisner, 2006, p. 95). The term Arts-Based Educational Research (ABER) was introduced by Barone and Eisner to use Arts-Based Research in educational contexts. In other words, my research process can be seen as ABER. Rather than seeing art and science as two opposites, ABER looks at what new knowledges this combination can offer to pedagogical research. Leavy (2015) draws our attention to the fact that these fields are not as different as we might think at first sight:

> There are many synergies between artistic and qualitative practice. In both instances, the practioner may aim to illuminate, build understanding, or challenge our assumptions. For instance, artists and qualitative researchers alike may aim to illuminate something about the social world, sensitively portray people and their circumstances, develop new insights about the relationships between our sociohistorical environments and our lives, or disrupt dominant narratives and challenge biases. (p. 17)

The space in between arts and science literally gives me, as a researcher, room to move and not be fitted into a methodological straightjacket. The in-between space characterising arts-based education research offers possibilities to deviate from a predefined path and, in my case, to explore the stories and creations of Sercu with sufficient openness. Barone and Eisner (2012) emphasise that Arts-based (Educational) Research has an eye for detail that we might otherwise overlook:

> It addresses complex and often subtle interactions and that it provides an image of those interactions in ways that make them noticeable. In a sense, arts-based research is a heuristic through which we deepen and make more complex our understanding of some aspect of the world (p.3).

Arts-based practices are transdisciplinary, with method and theory being blurred and challenged (Leavy, 2011). Theory is contained in form. Shape and

content are deeply interwoven. "A rigorous arts-informed 'text' is imbued with an internal consistency and coherence that represents a strong and seamless relationship between purpose and method" (Cole & Knowles, 2008, p. 67). The search for an adequate shape is an affective journey. As Leavy (2015) states: "Qualitative researchers do not simply gather and write; they compose, orchestrate, and weave" (p. 17). The researcher attempts to grasp something that cannot be measured. It is a different kind of knowledge than the measurable knowledge with which we are traditionally familiar. It is about subjective and holistic knowledge of experiences (Eisner, 1997). Research that "goes to its core. Research is penetrating: it is sharp in the manner in which it cuts to the core of an issue" (Barone & Eisner, 2012, p. 148).

This reminds me of Donna Haraway's (1988) comparison of research to a conversation with one's ecology. Haraway departs from the idea that researchers create the world. They engage in a dialogue with research data which implies that researchers are part of their research—you touch and you are touched. Maggie MacLure (2013) describes affective/creative moments in research as moments where data "glow": "during the process of coding, some things gradually grow, or glow, into greater significance than others, and become the preoccupations around which thought and writing clusters" (p. 175). This can start from something small. By zooming in on one small element a whole new world—which was previously invisible —can open. This way of working can take the researcher/maker, the participant, and the audience, on a trip to a hidden world they were not aware of (Eisner, 1997).

These affective methods in arts-based (educational) research offer opportunities to introduce people to the multiplicity of reality (Leavy, 2015). I am drawn to the transformative power of visual arts. Visual arts are powerful, and speak in a way that is different from written language. For example, painter Edward Hopper said: "If you could say it in words there would be no reason to paint" (Hopper, n.d. as cited in Leavy, 2015, p. 228). Anthropologists have a long tradition of using the power of images to collect and represent data (Leavy, 2015). Images are open to multiple interpretations, they can make people look at things differently. I have chosen to move away from animated film—the medium with which I am familiar, and which I used for my autoethnographic family research (Vandecasteele et al., 2019)— and dive deeply into another visual arts-based practice: the world of making collages (Leavy, 2015).

I experimented with different printing techniques, combined with stitching and using a patchwork of fabrics. Collage means *glued work* in French. Collages are made by selecting images from magazines, newspapers, textured papers, or other sources, and then cutting, placing and attaching them (often with glue) (Chilton &

Scotti, 2014). I, however, stitch my collages together with a stitching machine on a surface of a piece of paper, fabric or cardboard, and combine them with different printing techniques such as monotypes and/or etching. The time-consuming nature of etching forces me to take a longer look at a single image and to immerse myself in it. The advantage of etching is that, once the board (the negative) is made, it is very easy to print several copies of the same image and experiment further by covering/ cutting out/adding things. With every transformation, new ideas can emerge (Chilton & Scotti, 2014). As Leavy (2015, p. 235) puts it: "Collages often bring disparate elements together and can be a powerful way of jarring people into thinking and seeing differently, performing cultural critique, producing connections of refining or enhancing meanings."

What draws me to working with collage is that it allows old objects to be transformed by pulling them out of their context and giving them new life, while always retaining an air of alienation that resonates with the complexity of human relationships. One of the most famous collage artists, Pablo Picasso, describes it as follows: "In collage the displaced object has entered a universe for which it was not made and where it retains, in a measure, its strangeness. And this strangeness was what we wanted to make people think about because we were quite aware that the world was becoming very strange and not exactly reassuring." (Brockelman, 2001, pp. 117-118, as cited in Vaughan, 2005, p. 31).

My stitching machine and graphic techniques assist me in *re-collaging* words and sentences from conversations with Sercu, not to capture meanings, but to bring them to life (again) by stitching and etching (see Figure 1).

It was impossible to anonymise our research as we worked with the published series of *Marsman*, with a publicly known author. Ethical vigilance was an absolute necessity. I followed Neuman (2011) and Claes (2014), who state that the quality and ethical acceptability of research increases when control over the research process is given to the participant as much as possible. Sercu gave me full freedom to process and experiment with his family photos after our conversations. I regularly communicated with him about which material I would be working with and how (in which form) it would be shared. Permission had to be renegotiated during every stage of the research. Rallis et al. (2007) rightly state that informed consent is much more than a procedure: it involves building a relationship of trust. I also concur with the relational ethical research advice described by Ellis (2007):

> We do not act on principles that hold for all times. We act as best we can at a particular time, guided by certain stories that speak to that time, and other people's dialogical affirmation that we have chosen the right stories…. The

best any of us can do is to tell one another our stories of how we have made choices and set priorities. By remaining open to other people's responses to our moral maturity and emotional honesty … we engage in the unfinalized dialogue of seeking the good. (p. 23)

Figure 1

Re-touche

I was mindful of the need for sensitivity in representing the multidimensionality of Sercu's stories. The fact that arts-based methods were used here created opportunities to make the personal stories more universal so that other families could also identify with Sercu's story. I also felt it was a matter of ethics to acknowledge and portray my own vulnerability and role as a portrayer (Leavy, 2015). Our

encounters were interactions in which we were both touched by each other's stories emerging in those very moments. I did not set out to strictly analyse or represent the meanings attached to Sercu's artistic work and his biographical story. Rather, I created a patchwork, an experiment to make something of of the understanding we shared being "brother or sister of/to." This patchwork is not to be seen as static and final: it is a temporary explication of an on-going process, an open-ended experiment.

Several Layers of the Re-Touche

Rudy Marsman sees himself as a retoucheur. Re-touche. Touche… The word resonates. It touches me and re-touches me. I sense that it can be the guiding thread woven through this written patchwork. Through the process of etching, several layers of the content and shape of *re-touche* come to the surface (I made a short video in an effort to keep this process alive in some way). In the following sections, I will explore and describe these layers extensively.

The Touch of the Warm Nest

The word *re-touche* puts forward touch. It is a sensitive word, both fragile and direct. It touches, it stirs, it comforts. You can feel it, but you cannot capture or hold it… It causes a strange sensation. Karen Barad (2012) talks about touching as an invitation that brings you closer to the otherness of yourself:

> When two hands touch, there is a sensuality of the flesh, an exchange of warmth, afeeling of pressure, of presence,a proximity of otherness that brings the other nearly as close as oneself.Perhaps closer. And if the two hands belong to one person, might this not enliven an uncanny sense of the otherness of the self, a literal holding oneself at a distance in the sentaion of contact, the greeting of the stranger within? (p. 206).

The word *retouche* proved a fruitful entry to my conversations with Sercu. It affects something inside of me that I cannot grasp in words. It pushes me to reflect and create. Barad's idea of invitation speaks to me: re-touche is an invitation to jump into a world that you might know very well but which you simultaneously do not wish to know.

Sercu's family picture is vividly engraved in my mind. It is an image of his mother with all her children, on the sofa (See Figure 2). The warm family nest: that is how Sercu describes the family he grew up with. The mother with her little ones in her lap. She is present, watching over them. Her posture, her arm slightly stretched.

Sitting together in the sofa for the family portrait breathes out comfort and security. Mathias Sercu comes from a family of seven children in a small country-side community in Belgium. He was number five in line. Numbers three and four are twins. One of them received the label of autism later in life.

Figure 2

The Warm Nest

Their father owned a printing business in the garden of their home. The garden adjoined their grandmother's garden, and the children could visit her through a hole in the garden wall. Sercu's mother quit working after the youngest was born. Madam Adrienne was invited into the family to help, and became part of the nest. Sercu's father was the youngest of ten and his mother the oldest of seven, so Sercu had many cousins; his childhood was characterised by circulation within this big family. In primary school, Sercu played a lot with the twin brother without a label. Nearly every Wednesday they played at a farm nearby. In summer, they romped around in the hayloft or raced on their bikes through wasteland and, in winter, they played in the hay with the cows. The twin brother without a label was Sercu's buddy; they were always together. When they were teenagers, they formed a rockband.

Watching the *Marsman* series, I recognised the lively nest feeling that Sercu described in the narration of his home. *Marsman* follows Nico and Rudy Marsman, two brothers in their forties. Rudy is labelled with autism. He loves routine, structure, and order. *Retouchke*s (i.e., the repair and/or adjustment of clothes) offers him both peace and social contact. His brother Nico senses that their parents' house is extremely important for Rudy, so he decides to return and take care of his brother there. This enables Rudy to do what he was used to doing: repairing lingerie. Nico's former partner Vera is not up for moving with him, which accelerates their break-up. Nico's 20-year-old daughter Femke and her girlfriend do move with him to the family nest, and, as co-nesters they assist in taking care of Rudy and the lingerie boutique. Nico's music colleagues, De Mannen Van Mars (translation: The Men from Mars), are very supportive friends among whom Nico can vent. And then there is Rosa, a regular customer who takes up an important function in the Marsman family. She knows Rudy well, and helps by translating to outsiders (e.g., in the grocery shop) which helps Rudy to calm down when he is panicking.

The warm nest in Sercu's autobiographical story and in his fictional story, *Marsman*, resonates with the nest I grew up in. I come from a tightly-knit family where we share our joys and sorrows. There are also many other people around us (such as my brother's personal assistants, the cleaning lady, and others) who belong to our nest. Similar to the vibe in the *Marsman* series, there is a touch of nostalgia in our nest. We share a preference for everything to remain as it once was, and a strong belief that rifts and cracks should be avoided as much as possible.

Fissures

The word *retouche* also leads me to fissure or tear. The layer that is usually hidden by re-touching it. A fissure tends to be framed as something painful and difficult, accompanied by fear. It exposes, reveals. It does not speak, yet it is alive. People carry fissures with them through their lives, sometimes over generations. Haraway (2016) takes us back to the 13th century meaning of the word *trouble* in French: stirring up, obscuring, disrupting. Trouble disturbs the "normal," what we are used to. It makes expectations less clear and simultaneously inspires the need to be creative and search for alternatives. What if we "stay with the trouble" or fissure, rather than repairing it according to a normative pattern? What can the trouble/ fissure tell and teach us to rewrite and re-create (Haraway, 2016, p. 1)?

Every family has its fissures. Sometimes they become visible, but often they are hidden under layers of rigid retouching. Haraway (2016) refers to "a risky game

of worlding and storying" (p. 13) that helps us to stay with the trouble. The risky game is about "giving and receiving patterns, dropping threads and failing but sometimes finding something that works, something consequential and maybe even beautiful, that wasn't there before" (p. 13). These patterns, "attached to ongoing pasts, they bring each other forward in thick presents and still possible futures" (Haraway, 2016, p. 133).

I was drawn to touch this fissure carefully through creation. I decided to add an extra layer to the received photograph with tracing paper, which is often used to copy drawings/photographs or divide them in layers for etching or silk screen printing. While I was etching, I did not trace everything exactly, but only those details that felt relevant at that point in time. The drawing became more abstract: only the mother and her children's heads remained, and I played with the idea of a nest by transforming the sofa into a bed of hay. The hay radiates warmth and security, offers a place to hide for the children as well as protection against danger, like a bird's nest. The mother keeps her nest close in her arms: "Come a little closer" (See Figure 3).

Figure 3

The Fissure

I also noticed, however, the distance I created by leaving out their facial expressions and using grey pencil. All my travels with my drawings have worn out the tracing paper, now featuring tears. The tear/fissure presented itself to me as a metaphor to talk about fissures or moments of transition within families. Often something is torn apart because it is under pressure, because the fabric can no longer move sufficiently.

Both in Sercu's family and in the *Marsman* series, I sensed a certain kind of tension in the family nest. One fissure that surfaced strongly in the biographical story of Sercu was his experience of unfairness; he did not find it fair that his brother labelled with autism never received the same opportunities in the warm nest. He found it appalling. His brother was the only one of the seven children forced to go to boarding school. Sercu remembers his mother telling him about the moment that their brother got on the school bus. She told him that when he was looking at his parents from his spot on the bus, he seemed to look right through them, with a gaze of non-recognition. A crack each time, their hearts breaking.

Another of Sercu's memories takes us back to his mother telling him about the moment that their brother with a disability label was at home for three weeks because he had pneumonia. The mother spent much more time with her son than usual during that stay because of a parental feeling of guilt. If the children in the Sercu home were ill, they were welcome in the parental bed. The windows would be open just a crack, letting through the sound of children playing outside on the local school grounds. There was also a piano in the room. That day their mother was playing piano for her labelled son. Suddenly he jumped up and asked: "Aunt Bietje" (that is how he called his mom), "What is worth more: a mother or an attendant?" Their mother, puzzled, replied: "A mother, of course." "Then why do you send me to a boarding school?", he bounced back. In those three weeks at home, he called his mother "mother" for the first time ever. Towards the end of that period, the family doctor examined Sercu's brother and declared: "You have recovered. You can return to school." Immediately, their mother was "Aunt Bietje" again. Sercu told me this story repeatedly. He empathised with his mother's pain, the pain she felt when her son addressed the issue that she might not be present enough as a mother to him. Mathias Sercu was not forced to go to boarding school. And, as a teenager, he could easily leave the nest when he considered that time had come. For his brother labelled with autism, this was more complicated. Living on his own would be impossible; he needs some level of support.

Sercu talked about their parents' anxiety: What about when they cannot be there for him anymore? Organisations offering this support have long waiting lists. Realising that not all of their children had equal rights to leave the nest, their parents

decided to set up a place themselves for their son labelled as disabled. At present, Sercu's brother has lived there for 14 years, together with eight other people labelled with autism. Sercu's brother remains ambivalent about the place. He calls it his home but, if he could choose, he would rather not live there. "Everyone has this feeling once in a while, of wishing to leave," Sercu says. "We simply have the possibility to choose. He does not have this possibility… I have my house, my motorbike, my van, a job that I like… I live the life I want to live. My brother with the label of autism lives in a residential entity where he is not happy, although he knows it has good aspects. He has found peace with my father's explanations… but sometimes it makes me unhappy to read his e-mails about the new Ford Neo Connect with a raised roof, the most magnificent car ever, about his computer freezing again… and then suddenly in one email 'The evenings are long, I feel lonely'… It touches me deeply."

The scene that touched Sercu most deeply was one featuring the word "leefgroep" (translated: adult care group, community group), when Rudy stops sewing and realises: "I will not be allowed to stay here…" Nico Marsman gently states: "There might be other places where you can live, a cool community for instance?" Rudy looks his brother straight in the eye: "I don't want to!" For Mathias Sercu it feels like betrayal. The betrayal of the older brother. A solution is urgently needed. The situation with the two brothers in the parental home cannot last. Nico Marsman will not (be able to) take care of Rudy indefinitely. That is not how things go. Nico is neither Rudy's father, nor his mother. He is Rudy's brother. Rudy knows it somehow, but it still hits him hard. Nico cautiously approaches the topic. He senses the uncertainty, the pain, the abandonment… an image that does not leave the beholder untouched.

The community group scene and the way Mathias Sercu talked about it afterwards also touched me. What if my parents were no longer around? How would we deal with the family rift that will probably appear? Currently my brother with a label still lives at home and is very attached to his fixed habits; he reminds me of Rudy. My brother needs space, space to move. Somehow the thought of my brother living in a care facility worries me. I imagine it to be clouded in a rather distant atmosphere, an overwhelming contrast with what my brother is used to. He is not a group person, so he often clashes with the rules of institutions. I also fear that it will be more complicated to directly contact my brother. I could take on a role in this as a sister, but what could that role be? Would I do the same as Nico does for his brother Rudy? What expectations do my parents carry about this? It is a subject laid bare in this scene.

The "Re" in "Re-touche"

Figure 4

Re-touche

The preposition "re" catches my attention. "Re"; "again"; the ceaseless process in which movement is central. Tears can be processed and re-covered, yet

we never return to what once was before the tear, thereby introducing a new dimension. Karen Barad (2014) talks about *re-turn*. Returning to, in order to turn it again, and hence to re-create:

> By going forward to the past—not in order to recount what once was, but by way of re-turning, turning it over and over again, tasting the rich soil from ideas spring, and opening up again to the uncountable gifts given that still give, to proceed to the place from which we never left/leave. (p. 184)

Fissures/cracks that have been carried along for a lifetime are re-turned to and take up diverse shapes in the process of creation. The role of fantasy offers the opportunity to visualise alternatives of thought and action in seemingly hopeless situations. As Donna Haraway (2016) encourages: "We need stories and theories that are just big enough to gather up complexities and keep the edges open and greedy for surprising new and old connections" (p. 101). To re-turn and re-create we need imagination with an open ending. We need an attitude and processes of receptivity towards the unknown (Barad, 2012).

In this stage I wished to re-create the image of the warm family nest I received from Sercu by etching it. I chose abstraction, and only kept the mother with the child on her lap in red-brown ink. Abstraction makes the image more universal for me. I continued working on the print by stitching the baby's body with my sewing machine. Stitching softens it somehow. With the yarn, I carefully try to restore the sensation of the nest. The sound of the machine allows me to be guided by the machine itself. Where will it take me? Lengthening the mother's hair, I noticed the birth of a veil. Suddenly an iconic image of a mother appeared (See Figure 4). The association with Mother Mary and her child seemed relevant, given that Sercu's brother is fascinated by Russion icons, and a Russian Mary image hangs above his bed. The image radiates warmth and security yet also mystery, something powerful that cannot be captured.

Similarly, the writing of *Marsman* is like stitching a veil that hides many meanings which, in turn, hide other meanings. So many layers have not been tapped into. Sercu dreams about creating a warm place for his brother. He sees *Marsman* as a fairytale, a tale in which people like Rudy can stay and live where they want to live and do what they are good at.

It is noteworthy that the mother in *Marsman* remains visible even though she has passed away. Nico Marsman continues talking to his deceased mother; he feels insecure and he finds safety in the conversations with her. In the series, Rudy climbs the roof, as a final attempt to save their mother's old lingerie boutique. He refuses to

let the boutique be demolished. Nico finds his brother in the gutter and joins him. Mathias Sercu tells me that Nico, at that moment, does not need his imaginary mother anymore and decides to hand her over to Rudy so his brother can always talk to her whenever he is in need. Whilst sharing with me, Sercu noticed that searching for a mother seems to be a red thread running throughout his past and current work.

Sercu's brothers and sister are all in their forties now. Even now the nest remains important and Sercu continues re-creating it. When I ask him about his relationship with his brother labelled with autism, he hesitates. They still go out and about on weekends and Sercu sees the evolution, the growth of their relationship. He has only started realising in the past three years that he is actually the younger brother. He tends to view his brother as the younger one, because of his label and because he is in more need of care. It is only recently that Sercu has taken up a conscious effort to approach his brother as an adult and actively invest in their bond by spending a whole day with him once every two months. Sercu picks him up at the train station and then they scour all the thrift shops in and around Ghent (a city in Belgium) for the keys that his brother likes to collect. They combine it with a coffee at their sister's or brother's place. Sercu and his brother love being on the road together all day long. His brother talks during the whole drive about topics he might not share as easily with others. Sercu currently sees himself as his brother's confidant. He tries to give as little advice as possible and listen. He is fond of his brother's particular sense of humour and enjoys joining in the flow. In between conversations about sexuality, orthodox liturgies, and assistance in the residential unit, they search for their favourite cars. Sercu cannot fully grasp his brother's taste, but that does not matter.

The *Marsman* series and the many conversations I had with Mathias Sercu pushed me to reflect on my own position as a sister of a brother with a label. I increasingly see it as a search, a process, rather than as something I need to grasp and know for sure, and that is refreshing. I try to notice the nuances between black and white: it is not about taking care or not taking care. It is about what works in this very moment. I have become a mother myself and I find it important that my children can spend sufficient time with my brother Lode so they can get to know their uncle. I hope that, over time, more space will become available to go on brother-sister outings as well. Above all, I remember that we can connect in many different ways, and that this connection is always evolving, so there is nothing to fear. Sisterhood should not be pinned down to one fixed ideal, just as motherhood should not be. What happens when we give space to what can still become?

(In)conclusion: RE-TOUCHE as an invitation?

With touch, Mathias Sercu and I started our journey searching for the hidden stories of growing up with a family member who is labelled as disabled. We were immersed in the intra-action that arose (Barad, 2012), and through which traces of a family fissure showed themselves: the searching for a position as *a brother/sister of*. Several layers of such a family re-touch(e) were assembled together (the script of the *Marsman* series, Sercu's biographical story, my etchings); I refuse to secure these layers… Families of people with a disability label are blocked all too often. Both the relationship between Sercu and his brother on the one hand, and my creation around this on the other hand, are still in progress. I find it remarkable that the position of *sibling of* cannot be regarded as something separate that stands on its own. In this arts-based analysis I quickly became aware that there is a tremendous intertwining with parents, family, family context, materiality of the house, past/present/future, etc. As Haraway (2016) says:

> We relate, know, think, world, and tell stories through and with other stories, worlds, knowledges, thinking, yearnings.… We are compost.… Critters—human and not—become with each other, compose and decompose each other, developmental earthy worlding and unworlding. (p. 97)

Without really knowing where I was going, I followed the rhythm of my conversations with maker/brother Sercu and allowed myself to be touched by moments. Moments that I could sense in my body. Moments that were rather difficult to capture in words, but which were strongly present and drove creation. Who are you as a mother, as a father? What does it mean to be a sibling?

With touch/affect as entry, this article explored how scenarist/brother Sercu creates possibilities for his family to remain a family and keep becoming through imagination. Affect can move family fissures as well as new stories, touching other people. We tend to cover fissures, transforming them into stories with happy endings. This makes it impossible for some things to show themselves, things that surreptitiously affect families. In my encounters with Sercu I became aware of how affective moments in a nest can be brought to life through creation, and develop new dimensions—even after years. Indirectly we can re-turn to and work with fissures, and search for re-configuration, softening, re-exploring, re-newing. A path which takes us indirectly back to a fissure is accompanied by fear and requires time. Creations cannot be forced. They are not miracle cures, they do not (dis)solve family fissures. Creations are temporary and never offer conclusive answers (Deleuze & Guattari, 1987). There will always remain small cracks or fissures that are unknown

and/or unpredictable. This openness is not necessarily to be feared; it can function as the motor of movement, the motor of a new creation.

This is how Sercu's story pushed me to create, to etch, to stitch, and to reflect on my own position as a sister of my brother Lode. I discovered that I strongly wanted to capture this position of what-a-sister-should-do and that this felt suffocating. Through the many conversations and by following the flow of my fantasy, it gave me both peace and energy to embrace different ways of becoming a sister, and to embrace an indeterminate searching attitude. I started a tumbler page where I collect all of my little arts-based research experiments (https://re-touche.tumblr.com/). I wish to espouse this searching attitude of creation as a central key in any professional field concerned with caring for people. The path of fantasy can explore challenges or things that were previously walled up safely in ways that do not force and do not make static, and, in this way, re-introduce movement. What opens up when we "release the energies of the past, present and future" in new creations (Haraway, 2016, p. 168)? Lets us re-member the "re" of that which re-turns yet is always changing. (Re)-touche can be seen as a continuously re-turning invitation to trust the creative potential of the unknown: "indeterminacy is not a lack, but an affirmation, a celebration of the plentitude of nothingness" (Barad, 2012, p. 223).

REFERENCES

Ahmed, S. (2004). *The cultural politics of emotion*. Edinburgh University Press.

Barad, K. (2012). On touching–The inhuman that therefore I am. *Differences: A Journal of Feminist Cultural Studies, 25*(3). doi 10.1215/10407391-1892943

Barad, K. (2014). Diffracting diffraction: Cutting together-apart. *Parallax*, *20*(3),168–187. doi 10.1080/13534645.2014.927623

Barone, T., & Eisner, E. W. (2006). Arts-based educational research. In J. L. Green, G. Camilli, & P.B. Elmore (Eds.), *Handbook of complementary methods in education research.* Routledge.

Barone, T., & Eisner, E. W. (2012). *Arts-based research.* Sage.

Blackman, L. (2012). *Immaterial bodies: Affect, embodiment, mediation*. SAGE Publications Ltd. doi:10.4135/9781446288153

Blancher, J., Neece C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry*,*18*, 507-513. doi 10.1097/01.yco.0000179488.92885.e8

Cavendish, W., & Connor, D.J. (2017). Introduction to special issue: Parent voice in educational decision making for students with learning disabilities*. Learning Disability Quarterly, 41*(1), 4–6. doi:10.1177/0731948717692308

Chilton, G., & Scotti, V. (2014). Snipping, gluing, writing: The properties of collage as an arts-based research practice in art therapy. *Art Therapy, 31*(4), 163– 171. doi:10.1080/07421656.2015.963484

Claes, L. (2014). *Mensen met een verstandelijke beperking in een vastgelopen situatie: onderzoek naar levenstrajecten vanuit een kruisbestuiving van de theoretische perspectieven Disability Studies en Social & Cultural Geography.* [unpublished doctoral dissertation]. Ghent University . Retrieved from https://biblio.ugent.be/publication/8087991/file/8088020.pdf

Clough, P. T. (2007). Introduction. In P.T. Clough, (Ed.), *The affective turn.* Duke University Press.

Cole, A. L., & Knowles, J. G. (2008). Arts-informed research. In J. G. Knowles, & A. L. Cole (Eds.), *Handbook of the arts in qualitative research: Perspectives, methodologies, examples, and issues* (pp. 55-70). Sage.

Connor, D. J., & Berman, D. (2019). (Be)Longing: A family's desire for authentic inclusion. *International Journal of Inclusive Educa*tion, *23*(9), 923– 936. doi: 10.1080/13603116.2019.1602361

Damiani, V. (1999). Responsibility and adjustment in siblings of children with disabilites: Update and review. *Families in Society: The Journal of Contemporary Human Services, 80*(1), 34–40.doi 10.1080/02560046.2019.1627473

De Schauwer, E., Daelman, S., Vandenbussche, H., Sergeant, S., Van de Putte, I., & Davies, B. (2021). Desiring and critiquing humanity/ability/personhood : disrupting the ability/disability binary. *Disability & Society*, *36*(2), 286–305.

De Schauwer, E., & Davies, B. (2015). Crossing thresholds with a child with a disability. *Departures in Critical Qualitative Research*, *4*(4), 83–98.

Deleuze, G.,& Guattari, F. (1987). *A thousand plateaus: Capitalism and schizophrenia*. Continuum.

Eisner, E. W. (1997).The promise and perils of alternative forms of datarepresentation. *Educational Researcher, 26*(6), 4–10. doi: 10.2307/1176961

Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry, 13*(3), 3–29. doi: 10.1177/1077800406294947

Ferguson, P. M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education, 36*(3), 124–131. doi: 10.1177/00224669020360030201

Ferguson, P. M., & Ferguson, D. L. (1993). The promise of adulthood. In M. E. Snell (Ed.), *Instruction of students with severe disabilities* (4th ed.,pp. 588–607). Macmillan.

Ferguson, P. M., Gartner, A., & Lipsky, D. G. (2000). The experience of disability in families: A synthesis of research and parent narratives. In E. Parens, & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 72–94). Georgetown University Press.

Gibson, M. F. (2014). *Queering motherhood: Narrative and theoretical perspectives*. Demeter Press.

Goodley, D. (2007). Becoming rhizomatic parents: Deleuze, Guattari and disabled babies. *Disability & Society*, *22*(2),145–160. doi:10.1080/09687590601141576

Gorovoy, J. (Ed.). (2014). *L'Araignée et les tapisseries* (in conjunction with the exhibition organised by Hauser & Wirth). Hatje Cantz.

Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, *14*(3), 575–599. doi: 10.2307/3178066

Haraway, D. (2016). *Staying with the trouble*. Duke University Press.

Hassall, E. W., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognition in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405–418. doi: 10.1111/j.1365-2788.2005.00673.x

Hill, R. (1949). Families under stress: Adjustment to the crises of war separation and reunion. *Social Forces*, *29*(1), 102–104. doi.org/10.2307/2572778

Knudsen, B. T., & Stage, C. (2015). *Affective methodologies, developing cultural research strategies for the study of affect*. Palgrave Macmillan. doi:10.1057/9781137483195

Law, J. (2004). *After method*. Routedge.

Leavy, P. (2011). *Essentials of transdisciplinary research: Using problem-centered methodologies.* Left Coast Press.

Leavy, P. (2015). *Methods meets art*. Guilford Publications.

Leys, R. (2011). The turn to affect: A critique. *Critical Inquiry*, *37*(3), 434–472. doi: 10.1086/659353

Maclure, M. (2013). Classification or wonder? Coding as an analytic practice in qualitative research. In R. Coleman, & J. Ringrose (Eds.), *Deleuze and research methodologies* (pp. 164–183). Edinburgh University Press.

Murray, P. (2000) Disabled children, parents and professionals: Partnership on whose terms? *Disability & Society*, *15*(4), 683–698. doi: 10.1080/09687590050058251

Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. *Nasenjournals, 31*(4), 199-206. doi:10.1111/j.0952-3383.2004.00355.x

Neuman, L. W. (2011). *Social research methods: Qualitative and quantitative approaches.* Pearson Education Inc.

Nixon, C. L., & Cummings, E. M. (1999). Sibling disability and children's reactivity to conflicts involving family members. *Journal of Family Psychology, 13*(2), 274–285. doi: 10.1037/0893-3200.13.2.274

Rallis, S. F., Rossman, G. B., & Gajda, R. (2007). Trustworthiness in evaluation practice: An emphasis on the relational. *Evaluation and Program Planning*, *30*(4), 404–409. doi: 10.1016/j.evalprogplan.2007.06.006

Roper, S. O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems & Health*, *32*(2), 241–246. doi: 10.1037/fsh0000047.

Ryan, S., & Runswick-Cole, K. (2008), Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society, 23*(3), 199–210. doi: 10.1080/09687590801953937

Salviita, T., Itälinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double abcx model. *Journal of Intellectual Disability Research, 47*(4-5), 300–12. doi:10.1046/j.1365-2788.2003.00492.x

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, *27*(8), 699–710. doi: org/10.1093/jpepsy/27.8.699

Smith, L., & Elder, J. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing, 23*(3),189–195. doi: 10.1111/j.1744-6171.2010.00240.x

Van Hove, G., De Schauwer, E., Mortier, K., Bosteels, S., Desnerck, G., & Van Loon, J. (2009). Working with mothers and fathers of children with disabilities: Metaphors used by parents in a continuing dialogue. *European Early Childhood Education Research Journal*, *17*(2), 187–201.

Vandecasteele, M., De Schauwer, E., Blockmans, I., & Van Hove, G. (2019). Research through a camera lens: A rhizomatic search for lode's code. *Critical Arts*, *33*(1), 30–43. doi:10.1080/02560046.2019.1627473

Vaughan, K. (2015). Pieced together: Collage as an artist's method for interdisciplinary research. *International Journal of Qualitative Methods*, *4*(1), 27–51. doi:10.1177/160940690500400103

Verbeeck, D. (position on series, i.e., Executive Producer, Writer, etc.). (2014). Storyline*. Marsman* [TV series]. Retrieved from: https://www.imdb.com/title/tt3396596/

Wetherell, M. (2012). *Affect and Emotion.* Sage.

ENDNOTES

[1] More information about the storyline and other aspects of the television series Marsman can be found on the Internet Movie Database (IMDB): https://www.imdb.com/title/tt3396596/. Netflixlink: https://www.netflixtvseries.com/tv/61548/marsman