Others like Me? Growing up with the self and ‘otherness’ in a special school context, reflecting on the past and thinking of the future
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Disability and the Family
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Abstract

For the last twenty years children with disabilities have been routinely integrated into mainstream educational settings. My childhood, spanning the 1980s and early 1990s, was by contrast spent in a special school. I felt isolated and as a result of this was left with a profound sense of having missed out on something. I have spent many years advocating integration and was firmly of the belief that this was the way forward however, I am increasingly aware when talking to other young people with disabilities that providing a stimulating, challenging and inclusive educational setting (that in theory allows these learners to access the same opportunities as their non-disabled contemporaries) can mean that they miss out on other equally valuable social experiences that can come from being around people with a similar diagnosis and who are facing some of the same life challenges.

What is the way forward?
Introduction

This paper is primarily the result of personal experience. Its aim is to look at the special school experience as a whole, examine the history and reasoning around special educational placement along with the outcomes and consequences, both positive and negative, of the different options both historically and today.

Background

Special education has existed in one form or another for well over a century, beginning largely as the result of charitable endeavours. Some writers have discussed this beginning in the context of the wider social concern of the treatment of poor people, who as a result of their situation became dependent upon state support (Hunt, 1989) (Winzer, 1993). Special education provision aimed, the authors argue, to render the disabled person a functioning, productive member of society, thus reducing the perceived social burden their disability or illness was seen to create.

The presence of disability was often seen to be a blight within a family, a source of great shame and even in some cases, as something that could be 'civilised' out of the affected person (Winzer, 1993). In the UK it was not until the 1944 Education Act that the need to educate children
with disabilities featured in the main part of the legislation, prior to this it had featured in separate sections of prior Acts (Hunt, 1989 and Borsay, 2005).

The 1944 Act gave rise to standardised classifications of different disability needs (Hodkinson and Vickerman, 2009), these were:

Blind

Partially sighted

Deaf

Delicate

Diabetic

Epileptic

Maladjusted

Educationally subnormal

Physically handicapped

Speech defect

The school I attended was originally classified for delicate children
(these were children who had conditions like asthma that were severe enough to interfere with their ability to cope in a general education setting). The school opened in the early 1960s, by the time I arrived there in the 1980s the school population was predominantly affected with physical disabilities, many had Cerebral Palsy, as I did, Spina Bifida or Muscular Atrophy/Dystrophy.

Some years ago I ordered copies of parts of my medical records from my early life. In with the results of diagnostic tests, treatment plans and conjectures regarding my general prognosis were reports about what route my education should take. A Paediatric Specialist Physiotherapist carried out a home visit; he assessed my physical progress, my mobility (or lack thereof) as well as my upper limb function, all of these were well below what was expected for an almost three-year-old, compared to my cognitive scores which were in the superior range. The subsequent report recommended that I would benefit from the stimulation of an educational environment and the company of other children. In an additional handwritten note to my consultant he queried the possibility of my placement in one of two special needs schools in the county. In response to this my consultant wrote a letter, which stated that in his opinion my physical disabilities were such as to be incompatible with mainstream education
and thus he recommended that I attend a special school where physiotherapy and medical treatment would be embedded within provision.

My parents were not consulted about this decision, they were just told that access to physiotherapy was paramount and anything else had to be a secondary concern. They were I think more than a little overawed, they had wanted to look into mainstream placements for me but the idea was not taken seriously by any of the staff involved in my care. Mainstreaming was seen as not giving me the opportunity to maximise my physical potential. This was in stark contrast to some of the high profile political and educational ideology emerging around this time. The Warnock Report (1978) proposed major changes in the ethos of educating children with special needs, indeed it was this report that first used the term Special Educational Needs or SEN.

Starting school was something of a watershed, it was the first time I became aware of my bodily difference, both in terms of my own body and of those around me. There were people in wheelchairs, with walking sticks, crutches and calipers or splints. Every part of my early school experience was structured around learning to approximate an almost proscribed vision of normality set around the physically able body. One's body is perhaps, where a sense of autonomy begins. Giddens (1991)
discusses the creation of self and personal autonomy and argues that the body plays a pivotal role, as for most people their bodies are the first thing they experience control over. Social norms were imposed based on expectations of functional attainment because as Ramanathan (2010) points out impairment, disability and 'normal' ability can for some become intrinsically linked as the presence or absence of one comes to define the other. This can and did create interesting social dynamics within the educational setting. There was a very definite sense of hierarchy, this seemed to centre upon individual physical and, in some cases, mental capability. There were, I believe, a multitude of factors that co-existed within the social world of my childhood that influenced this hierarchical view of disability in this group of affected persons and even to some extent, the wider social landscape of which they formed a part.

It is here that it becomes necessary to examine disability as it interacts with the social process. One of the first experiences you have as a disabled person is the application of this category as a "descriptive label" to your person. Jutel & Dew (2014) look at the application of the diagnostic label and how it opens up a new book of social rules for the affected individual to act outside of conventional norms or be absolved of the need to do expected daily life activities. However, in the case of lifelong congenital disability expectations become subtly different;
whereas adults may become unwell and are by nature of their situation at
the centre of the experience, when a child is ill or disabled it is the parents
who are at the forefront of the experiences surrounding diagnosis. My
parents were then, and parents are still today, in a very vulnerable
position.

Sometimes parents have to make choices about provision almost
directly in the wake of diagnosis. I think my parents feared being seen as
'bad' if they went against professional recommendations and did not
realise that a decision they made about my education aged two, would
not be monitored and revisited during the remainder of my education.

The classroom had very distinct hierarchical overtones and many
classroom activities were aimed at increasing functional ability; the more
skills you had the better you seemed to be perceived by staff. Integrated
into early years classes were tasks designed to help you learn to wash,
dress and toilet yourself, with as little help as possible. From the
beginning you were defined by your needs, for example one of my earliest
memories of school life was getting ready for a day trip and hearing staff
say that there were, ‘....six walkers and four wheelchairs.' In later years on
school holidays the 'walkers' would be given much more freedom such as
being allowed to stay up later. Within school they always got the lead in
school plays and had more social opportunities as we grew older, like
shopping trips. This seemed to be because those who relied on wheelchairs or other equipment almost inevitably required more help and additional support. To participate in these activities individuals were defined purely on their self-sufficiency and the ability to best emulate able contemporaries. We were compared to one another and this fostered an interesting social dynamic, fuelled by the perceived negative power of our bodies. These became battle-fields, they bridged the gap between what Williams (2011, p.89) calls an ‘intangible concept of power’ which in his view, is a social construct that results in the ability to gain control over a particular set of circumstances to achieve a desired outcome. For many friends and colleagues who have talked to me about their disabilities over the years it was placement in special school that cemented their status as different.

Our bodies became a canvas allowing us to illustrate our own social worlds and had a determining effect on those who could not conform to this normalising ethos. In my case I had significant problems with writing, I could only do so very slowly and the end result was often illegible.

School staff emphasised doing things in a 'normal' way, this had a detrimental effect. I left school with a body that functioned reasonably well, but very far behind academically and with no qualifications. This was due to their focusing on my writing for myself, without reliance upon
technology or a scribe, inevitably I fell farther and farther behind.

Bullying and abuse have been recognised as an issue for many children with special needs, historic accounts of special school life make reference to it (Shakespeare, 2006) and a 2014 BBC news report on statistics relating to this issue released from the Millennium Cohort Study into the social lives of children in the UK concluded that this remains an issue today. For me, I believe the experiences I had occurred for the most part out of fear, individuals who bullied did so to distance themselves from the shortcomings they felt as the result of their own disability and to assert themselves as capable and productive by pointing out the shortcomings of their fellows.

Eating disorders and more general issues with food were commonplace, something that I have discussed with many of my friends in the years since leaving school. It was not until then that we all became aware of how deeply the enforced preoccupation with our bodies had affected every aspect of how we thought, acted and saw ourselves even in adulthood when there has been a significant change in both the reactions to disability and disabled people generally, in stark contrast to my own special school experiences. The BBC presenter Peter White (1999), who is visually impaired, discusses in his autobiography ‘See It My Way’ the dynamics of social interaction and hierarchy in relation to those with
differing degrees of sight loss at the residential school he attended. His contemporaries with more functional vision were seen as valuable due to their ability to access printed copies of magazines that they would read out loud to those who were unable to do so, giving them power and status. This was something he perceived as a positive on both sides.
Changing Times

Today the educational landscape has changed. The social isolation that can come about as the result of a segregated educational life is increasingly recognised by both parents and professionals alike (Hewitt-Taylor, 2008). From 1997 onwards there was a major push for inclusion in schools, a newly elected Labour government asserted that this was one of its foremost priorities (Hodkinson & Vickerman, 2009). On a personal level I noticed a subtle change in attitude to my presence in mainstream classrooms. I had begun attending a local sixth form college in 1995, just as the Disability Discrimination Act (1995) was coming into force. Growing up I had always felt I straddled two worlds, my home life and friends who were not disabled, and my real life. At school I was on the periphery of both worlds. At home with my friends I did not feel disabled, in retrospect I am aware that the acceptance I found at home was in part at least due to the physical independence I had been driven to acquire by staff at school and other professionals involved in my care. I think another factor that was influential in the acceptance I got from others in my home and later in a mainstream environment was also partly to do with the fact that my contemporaries had formed a wide range of academic ability, there were those who struggled with reading and writing as I did, who readily mixed with academic high flyers and my differences passed largely unremarked
in a way that would never have happened in the context of my school life. There I found myself in a class of comparatively physically and academically able individuals and in this claustrophobic atmosphere was destined to be singled out for my shortcomings.

Mainstream college was my first positive experience of needing support to assist in my integration. I received 2 hours additional support to help me complete coursework. For the first time I was viewed as a capable person and my success was not judged by my ability to produce work completely unaided. However, at the time many teachers were unwilling to allow me to have an assistant in the classroom setting as they felt this would be too disruptive, both in terms of their own teaching styles and for other students in the class. When I entered university for my undergraduate degree it was widely accepted that students with disabilities had access to this kind of assistance and that their needs in relation to accessing the curriculum were paramount. In retrospect, I do not think that my having support within the classroom had any negative effects upon the education I received. I do not think that my tutors found the presence of an extra body off-putting, but then a university classroom is a different place from that of the secondary or further education classroom. These days the classroom itself has become less of an "Ivory Tower", where the teacher alone knows best.
The extra support I received also had an unexpectedly negative effect on me. Yes, I was able to excel in the classroom, I was able to contribute and to work alongside my non-disabled peers, I worked in real-time producing work at the same rate and speed as they. However, I found having a support-worker left me socially isolated. In lectures, tutorials and for mobility around the campus I needed help and always had someone with me, meaning students were reluctant to approach me both to work with me and for casual conversation. This impacted very much on the wider university experience as it limited my ability to mix and I lost a great deal of confidence socially.

It was this that first made me question the integration ideal. Although I, and others I have spoken to over the years, have had negative and sometimes abusive experiences whilst at special school, we have with hindsight come to recognise the value of shared history. In many respects we are as close as family; with each other there is an almost brutal honesty when discussing our life, our past and the issues that we will face in the future. This is something that I think those who have undergone a mainstream placement may lack as they will often be the only one with their condition in their class or even their entire school. Some individuals have told me how they felt singled out, vulnerable and lonely in the mainstream setting. Children attending mainstream school almost
inevitably miss out on regular, long-term therapeutic interventions that are built into the special needs setting. This has to impact upon their independence, but does it really matter?
Concluding thoughts on the way forward

As a child I was almost indoctrinated with the need to be able and self-sufficient. To what end? Yes, I left school with the ability to walk, wash and dress; I was about as physically capable as it was possible to be. However, I had few of the other skills necessary for independent adult life, I was barely literate. This was an issue that had not seemed to register with any the professionals involved in my care, to them I was as good as I could be. As my special educational needs teacher at the time put it, I had "reached the ceiling". This was a statement he reiterated to my prospective teacher in mainstream placement. Within ten years of this statement, and with the appropriate support and access to assistive technology, I obtained both Undergraduate and Masters Degrees, going on to write and publish papers and articles. Those years also saw me become a permanent wheelchair user.

The point I am making is that whatever educational path a child with special needs takes it must take into account their needs as a whole. As a society we have come to think that for children to be educated in a mainstream setting is automatically seen as a better option as it theoretically allows them to create and maintain relationships and links with the community in which they live, rather than travelling many miles as I did. The answer I think is to make the system more flexible, have
more special units and possibly even therapy resources within mainstream schools, or linking special schools with their mainstream counterparts. Of course we need to implement access to support that reaches beyond education itself to ensure children with all levels of disability reach their full potential and become adults capable of leading fulfilling lives.
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