

“BORN DIFFERENT, BUT STILL THE SAME”

MY JOURNEY AS A SIBLING OF PERSONS WITH SPECIAL NEEDS CONTEMPLATIVE PRACTICES IN AN ACADEMIC ENVIRONMENT

ANNEMARIE CUCULIZA-BRUNKE

ABSTRACT:

This article is an autobiographical exploration of the author’s experience as a younger sibling of two people with a cognitive disability. It comprises nine years of conscious self-work and shows how an academic environment can nurture reflection on complex personal issues, and through this reflection, aid in the process of self-discovery and healing. The author explores autobiographical writing and poetic inquiry as a method to develop witnessing consciousness. The purpose of this piece is to contribute to the conversation about the challenges that siblings of people with disabilities face, as much attention is focused upon parents and the people with the disabilities themselves. The author seeks to find ways of sharing her experience and to work with other siblings who have similar life experiences.

BIO:

Annemarie Cuculiza-Brunke is a Peruvian musician, a communicator, and an educator who works in the field of creativity, wellbeing, and social and emotional learning. She holds an MA from the Faculty of Integrated Studies in Education (University of McGill). Currently, she teaches at the Education Faculty of the University of Applied Sciences (UPC), in Lima Peru. She also develops different social projects for public and private organizations. She writes a weekly column about education in a local Peruvian newspaper.

In the Foreword to *Arts-Based and Contemplative Practices in Research and Teaching* (Walsh, Bickel & Leggo, 2015), Pinar (2015) writes that “contemplative practice and research in education acknowledges that reality is a matter of revelation” (p. xv). Even though reality is constantly changing—revealing itself before us—we can engage in practices that enhance our ability to be present. This process of becoming ever more present is at the core of a contemplative educational practice. It also requires us to recognize that “study is the teacher’s way” (Pinar, 2015, p. xvii).

Susan Walsh and Heesoon Bai (2015) explain that, “witness consciousness is the ability of our consciousness to watch and observe in

a non-judgmental way its content and also the process whereby the content, occurring as events, constantly shifts and flows, thus creating a ‘stream of consciousness’” (p. 25). In order to practice witness consciousness, we need to first, feel at ease with our role as witness. How can we become responsible observers? How can we develop witness consciousness in academic environments, and in what ways may it be illuminating for ourselves and others? I’ve found that educators who set the example, creating safe spaces for exploring our autobiographical experiences, generate a movement in their students that leads to surprising outcomes.

Dr. Teresa Strong-Wilson set the example for me, in her *Autobiographical Approaches*

to Education course. My experience in autobiography had been confined to psychotherapy. As every person who has attended psychotherapy knows, for the process to be successful, patients need to commit to self-work, inside and outside of the therapy sessions. As a child, I had been trained in music (piano) and also in storytelling. Reading and writing was important in my family, as well as in the school I attended. Therefore, when I started attending therapy as a teenager I was very conscious about how and which methods were helpful in advancing the purpose of the sessions. I had used writing informally as catharsis many times. For many years, I practiced a method that served me well: I wrote in a diary the issues I was working through. After a period of time, generally two months, I'd revise my diary and decide which thoughts and feelings I found valuable. I tore apart the pages that I considered not useful for my wellbeing, and many times burned these pages.

This ritualistic method of self-work had always been in the margins of my formal education. I would have never imagined that "digging up our dandelions" and "taking our love medicine," in Cynthia Chambers' (1998, p. 14) words, in an academic context, would make me continue healing lifelong wounds that resisted becoming painless scars. After more than fifteen years of deep psychotherapy, and having participated in all sorts of energy healing therapies, the last place I was expecting to find restorative practices was in a university course.

Teresa created a safe space where students were nurtured with carefully selected writings, a space that had the potential of removing layers of (un)consciousness, long forgotten (or hidden) aspects in our psyches. Her course combined provocative readings and rich class discussions, where we would

be asked to respond to prompt questions or thoughts. Teresa wrote in her doctoral thesis that she developed her method, called "Bringing Memory Forward," inspired by Gendlin's understanding that "to explicate is always a further process of experience" (as cited in Strong-Wilson, 2003, p. 15). I will always be thankful for Teresa's generosity in creating this course and for the way she accompanied us, as we created short pieces of autobiographical writings.

Thanks to Teresa, who was also my thesis advisor, I've learned that sharing our creative and honest writing with other educators-witnesses, (especially if they are more knowledgeable than us), is fundamentally transformative. If "teaching...has to deal not so much with knowledge as with resistance to knowledge," as Felman (1982) says (as cited in Strong-Wilson, 2003, p. 16), autobiography in education is necessary for the advancement of a pedagogy that continues to grow and learn.

At the Provoking Curriculum Conference (Montreal, 2017) and the ARTS Pre-Conference Retreat at the annual conference of the Canadian Society for the Study of Education (CSSE) (Toronto, 2017), I met many more wonderful scholars who consciously work to create spaces for mentoring in higher education. I honor and cherish with all my heart the guidance, care, and growth opportunities these scholars provide for students. The caring space of the retreat encouraged me to write this article.

As Susan Walsh and Heesoon Bai (2015) explain, "writing together (collaborative writing) can amplify the witnessing capacity. This is particularly so when our own witnessing capacity is not yet ample and stable, especially when what we need to witness is difficult" (p. 25). In some ways, I feel that

my writing and revising process, over time, has involved a kind of witnessing of myself. Also, the process of creating this paper is, in a way, one of collaborative writing, as I feel held and assisted by Susan Walsh and Barbara Bickel as we advance in the revising and editing process.

In this text, I'd like to share a very personal process that includes poetic and reflective writing regarding my relationship with my two older sisters, Anja and María Pía, both of whom have a cognitive disability. I asked my parents (their legal guardians), for consent on behalf of my sisters to publish this article and the photograph that appears later in the text. My parents have been supportive of the process and granted permission for me to share this experience. When I asked for consent, I learned that they had written an article for the French magazine *Ombres et Lumière*, in 1987, about their experience as parents. When they wrote this article, I was already three years old. My parents' experience was deeply influenced by their faith in God, which is where they found meaning and strength to endure the complexities of having two children with a disability. It was interesting to learn about the ways in which my parents tried to inspire other similar families. In a way, it's what I'm trying to do now, as a sibling.

Growing up with Pia and Anja: Born different, but still the same

I am the youngest of three sisters. My two older siblings were born with a cognitive disability: a syndrome that hasn't been dignified with a name of its own, since it is quite rare worldwide. Fourteen and six years older than me, my encounters with Pia and Anja always confronted me with the meaning of life itself, particularly, the significance of human suffering.

When a child grows up in an unusual environment such as a family with members who have special needs, complex pedagogical moments tend to appear constantly. For example, being in public spaces implies dealing with uncomfortable staring—especially from older people, and also from some adolescents and small babies. Each social event with my family was difficult. It was especially hard and exhausting to sustain the effort of hiding my shame and social anguish.

As I continue in the path to becoming a teacher, I've learned that nurturing consciousness in a child is a delicate matter that requires great "pedagogical tact," as Max Van Manen (2016) explains. In his understanding, a pedagogy of tact requires being sensitive to the intuitive elements present in teaching. It also requires that the teacher develop the ability to recognize events that may mark children deeply, pedagogical moments that imply a *latency*—as they may remain as imprints in the hearts and minds of each person. An important part of tact is knowing that children may hide their true feelings ... or may not even be sure of what their emotions mean.

Children who have siblings with a disability may be sensitive to their parents' suffering and try to avoid causing them further pain. Therefore, they often hide their difficult feelings, such as shame, anger, and guilt, which can lead to stigma and, what is worse, self-imposed stigma. Erving Goffman (2006), in his extensive study about stigma, explains that once stigma is interiorised, the person isolates herself, limiting possibilities for development and wellbeing; before facing rejection, it is "safer" to avoid potential situations that may lead to negative outcomes.

Because of the obvious advantages a normally developing sibling has in comparison to her sibling with a disability, expressing anger is usually a family taboo. Actually, a more tactful pedagogy would find spaces for normally developing siblings to express their difficult emotions, without encouraging abusive behaviour. In time, siblings learn to sublimate and deflect aggression, using it wisely and constructively. Bank and Kahn (1982, p. 199, as cited in Meyer and Vadasy, 2008, p. 15) recommend to view sibling aggression as a “constructive function” that, well guided, may help the normally developing sibling and the sibling with a [disability] to learn to manage and resolve conflicts.”

Reflecting back to my childhood, probably because of the age difference between my sisters and me, and the characteristics of their disability, my feelings of guilt were overwhelming. They were also un-confessable. For example, I remember anger building up inside of me when Anja tried to hit me in her desperation of wanting to do the same things I did: going to the same school, having the same lessons, having the same attention and admiration from my parents. For some years, Anja tried to hit me in the midst of her despair, but never succeeded. This made me feel extremely angry and guilty. Compared to her, I had so many advantages: just by moving a little bit faster I’d avoid any hits. Today, I realize that I would have preferred to receive a slap from Anja, because it would have given me a justification to fight back, to defend myself, and to let out some of the tension boiling up inside of me like a geyser ... even if it were just a scream of help!

I remember as a child trying to work through these moments in different ways: through prayer, by putting my emotions into my pi-

ano playing, in writing stories for children, or just by trying to forget—going back and forth in the garden’s swing. I understood the collage of religion, arts, and intellectuality that my parents wanted to provide for me, as a command that I should not disobey to be “good hearted,” “talented,” and “smart.” As a child, I tried to comply with all of these checks, which I felt were “requests,” and “musts.” At the same time, I felt confused, as I constantly compared myself with my two sisters. It has been in the last months, thanks to the process of writing this article, that I’ve realized that the feeling that I “had” to love my sisters, made it much more difficult for me to accept them as they are, and accept myself, as they are also a part of me.

I’ve learned that by recognizing that love cannot be imposed—by removing the message “you must love”—we may find that we *can* love.

Witnessing surfacing feelings

For most of my life I’ve not known for sure where I belonged. It felt as a betrayal to my family to want to live differently, without the limitations that sharing daily life with people with disabilities imply. This confusion made it very difficult for me to relate to people of my own age who didn’t have a disability. As a child and adolescent, it was very easy for me to be with a group of people with all sorts of disabilities, as well as older people. The problem was that I had no idea how to socialize with people who are not living with disabilities.

What was my role? What was my position in our family? Today I feel that my role is the one of a conscious witness. Life has given me the opportunity to intimately know the challenges people with a cognitive dis-

ability face, as well as their families.

In 2011, I wrote a poem named “Crystal Hearts,” dedicated to my sisters. The poem represents a very important moment in my life, since it is about the time when I started to be able to differentiate myself from my sisters. Until that moment, I was under the emotional impression that my sisters were like a huge backpack that haunted me, but I could not express myself. I didn’t want to accept this feeling, because it meant I had to acknowledge my difficult feelings and experiences.

I remember feeling enormous amounts of emotional pain when I wrote the first version of the poem. After all, it had been twenty-seven years of trying to deny and hide conflicting emotions. Then, in Teresa Strong Wilson’s class in 2016, the last assignment was a creative piece of writing. I chose to revisit “Crystal Hearts.” The writing and revision process has become an ongoing contemplative practice, as I continue exploring my relationship with my sisters, and it has also led me to move forward, as I’m currently creating an arts-based workshop for siblings of people with special needs. As Maxine Greene wrote, when we tap into consciousness and awaken it, “we are breaking through to new horizons of sound and feelings. We are beginning, just beginning, to suspect what still lies beyond” (Greene, 2001, p. 17; as cited in Pinar, 2015, p. xv). From an educational perspective, I began my contemplative writing process in Teresa Strong-Wilson’s class.

To revisit and revise the poem, I read it several times and scratched out the phrases that didn’t resonate within me anymore. I also added some new lines, which are marked in the text. This process was, in some ways, similar to my initial method of writing in a

diary and some months later, deciding what still resonated within me, as I described previously. This process is also a form of the *Lectio Divina* practice Mesner, Bickel, and Walsh (2015) describe, where “one reads aloud a short text four times, each time with a different focus. Traditionally, the process involves reading (*lectio*), meditation (*meditatio*), prayer (*oratio*), and contemplation (*contemplatio*)” (p. 20). However, in this case, the meditation, prayer, and contemplation process has been over a nine-year time frame.

I include my poems and revisions below. After the poems, I respond to my older self with a brief letter to my sisters. To engage in this process, I read each poem several times and wrote down the memories that came to me. Canadian poet Lorna Crozier says that, “memory is not a fixed thing but a process and one that involves at least two parts of you—an older and a younger self” (as cited in Chambers, 1998, p. 13). I invite you to join me, as readers, as conscious witnesses, in this exercise of contemplating my autobiographical process of trying to make sense of my lived experiences with my siblings.

The poem you are about to read was first written in 2011. As noted above, I came back to it in March of 2016, during Teresa’s class. The second version of this poem includes the edited lines of the first version.

Crystal Hearts (2nd version, revised in Teresa Strong-Wilson’s 2016 class)

*For Anja and Pia
My crystal-hearted sisters
For you were sitting on the edge of a star
Contemplating everything that would come
And accepted this strange film
Without losing your smiles.*

Earth can be a terrible place,

But also, wonderful.

You will be pointed out
Because of your differences
And I won't be able to resist
To fall into that trap for many years

I promise,
I will never stop
trying to be a better sister for you

Some will look at you with distrust
And others with joy
For they will recognize you.

**My girls of a strange beauty...
Those who don't know how to look at you,
Are the ones that need you the most.**

~~And the day will come,
where I will not be willing to sit besides you...~~

~~I wish you only knew
That on that day I'll be needing you the most.~~

And yes, the day will come where I will not be willing to sit beside you.
It will be a difficult day, and I will feel my heart break,
But in order to heal
We need to part
And I need to feel I have a (normal) space of my own.

There is still so much I have to learn from you!
From you, Anja; the passion you have for knowledge and your perseverance.
From you, Pia; the loyalty of your affection and your dignity.

I beg for your patience.

It takes a long time for me to learn what *really matters*.

My dear sisters: *extra - ordinary* companions

In you I find the missing piece, the one I thought was long gone, the gear at the heart of my soul:

~~Not accepting your love~~

Not accepting that our love is a difficult one
Is denying myself

Denying myself
Is an act of pure ignorance
That I am so tired of repeating.

I start to understand

~~That it is good to be us three.~~
That it was just the way it was meant to be

I remember the countless hours we passed contemplating the march of the ants
in the garden...The games, the songs, the jokes, and the dances.

I would have loved so much to learn how to braid my hair from you, to have
a long and enlightening conversation about the meaning of life and suffering,
to understand all the words you say, to present you to my friends (without
shame), to be able to bring friends home, to go to the movies, to talk about
boys, to swim in the sea with you...

I would have loved so much to have had a common and regular sisterhood
with you...

~~The discovery of joy beyond all pain.~~

As time goes by
we all get older
it is time to let go from the past
leave the fantasies behind
concentrate in the dreams

For if something could not be in the past
it doesn't mean it can't exist
maybe in another form in the future

Someday I'll experience "regular" sisterhood
through children of my own
through my nieces and nephews
through my students
or social projects
I hope that soon,
life will give me the opportunity to bring some normality to your life as well.

Maybe then, we can shop for some nice clothes
have a lot of ice cream

When that day arrives
I will feel that my mission was accomplished
and that I was a good sister to you.

Annemie, 2016.

Becoming ourselves is a long process, similar to the peeling of an onion. As time passes by, the layers continue falling, and I feel that I see more clearly each day. Somehow, I've stopped asking things I want from life. I find this is not our role. At least not regarding what we cannot change: for example, the past. Today I try to concentrate in finding out what life expects from me. What does this particular experience demand?

How can I better serve my community and become a better version of myself? Again, I am a witness in my family. And I witness myself becoming more honest. Therefore, to close the present article, I chose to write a letter to my sisters, based in our relationships and the poem above. With my parents' permission, I also share a picture I took of my sisters, one happy weekend at the beach.



When we take pictures, we learn to see in a different way. The frame becomes our canvas. We can show what we truly see, what our heart sees. Taking pictures can be a way of practicing witnessing consciousness. I remember the day I took this picture. We were at the beach house of our parents; it must have been around 2009-2011. I started taking pictures and even explored the possibility of becoming a photographer, because I took some pictures of Anja, and she appeared beautiful. This is when I realized that beauty truly "is in the eye of the beholder." If I only watched carefully enough, with enough openness and kindness, I could always find beauty, no matter how unorthodox this expression of beauty might be. This picture is, for me, a celebration of the fun times we had (and still sometimes have!) When we are all in a good mood, we can play, as children, and just be companions, sisters, souls in a journey.

The long road to honesty

My dear Anja and Pia,

Many years have passed since I first wrote to you. Revisiting the first version of this poem, there are some lessons that remain. For example, I do believe that those who cannot see beyond disability (of any kind), need to learn to do so. To find beauty in the journey we need to be able to appreciate what is difficult. Tolerating is not enough. I've looked so many times into your eyes, trying to reach your souls...

There is nothing more illuminating than your untimely laughter, my dearest Pia. It arrives out of nowhere ... which makes it even more enjoyable. You make me so happy when I see you watching Mr. Bean in the television, twisting your body in a fashion that resembles a trance dance, because you are laughing so hard. I don't know if you understand, just how much you and Mr. Bean are alike! It sure seems so....

And you, my dearest Anja, when you surprise yourself, and open even more your (already) huge eyes. I admire so much how you continue learning and progressing, because of all the effort you put into each of your drawings and writings. You read and write, and we don't really know how you learned, since your formal education didn't go that far. It's your practice, your daily practice of sitting down and writing and reading for hours and hours. How could I not love to learn? How could I not want to continue learning, having your example?

I have also learned to pray from you, especially from you, Pia. The soul has no disability. I can see your spirit when you communicate with your God.

Still, in this poem, there are other thoughts, that are not so true, although I sure wanted them to be. You see, the problem was not that I didn't accept your love. It was always easy for me to be with you, us three. To play like little children, to be physically affectionate. What I didn't know was how to be with others, different to you. I lacked "social codes," and I can tell you it is very difficult to learn social code as an adolescent or young adult!

I also felt that I *had* to love you. And love cannot be imposed. Today I accept that I *can* love you.

As I re-elaborated in the second version of this poem, I don't know if it was good for us to be three. I've come to feel that it doesn't really matter. It's not like we had a choice, right? We are siblings for a reason (or many reasons), that continue to reveal themselves. I've asked myself many times "why did I have to grow up surrounded by people who are so differently abled? It still puzzles me that there are people who never get to know somebody with a cognitive disability.

I also cannot say that I've been able to master the "discovery of joy beyond all pain," as I wrote in the first version of the poem. I'm still struggling, trying to learn how to be authentically free. To be free is actually an act of profound responsibility. It is to become masters

of our own fate. First, we need to conquer our own stories, or our storied beings. This is why it is so important to recognize the stories we tell ourselves (and others) about ourselves.

I'm also letting go of the feeling that has pressured me for so long of trying to be a "good sister." I'm trying just to be a sister. I've found that it's all I can be for you, and that it probably is enough.

When I started writing this article, I thought that I'd write a third version of this poem. But today, I feel that I no longer need to work on this poem. I'm beginning to feel truly ready to start a completely new poem, where I will not be a protagonist, nor you. It will be other families, and the voices of other siblings shall be heard.

We're moving forward, my dear Anja and Pia.
With love,
Your little sister.

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