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Bioethical Voices

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Special Issue:

DISCRIMINATION AND DISABILITIES AS DIFFERENT ABILITIES

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Siblings of Persons with Disabilities

Federico Girelli

My sister Maria Claudia is a 47-year-old woman with Down syndrome. She was born when I was almost six. I found it a bit strange that several days passed before she and our mother came home from the hospital. I remember that my father was in a bad mood (something that, at the time, I couldn't quite understand) but I don't have any clear memory of my mother from that day.

Something was clearly wrong.

I'm not sure if it happened that day or soon after, but I remember turning to Giovanni, our older brother. He told me that Maria Claudia was ill, that her heart didn't function properly, and that, despite being so young, she would soon have to undergo a very delicate surgery.

I asked him if, assuming the operation was successful, she would be cured. He replied that she would be. But then he added that there was more to it. So I asked: «Will she be healthy after the surgery?» He said yes. That was enough for me.

Time passed (months, perhaps a year) and I began to hear a strange new expression being used around the house: “mental retardation.” This time, I knew I needed help from a different kind of specialist, not Giovanni the “heart surgeon”, but our sister Raffaella, the second eldest. She explained it to me the way Maria Claudia's doctor had explained it to her: «You know how in Mickey Mouse comics, when a character has an idea, or solves a problem, a light bulb appears above their head?», she asked.

«Of course», I said.

«Well, Maria Claudia gets that light bulb too. Just a little later, sometimes much later».

That was “mental retardation” (nowadays the term would be “intellectual disability”). I understood perfectly. I grew up knowing that Maria Claudia had Down syndrome. There wasn't a precise moment of revelation.

This is just a small example of solidarity between siblings (or, more precisely, little siblings) without disabilities.

Mutual support among sisters and brothers of persons with disabilities can, and does, extend much further. That is precisely the focus of the [Siblings Committee – Sisters and Brothers of Persons with Disabilities](#), which has been active in this field for many years.

Almost thirty years ago, the Siblings adventure in Italy began with a phone call from my (now) brotherly friend Giulio Iraci. He asked if we could meet, to talk about ourselves, not to talk about our siblings with disabilities.

Together with the other people who joined us in that first experience of mutual exchange and support, we decided - on the advice of Anna Serena Zambon Hobart - to call ourselves “Siblings.” We chose the English term because it includes both genders, whereas the literal translation of “fratelli” in Italian refers only to male siblings.

The word siblings, then, simply means “brothers and sisters.” It doesn't inherently mean “brothers and sisters of persons with disabilities.”

If it has come to be utilized in the latter way today, perhaps we are partly responsible, for we

were among the first to emphasize that families with a member with disabilities consist not only of that person and their parents, but also of their siblings. In short, we wanted to say: «We are here too, as brothers and sisters, and we would like to be recognized as such».

When addressing the realities faced by persons with disabilities and their families, it is not helpful to indulge in fairy tales. What is needed is a strong sense of practical realism.

And yet, I find emblematic the fairy tale brought to the big screen by Disney: “Frozen”. It was my daughter Dora who introduced me to it. I recommend it to everyone.

The true protagonist of the film is not Elsa, but Anna. Anna overcomes countless trials and dangers in her quest to be close to her sister and to have her role as a sister acknowledged.

Above all, talk to your children. Trust them.

I’ve heard the same story many times: a child standing alone in a dark hallway, light spilling out from the half-closed door of their parents’ room. Whispering is heard inside the house. Grandparents enter the room. Aunt and uncle enter the room. Mom and dad are crying. Grandparents leave the room. Aunts and uncles leave the room. Everyone wears a serious expression.

«Why? Shouldn’t we all be happy? The new baby has come home; so why does it feel like something is wrong? Why is no one saying anything to me?»

Speak with your children. They will understand. In fact, they probably already understand by the time you choose to speak with them.

What matters to them is simply the chance to be a sibling.

To help avoid these (unnecessary) fears and confusions, the Siblings Committee actively contributed to the drafting of the “Multidisciplinary Guidelines for the Integrated Care of Persons with Down Syndrome and Their Families”, officially adopted by the Italian National Institute of Health (Istituto Superiore di Sanità).

Siblings are the first to advocate for their brothers and sisters with disabilities to lead free and dignified lives in a society that knows them and welcomes them.

The essential starting point for such a virtuous process is true inclusion in schools, an inclusion that benefits all students, not just those with disabilities.

The normative power of Article 34 of the Italian Constitution couldn’t find a better expression: «School is open to everyone» («La scuola è aperta a tutti»).

Let me say it again: this is not a fairy tale. It is all very difficult.

You will encounter painful experiences, but also enriching, transformative ones. My family was deeply blessed, for example, to meet people like Giorgio Albertini.

My sister Maria Claudia does not speak, read, or write, and her personal autonomy is very limited.

But that is not always the case. Many persons with Down syndrome, if adequately supported, can achieve a fair degree of independence and, in some cases, even find meaningful employment.

Growing up together was not easy: for me, for my other two siblings, for our parents, and certainly not for Maria Claudia.

But it has also been (and continues to be) something wonderful.

Spoken from the heart of a brother.

www.siblings.it

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