Abstract

In 2020, I started to write a PhD proposal. My interest is, how art-based communities can foster social justice for people with intellectual disability/learning disability. As an art therapist and as a graduate student, I wondered how visual art could be integrated in my research project, if seen from different perspectives. Underlying to the idea of appreciating art in my research project is literature that indicates that art-based approaches are helpful to explore, understand, and transform complex social issues (McNiff, 1998; Barone and Eisner, 2012; Savin-Baden and Wimpenny, 2014; Leavy, 2015; Goopy and Kassan, 2019), and that opportunities of art in research projects are expanding, inviting a clearer, embodied praxis (Bresler, 2006, 2018; Visse, Hansen and Leget, 2019).

In this story, firstly, I share my thoughts about social justice from a care ethics perspective, reflecting on the ideas of moral philosopher Margaret Urban Walker (1998, 2007). To her, social justice is a practice of responsibility in relationships. Secondly, I reflect on visual art as a medium in my art therapy practice and my PhD project inspired by German artist Joseph Beuys, and art therapist and researcher Shaun McNiff. To them, art is ahead of-, and challenging societal conventions, making way to new-so called- social sculptures. This story is a quest of visual art being a medium to connect and built relationships.

After selecting the sources that inspired me to answer the question how art-based communities can foster social justice for people with intellectual disability/learning disability I chose for a creative academic writing process. This helps to connect to inner thoughts and longings (Beauchamps, 2021) and can gave inner space for the complexity of feelings, images, and intuitions (Franke, 2015; Beauchamps, 2021).

While reading the story you will meet Miss Be, a picture of an art installation, people I met in my art therapy practice in Nepal and in the Netherlands, fragments from the history of my family, and people who inspired me finding answers. I learned art helps bring relationships to life, can help moving forward reflecting on personal experiences and thoughts, and feeling related to the complex world we are living in.
In conclusion, I have learned that art helps to bring relationship to life, can help moving forward reflecting on personal experiences and thoughts, and can help feeling related to the complex world we are living in.

At the beginning, I coincidentally saw this intriguing photo of the art installation “Between the lines” by Chiharu Shiota (2017), while I was surfing the internet. After downloading and printing it, it was laying on my kitchen table for weeks. Every time I walked by, I got the feeling that it was screaming for my attention. This image intuitively symbolised to me what my PhD research project would be all about. I knew that from deep down inside, but I could not find the words. Caught in what I thought the requirements of the PhD grant commission would be, I struggled with what others have written in journals and books about the subject of my interest. In a moment of frustration about another unsatisfying attempt, I walked away from my desk, sat down at the kitchen table with a cup of fresh mint tea, and started talking to her...

“At the beginning, I have full attention now,” I said. “Do you want to tell me what your story is about?”

“Of course,” she said, “and please call me by my nickname “Miss Be”. Because my story is about life, nothing less than that.” The sun was setting at that time, quieting down the house and the rest of the world. I had all night to hear her story, and to find out what it could mean to me.

I asked her: “Miss Be when I look at you, I see the red woollen threads coming out of what looks like boats. These boats seem to float, all in the same direction. The threads expand in many directions but there is a structure too, that makes it possible for the threads of all boats to meet. What story are you trying to tell me?”

“My story is about the endless human web,” Miss Be said. “It is about that we are all connected. Even if we want to, we cannot escape being bonded in an endless number of relationships. These relationships are not only bonded by friendship or love, but also by hate, pain, or ignorance. Some of them are easy to perceive, like when we are related to others by birth or close long-term
friendships, others are invisible like relationships with people we have never met and will never meet.” She took a breath, and after a while she added: “Well, you do now that of course. But maybe you miss the point. You should have a look inside of yourself and your relationships before talking about others in your project. Why do you want to do this project in the first place?” I thought that she was maybe right. Where did my interest in social justice for people with intellectual disabilities come from?

Images of grey clouds that veiled my childhood memories appeared before my eyes. Behind them, there was my oldest brother, born with disability and bullied most of his life. He was a small man, too small to stand up for himself. I felt the old pain in my stomach, and I felt guilty. The pain and guilt were fostered by images of him not being accepted, even in family situations. He was the stupid one, the one who failed at school, who did not have friends, and who was laughed at about his dreams of becoming a deejay.

From knowing my brother and parts of his (hi)story I knew that the problem in our family was only for a small part the way that he functioned and what he could do or not, but how he was accepted, treated, and supported. He could not fit in, in the world of the people around him, and the people around him did not understand his need to connect. We were all dis-abled.

Instantly, I looked at the other side of my kitchen to stop the memories as I could not bear them. “All of my life I am looking away, Miss Be. First, I was a child that did not understand what was happening and as soon as I grew up, I moved away. That made it easy not to look and see what was happening. I did not take any responsibility for his needs. Unfortunately, he died young so that was that,” I said. “Should I dig deeper into my family’s history?”

“No,” Miss Be said. “Look at my threads. They are red because they talk about vivid relationships. And therefore, they talk about responsibilities towards each other now. Not in a way you THINK about responsibility. No, stop thinking about your childhood right here. Show the world how you PRACTICE responsibilities towards others today. What are your responsibilities right now? To whom? Show others who you are and what you believe in by your actions. And then start telling stories about social justice (Walker, 1998, 2007). A good way of living together, in your words a “socially just” way, can only be shaped by how you people interact, and share responsibilities” (Tronto, 1993, 2013).

I recognised Miss Be’s ideas about social justice as a relational practice from the transdisciplinary field of care ethics. Political scientist Joan Tronto, one of the well-known care ethicists stated that social justice is not complete without care, meaning everything we do to maintain, continue, and repair our “world” so that we can live in it as well as possible (Tronto, 1993, 2013). Care, from that perspective, is a collective practice with implications on a personal, institutional and global level, necessary to meet the needs of everyone (Tronto, 1993). It presupposes recognising everyone’s vulnerability, and interdependence. Interdependence is thus the foundation of family affairs, encounters in the public domain, care structures, government regulation and policy, and global economics (Tronto, 2009, 2013). This focus widens the limited legal and political domains of social justice (Held, 2006, 2015), based on a fundamental difference from the ethics of justice conception of the human condition. In care ethics, people are considered to be relational.

Moral philosopher Margaret Urban Walker (1998, 2007) proposed a view of morality and an approach to an ethical theory which uses the critical insights of feminism and race theory to rethink
how moral theory is inescapably shaped by culture and history. To her morality is embodied in practices of responsibility that express our identities, values, and connections to others in socially patterned ways. She stated that ethical theory needs to be empirically informed and politically critical to avoid reiterating forms of socially entrenched bias.

“PRACTICE OF RESPONSIBILITIES…. What is my practice?” I thought. I thought about my work in Nepal. It was in the summer of 2019 when I stayed for some weeks in the crowded, noisy, and dusty city of Lalitpur to volunteer as an art therapist at a school for children with disability. Some small children could not talk, older children were paralysed but smart, and some did not react to caregivers' attention at all. Others had signs of syndromes like Down’s syndrome, which I knew from the people I used to work with at home.

In Nepal, I learned a lot from the conversations I had with the members of my host family and the people I met during my walks. They have told me stories about the bad influence of poverty on how a child with disability is appreciated, about the shame in the families, the guilt that the parents feel and the bad karma as causes for the disability. The plot of the stories touched me again and again: if you are a child with disability in Nepal, you are nothing but bad luck and your family will offer you basic care, such as food and shelter, but they will lock you up because of the shame that you have caused just by being born. At that time, I could imagine that without paper diapers and washing machines it must be difficult to accept that your child will never be toilet trained, that it is difficult to realise that your child will never be able to take care of you and fill the gap of a not existing pension system and that you have a never-ending problem paying medical bills for your child. But I found it painful to hear that guilt and shame were filling the moral space in this issue. In a land where Buddha was smiling at me from every corner of the street. Of course, I saw the similarity with the story of my brother. He was born only ten years after the second world war, the time when “healthy” and “smart” people were needed to build up a “decent standard of living”. Even though I could understand the burden of that contexts for the families, I could not get the words “social injustice” out of my head.

I could not speak Nepalese at all, but I had a suitcase full of art materials and trusted that children do speak the universal language of creating art. There they were again before my eyes: the proud and strong young man who was especially interested in two of the young ladies in his class, the girl who loved to dance but had trouble standing up due to spasms in her limbs, the young boy who angrily kept more toys than he could carry close to his chest, in order not to share them with others, the girl quietly lying on the floor with her eyes wandering over the ceiling. I did what I knew best by using art materials and the language of the body to invite them for moments of meaningful contact (Rutten-Saris, 1990).

Many children easily accepted the invitation to create and have fun with me and each other during the hot afternoons. We were drawing together, singing, dancing, or playing the guitar. There was a lot of movement and energy in the room. Others needed another, even more embodied approach to find a way to enjoy moments like this.

To get to know the girl who was lying on the floor better, I lay down next to her with my eyes wandering over the ceiling, like hers. What did she see? Was she drawing patterns with her eyes, creating artwork nobody could see?
I had to slow down my energy, and let go of any expectations. I felt like I had to shut out the world. The situation felt like our bodies were floating like boats in the sea. While we were lying there for quite some time she started to make noises. I picked them up and sang them back to her. And then her noises got louder. So, there it was, we were doing something together, we were connected at that moment by the language of embodied being (Rutten-Saris, 1990). At that time I felt responsible for that girl’s experience of life at that moment. Because I knew the approach of “Emerging Body Language” (Rutten-Saris, 1990), an art therapy method in which I was trained for and experienced in for many years. I knew what using the method could create meaningful relationships with people with even severe intellectual disability. That responsibility by knowing what could be done, felt unease at the same time. Because, who was I in this girl’s life? Could I be more than a stranger from Europe who flew in for some weeks and checked out when the holiday was over, leaving her behind lying on the floor?

“Hello! Are you still there?” Miss Be shouted at me and I woke up from my daydreams. “Where were we? Connection, relationship, responsibility, senses, movement, energy, mirroring body language, being attuned with all the senses to the other person…” I thought.

Even though I started to understand more about social justice as a practice of responsibilities in relationships (Walker, 1998, 2007), I needed a break from Miss Be, stood up, and walked to the bookshelf in my living room. There he was, my favourite artist, on the cover of a pocketbook with his hat on and his fur cape: Joseph Beuys, the German artist who proclaimed that “everybody is an artist” (Stachelhaus, 1995; Wildgen, 2015). He was one from the past that also resonated with feelings that I had about my childhood in West Germany during the cold war. I knew him very well, even though I did not know him at all.

As I opened the book, I found a folded paper that I had written some months before about him and his work. I read it out loud to myself.

“In Europe, especially in Germany, post-World War sources influenced the use of the arts for social justice and reform pedagogy (D’Elia, 2016). In the late 1950s, when Germany reappeared as a global player in the international political and cultural scene, the social activist and artist Joseph Beuys (1921-1986) extended the concept of art, known as “social sculpture”. Beuys tried to find a way that could lead out of the disaster of ideological dualities such as fascism versus communism. The innovative power of art was meant to find a new perspective beyond politically and intellectually proposed alternatives (Stachelhaus, 1995; Wildgen, 2015). He proclaimed “every person to be an artist” meaning that everybody is taking part in the creation of the social reality and that therefore the way we create society is art (Stachelhaus, 1995).”

The words “The innovative power of art” kept me busy. I sat down on the couch and thought about those words. But what is “art”? I knew the ideas of Beuys. To him, art is a free activity where rules and conventions can be followed or obeyed. Art can create a new reality according to him if every artist, which is every human being according to him, asserts himself against the conventions or rules given by society. According to Beuys, society was not a system that you have to fit in like my brother had to fit in, but a “social sculpture”, a work of art that all people shape together, that gives space to humans in the way that they are and what they need (Stachelhaus, 1995; Wildgen, 2015).
“So art could be anything,” I thought. “But, what more could be said about art in its essence?” I wondered. Shaun McNiff (2018), an American art therapist who uses art in research projects, known as art-based research, was standing next to Beuys on the shelf. “McNiff must have defined art in its essence,” I thought. Going through his pages I found that “[...] throughout its history, art has demonstrated a reliable pattern of being ahead of the convention and challenging it” (p. 24). So he was in line with Beuys.

“Then, this “being ahead of-, and challenging conventions” is maybe an or THE important aspect of defining art in the last 50 or something years,” I said to myself. “What could this mean for my PhD project?” I wondered.

For twenty years, I worked as an art therapist for people with intellectual disability. I remembered the young woman whose hands were strapped to her waist because otherwise, she would hurt herself severely. During the sessions with her and the nurse who took care of her, I invited the young woman to paint with me. The hands of the young woman weren’t supposed to be released, but I was able to convince the nurse that we should try to find a way to be creative together. I took a big but short brush in my hands, put some blue paint on it, put the tip of the brush on a big piece of paper, and waited for what was going to happen. Slowly but surely, the woman put her hand, still covered with the fabric of the straps, on my hand guiding the brush over the white paper. We made a long line before she guided my hand to the red paint and back to the paper. While painting, the woman got more attention for the artwork that we created and for me sitting next to her. I felt that she was connecting to the situation, me, the art material, and the artwork. That situation, spectated by the nurse, challenged the idea about the needs of that woman by her support team and therefore created a new reality. She was able to create and therefore “abled”, it was us, the people around her, who needed to learn about what she needed to live a more healthy and better life with us. We needed a new social construct, as Beuys maybe would have said.

I went back to Miss Be. She was still there on the kitchen table, next to the empty tea cup. “If social justice is defined by the practice of responsibility in relationships as described by Walker (1998; 2007) and art is defined as something that can create new realities by challenging conventions as Beuys (Stachelhaus, 1995; Wildgen, 2015) and McNiff (2018) stated, and, last but not least, my art therapy experience shows the practice of connecting and building relationships by the language of embodied being (Rutten-Saris, 1990), fostered by the use of art materials within an art-making process that result in an art product (Penzes, 2020), then what?” I looked at her and she started talking again.

“So, everything comes together in the web of relationships, but matters at that moment. What matters to you right now?” she asked.

“Well, I guess that I am talking to you?” I replied. “You are a piece of art, well, a photo of it. You are a thing, but I have learned a lot from you so far. Just because you are.”

My head started to slow down. This encounter with Miss Be, this picture, has affected me. Especially by evoking memories, images, feelings, and thoughts that are connected to the people in those memories. As Bennett (2015) wrote, that picture became an animated body, something alive and active with its own right, right here on my kitchen table. Bennett wrote that she likes “the notion of “animacy” as a way to think about vitality that is not dependent upon a dichotomy between organic life and inorganic matter” (p. 76). That “animacy encourages us to parse out the several different
aspects, elements, or registers of liveliness [...] even if not all qualify under the biological definition of life” (p. 76).

As an art therapist, I liked the idea that making art is a dialogue between the artist as an active, creative agent, as a spectator of his or her artwork, and the art form that has an active part in the dialogue (Penzes, 2020). Bennett (2015) adds that the artwork itself has an important part in that dialogue. The young woman guiding my hand while I was holding the brush created a thing, an image, a painting, and she was affected by the encounter with her artwork. The traces of her body language on paper, as Rutten-Saris (1990) defined artwork, kept her going (Grabau & Visser, 1987; Smeijsters, 2008). I guessed that if she would have been able to talk, she would have shouted out: “Look what I can do! I forgot about my creativity but look, it’s there!”

“That is not what I mean,” said Miss Be. “I mean, in practices of responsibility, what are you responsible for, and to whom?”

Looking back at my stories about my brother, the children in Nepal, and the people I was working with as an art therapist, I realised that I wanted to contribute to a new, better social construct for all people with, and without intellectual disability. As a privileged person, I felt responsible for discriminated and excluded people like my brother, underprivileged and marginalised people like the children in Nepal, and the segregated people like the institutionalised woman with the brush. But that was too big for one person.

As an experienced art therapist, I had the knowledge and skills to connect with people who are disabled, create relationships with them, and support them to express themselves. All with the possibilities of art materials, art forms, and cooperative art creation. This could open ways for others to hear the voices of people who face difficulties to talk and stand up for themselves; through their artwork, like I heard the voice of Miss Be. “Supporting others to have their voices heard. This is my felt responsibility to people with intellectual disability and the rest of society,” I thought.

The clock showed me that it was late. I was tired and I decided to go to sleep. Climbing up the stairs, I thought about the conversation with Miss Be. I felt grateful for what she showed me: the complexity and richness of the subject, the clearer picture of what I was going to do as a graduate student, the memories that came back and helped me find the context of my interest, and the encounter with Beuys and the others who would accompany me during my project. I suddenly felt deeply related to the complex world I am trying to understand and hopeful to contribute to better practices of relationships. Last but not least, I loved my profession more than even.

“Good night, Miss Be,” I shouted out loud. This was a happy voice. “See you tomorrow.” Then I switched off the lights.

References


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