Isabel Scott

Untold Stories of Autism

The Sibling Perspective

My brother has autism. Telling the story of how I grew up in the shadow of this diagnostic label in Luxembourg is challenging. It opens up a space where memories and emotions mingle with some unpalatable views on Luxembourg's treatment of a vulnerable and silenced part of its population. Before continuing, it could be helpful to briefly explain what this piece *is* and what it *is not* about.

Giving an account of autism from the sibling perspective is intrinsically subjective. This would include looking back at how I dealt with a challenging family situation that was made harder to bear by unyielding institutional structures as well as a mostly hostile public attitude and language towards my brother's disability. The conclusions drawn do not purport to deny the real work and dedication of individuals and organisations that are tirelessly working for the benefit of people with disabilities. But I want to reiterate that they are not my primary concern, nor do I attempt to unpick specific disability policies. Instead, my aim is to bring forth the sibling perspective which is rarely given a platform in discussions around disability.

Growing up in the presence of my brother's autism, I was not initially aware of our differences or the ubiquity of my family's dynamics. My brother's behaviour and way of communicating were simply part of who he was, not defined as symptomatic of typical autistic traits. Yet, that benign perception gradually faded due to a continuous stream of social situations and encounters leaving footprints of shame, loathing and anxiety.

Gradually I began internalising this emotional cluster and started to reject the autism label. In return, this made it impossible for me to accept my brother as he was. For a long time I was caught up in a desperate attempt to detach myself from the grip that this diagnostic label had over me.

'It is very difficult to pity someone and to respect them at the same time.'

Only recently have I come to acknowledge and accept the painfully simple fact that my brother is not to blame for the emotional turmoil I put myself through.

Disabling language

Language is a means of communicating and assigning a person's place within the given social order. For this reason the way in which disabled people are spoken of in Luxembourg has been particularly hard for me to stomach. I am not convinced that this can be brushed off as a case of nuance being lost in translation. Using words such as „handicapéiert", „behënnert" or even the words „Ettelbréck" or „Klappsmillen" in conversations around disability sends a stark message: disabled people are not 'like us', their disability will never allow them to belong.

These words are exclusionary, derogatory, condescending. Words can do more than describe, they have a performative effect, what J. L. Austin describes as 'speech act'. They bring into being what they describe (for example a priest pronouncing a couple man and wife). So not only are words and their connotations reflective of the broader socio-political context in which they are used, they also have concrete, tangible effects. In this case the examples given generate the exclusion of so-called disabled people from 'our' normative understanding of the Good Life. They also have a paralysing effect on both disabled people and their immediate entourage.

I have experienced this discursive violence time and time again, to the point that whenever I hear such words being used in conversation, it has a visceral, almost bodily effect on me. Anger is often considered to be a valid reason for both dismissing and refusing to engage with the angry person's line of argument. However it can be a productive emotion when it serves as a catalyst. Revealing my own anger at destructive discourses hopefully does just that.

Disabling encounters

I would like to share a small sample of my memories highlighting the traumatising consequences these hostile attitudes had on my relationship with my brother: I am six years old, *Éischt Schouljoer* at primary school. My brother goes to the 'special class', *éducation différenciée*, they call it. Outside where all kids mingle, *différenciés* or not, a group of kids chase him around the playground, calling him names. I run after the kids, shouting at them, leave my brother alone. No teacher, no *éducateur* intervenes. In Cactus, we're queuing up to pay for the shopping. I notice an elderly woman staring at my brother, who maybe is talking to himself or making jerky movements with his body. She presses her index finger to her temple, *deen doten ass verréckt*.

As a teenager, my brother and I go to the same secondary school. He is segregated in his special class, but we share the same open spaces. This time I fail to defend my brother, I deny him even the most basic acknowledgement, our paths cross in the corridor, he looks at me, I immediately look away and walk past him. During break-time I am queuing up to buy a croissant. I spot my brother a few meters ahead in the queue, my heart sinking as I realise he is struggling with his order, the person behind the till does not understand what he wants. As he tries to make his order some kids start to snigger and I helplessly look on but do not intervene out of shame of being associated with him.

It is painful to look back, and confront one's failure; the failure to stand up to public scrutiny and look out for my brother who's older than me but more vulnerable. Fortunately I also have more pleasant memories of spaces where my brother is welcome. Taking dance lessons together with an Australian dance teacher stands out as a safe space where we share a mutual love of music and dance, where we can be the most mundane of things: just brother and sister.

The importance of representation

How does this fit into a wider conversation around representation? Marginalised groups tend to be silenced by people outside of their lived experience speaking on their behalf. They are never listened to. Even voices like mine as a sibling are rarely heard. Retelling episodes of struggling to cope in a hostile social environment and the frustration accumulated by repeatedly banging against 'institutional brick walls', to quote Sara Ahmed, can trigger a defensive reaction. This goes along the lines of: 'Not everyone treats disabled people this way, I know x,y,z who does a lot for disabled people.' Responses like these operate on a similar discursive level as 'not all men rape' in reply to the charge that men should not rape, or 'all lives matter' in reaction to the call 'Black Lives Matter'.

Anyone citing examples of either themselves or others doing charitable acts for underprivileged groups may want to consider the following statement made by Moira Donegan in a piece for the *London Review of Books* on Mother Teresa's recent beatification and the problematic nature of charities: 'it is very difficult to pity someone and to respect them at the same time'. To me this sentiment resonates strongly in relation to a country as money-obsessed such as Luxembourg. A place where, come Christmas, heartstrings are pulled by litanies of sorry tales describing the predicament of those deemed less fortunate – with the added convenience of never actually hearing the opinions of those whom the charitable acts (mainly in monetary forms, the *Don*) are reserved for.

Shifting public attitudes towards disabilities such as autism could bring about desperately needed structural changes regarding issues ranging from education to housing, domains that have not been touched upon on this occasion. For such a shift to take place, there first needs to be a recognition of the problem. This can be done on a basic level by listening empathetically to those concerned and refraining from either speaking on their behalf or rebutting their lived experiences on the rare occasion when they feel safe enough to voice their concerns.

It means no longer adopting a patronising *Gutmensch* attitude offering pity that is uncalled for. It is also about refraining from simplistic charitable acts *à la* put-money-in-the-box *pour les handicapé(e)s* – a model well past its sellby date a long time ago. A deeper awareness of the power that language wields to either include or exclude and fine-tuning that language in order to reflect inclusivity. *Inclusioun* remains a smokescreen so long as it fails to generate a wider visibility of the disability realm. If roughly 1 out of every 100 people has some form of autism (the autism spectrum is broad, ranging from mild to severer forms), then I leave it up to you to calculate how many people with autism live in Luxembourg that currently has a population of around 576,000. ◆

Just brother and sister.

Simple Language

This article is about the Isabel's personal experience. She is a sister of a young man with autism.

She talks about her life with her brother.

She asks us to think about the words we use to describe people who seem different.

Using positive language could help people with disabilities feel included.