

# **Winston Churchill Travelling Fellowship 2013**

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*An exploration of the provision for individuals with  
autistic spectrum disorders*

## ***The Complexity and Ethics of Autism Teaching***

A gift disguised as a dilemma.

- Sharisa Joy Kochmeister, *Loving Lampposts* (2010)

Lindsay Webber is rewatching the video of her son, Matthew, on his first birthday. Matthew rolls a softball back and forth with his cousin. He is following the movement of the ball with his eyes and laughing.

You'd think this the common ritual of proud parents. Or those who have just moved house and found a box of old video recordings. But this is, in fact, part of an investigation. Both parents are doctors and Matthew was seen to be developing typically until his first birthday. He then began to display autistic-like behaviours, such as hand flapping and not making eye contact with those around him. Playing with his cousin a year later, Matthew had little interest in the softball and seemed to pay little attention to movement or people in his surroundings. At 3, Matthew was diagnosed with an autistic spectrum disorder (ASD).

Autism is a lifelong developmental disorder characterized by a 'triad of impairments': difficulty in social communication; interaction and imagination. Over half a million people are diagnosed with autism in the United Kingdom and many need lifelong education and care support. The causes and mechanisms of autism are not fully understood despite much research into the genetic, cognitive and neural dimensions of the disorder.

This mystery is exemplified by Matthew's puzzling regression. And for individuals with autism, parents and professionals, the mystery does not end with diagnosis. For me, a mainstream secondary school teacher with an autistic brother and autistic pupils, the huge

mystery is how to effectively teach individuals with autism and how to support them practically and ethically later in life. So, with funding from the Winston Churchill Memorial Trust, I travelled to New Jersey in the USA to visit the best autism programmes in the world.

New Jersey is the most progressive state for early intervention and private services for autistic children. It is well known for its long history of outstanding programmes for individuals on the autism spectrum. This reputation is a direct result of landmark laws and regulations in the 1970s that established aggressive practices to identify children with learning difficulties and provide programmes to respond to their needs as set out in the Individuals with Disabilities Education Act (IDEA). Since then, the state's Department of Education has maintained a strong commitment to educating all pupils with autism. Many believe that the quality of services encourages families to relocate and this is what has led to the increased prevalence of autism in the state: 1 in 57 are affected in New Jersey compared with 1 in 94 elsewhere in the nation. Furthermore, there has been a 63% increase in the prevalence of the disorder in the state since 2002. It was voted the best place to live for autism services by *Autism Speaks*, an autism advocacy organization.

The prevalence of autism in New Jersey has spurred extensive study and funding. Despite recent budget cuts, Governor Chris Christie has maintained his commitment to autism services. \$140 million has been set aside for early intervention services and \$8 million for research at the new Autism Center of Excellence. Practitioners in New Jersey believe that early intervention is key. Walter Zahorodny from the New Jersey Medical School states that 'treatment' when a child's brain is still developing will maximize their potential.

Professionals in all fields are trained to look for signs of autism: teachers; doctors; social

workers. 'Even your neighbour will be able to talk to you about it' I was told by a teacher at a school I visited in Princeton. And this, I realised, is simply not the case in the UK.

My family has been very open about my older brother's autism diagnosis at the age of 27. And our friends and family have been very open with their ignorance. 'It's Asperger's, right?' 'He's so chatty – have you sought a second opinion?' 'What exactly is autism?' People's reactions and experiences range from knowing nothing whatsoever to having some odd hierarchy of quirkiness in their minds. BBC's Sherlock and Christopher from *The Curious Incident of the Dog in the Night-time* at the top – because 'they can remember lots of stuff' – and other autists at the bottom. The hand-flapping, less conventional ones. The ones who make the general public feel a bit uncomfortable. Where have these misrepresentations come from? Yes, I suppose the media glamourizing Asperger's syndrome as some sort of savant Rainmanesque gift hasn't helped. But perhaps we have not been very good at considering it in practical terms. What is it? How can we support individuals with autism at school and in the community? And what does effective support look like? Reducing autistic behaviours or working with them?

In a recent study published by the British Medical Journal (*Families with Disabled Children*), researchers found that provision in the UK is particularly inadequate for children with an ASD. At the same time, the National Autistic Society (NAS) carried out the largest ever survey on autism and education in the UK. This provided the evidence base for the *Make School Make Sense* campaign to improve educational provision for children with autism. The survey found that school provision is often limited, teacher training is inadequate, over 40% of pupils with autism experience bullying at school and 20% find themselves excluded, perhaps due to teachers' lack of autism awareness or the school's unsuitable provision.

Schools for children with autism are understandably expensive and few in number. There are an estimated 90,000 children with autism in the UK and approximately 7500 specialist educational places. An Ofsted report on inclusion stated that ‘specialist autism support services are limited and patchy across the UK’ and the NAS is concerned that existing outreach services are currently being eroded as a result of the delegation of Special Educational Needs (SEN) funds from Local Education Authorities to schools. A House of Commons report remarked that ‘where training and resources are not met, the principle of inclusion is undermined.’ It also commented on the need to ‘urgently’ change initial teacher training courses if inclusion was to become more than a rhetoric. And SEN numbers are now so sufficient that mainstream schools will encounter many more pupils with an ASD. The NAS is calling for a renewed commitment to teaching those with autism in a mainstream setting. Yet, as we enter the final year of the ten-year strategy *Removing Barriers to Achievement*, 90% of autistic pupils are making disappointingly slow progress in mainstream schools.

Individuals with autism have an unusual profile of skills and deficits. Training for teachers and other school staff is absolutely necessary in order to improve the school experiences and learning outcomes of young people with autism. In a recent NUT survey, 44% of teachers responded that they felt uncomfortable and unprepared to teach autistic children. And, as I enter my fifth year of teaching, I look back through my training documents. I have syllabus textbooks, behaviour guru guides and files of evidence to prove that I have met the required Teachers’ Standards. I look through hand-outs from training courses and INSET days I have attended over the last few years: *Don’t let dyslexia get in the way of success; Teaching young people with poor literacy* and *Supporting the hearing impaired*. I’ve been made to think carefully about ADHD, pupils’ religious outlooks and what to do when it

snows (another classroom mystery – mayhem when the first flake is spotted through the window). Yet, bizarrely, no mention of autism. So I had to get to some schools that were doing it right so I could bring back this expertise to the many thousands of entitled pupils in the UK. Hello New Jersey.

My journey began in Princeton, New Jersey at PCDI – the Princeton Child Development Institute. Founded in 1970 by a group of parents frustrated by the services on offer to their children, PCDI is a private, non-profit programme offering a broad spectrum of science-based services to children, youths, and adults with autism. The Institute not only provides quality treatment, education, and professional training and mentoring in New Jersey, but through its research, has pioneered comprehensive intervention models that are used nationally and internationally for the benefit of people with autism. These programmes teach young children to talk, play with siblings and friends, and read and write. Adolescents continue academic and work-study programmes while learning to participate in their homes and communities. Adults perfect skills that allow them to maintain jobs and achieve greater levels of independence. In their research documents, PCDI describes itself as a ‘natural laboratory’ for the development of models for effective education of individuals with an ASD.

The methods used at PCDI follow the Applied Behaviour Analysis (ABA) philosophy and practices. I spent my first three weeks at institutions that used ABA methods: PCDI and Eden Autism Services, both in Princeton, New Jersey and Alpine Learning Group in Paramus, New Jersey. This technique aims to modify the undesired behaviours of a child or adult with autism – hand flapping, for example – by reinforcing desired behaviours. Each learner has personalised reinforcers to incentivize ‘typical’ conduct and gradually limit or remove stigmatizing habits or actions that could have a negative impact on their later lives.

ABA is also characterized by its personalized learning programmes and the robust data collection requirements. Pupils in the same room were working towards totally different goals: one learning how to brush his teeth using a video prompt, another practising conversational skills. These individualized learning goals are constantly monitored to assess progress and the need for any adjustments to their personal syllabus.

PCDI was a tangle of colourful and happy rooms with endlessly encouraging staff working one-to-one with the pupils. Each individual would have specific learning programmes designed based on their needs. During my week-long stay, I saw Grace working on her conversational skills by scripting lunch time discussions with peers; Ali working on sitting still and Roly, their eldest programme participant at 55, working on self care and cooking skills. Different reinforcing systems were in place for each individual: some were incentivized to cooperate and work hard by a chance to play on the scooter; others preferred a sugary snack or a cuddle with their teacher. I saw similar activities and systems at Eden and Alpine and was astonished at the impact these methods were having on reducing so-called 'stigmatizing' behaviours. Ed Fenske, the PCDI's Executive Director, proudly showed me from classroom to classroom and showed me a video recording of a young boy who had joined PCDI with limited expressive and receptive language and extreme 'stereotypy' – screaming, head-banging and echolalia (meaningless repetition of certain words and phrases). Within six months, Michael was speaking, enjoying his academic work and even graduated from PCDI three years later to reintegrate into mainstream schooling. ABA was like a magic wand, reducing the limiting and stigmatizing behaviours displayed by some individuals with autism and promising them a chance to lead more independent, satisfying lives and be less judged by their communities.

In order to find out more about this magic ‘treatment’, I volunteered at the 2013 Autism New Jersey conference in Atlantic City in late October. By the boardwalk and casinos, I discovered more about ABA and met enthusiastic professionals and parents. The conference was made up of a series of lectures on different aspects of the philosophy and practices of ABA and, as the final day drew to a close, and I had signed guests into the final lecture on employment for individuals with autism, something happened. A young man raised his hand and asked a question at the end of the lecture. “Can’t you just be honest and say that autistic people shouldn’t have jobs where they talk on the phone? I mean, I have high-functioning autism. I’m great over email but I’m useless on the phone. So, we should just come to terms with our skills and make sure other people do too.” I felt very confused, all of a sudden. This vocal conference-goer was right. Why should he be ‘taught’ how to do things he had no skills for? Why can we not bear to risk the public being made to feel a bit uncomfortable in the company of someone with autism? I had to find out more.

Alex was a 19-year-old who described himself as having ‘high-functioning’ autism. He was very chatty and open and told me that he had been to a number of ABA institutions during his schooling. As we were getting into the crux of ABA teaching methods, another curious volunteer addressed him: “you’re speaking very loudly”. A month earlier, this comment would have made me feel very awkward. But I had heard reactions like this throughout my visits to ABA schools, as teachers tried to explicitly reduce undesirable behaviours, like avoiding eye contact and flapping one’s hands. “Grace, look at me when you say hello!” “Ali, quiet hands!” – the ever cited and oft-bemoaned ABA catchphrase. Alex must have heard this many times. So maybe he had rehearsed his answer. But I liked how word perfect it was, nonetheless. “Does it harm you if I speak too loudly?” And with that

seemingly simple comment, I wasn't so sure about ABA and organized visits to some alternative programmes.

'ABA does not respect a person's identity. The fundamental message from the ABA practitioner is that what you are doing isn't normal, people won't like it and you shouldn't make people uncomfortable.' Lauren Blaszak stared at me intently as she excoriated the ethics of ABA. Co-Founder and Executive Director of Celebrate the Children school in Wharton, New Jersey, she continued: 'Look at you, you're fiddling with your pen. And I've noticed you've played with your hair a few times. Should I tell you to stop? Is it harming anyone? We don't go by the ethos of changing behaviour to save the discomfort of the general public. They need to become more tolerant of difference. You won't hear "quiet hands" here.'

I dedicated the second half of my project to visiting schools with different approaches to teaching young people with autism. And the highlight of my trip was visiting the Celebrate the Children campuses in Wharton and Dover, New Jersey and ECLC in Ho-Ho-Kus, New Jersey. These schools use Floortime and SCERTS (Social Communication Emotional Regulation Transactional Support) methods that support the individual in becoming a more confident and effective communicator. There is plenty of role-play and relationship building both in school and in the home programming and extra curricular activities. In both schools, I saw plenty of roleplay, games with 'working dogs' and visits to local shops and laundromats in order to familiarize the pupils with socializing and public routines. There was an emphasis on sensory and physical stimulation in both schools. The morning 'zumba' assembly at ECLC was a spectacle; the hall was pulsing with delight. Pupils were engaging in the stereotypy that ABA schools considered so damaging to their future

prospects in an autism-unfriendly world. But, they seemed happy and free. However, I did wonder which learners were being given a more realistic message about the unfortunate intolerance in society and who would leave school better prepared for the workplace?

I was not expecting my journey across New Jersey to become an ethical sticking point. I thought – and naively hoped – that I would return with a list of effective and practical methods for teachers in the UK who are struggling to provide for their pupils with an ASD in both mainstream and specialist settings. And, of course, I saw some inspiring practice and enhanced learning outcomes for the pupils of New Jersey. But my ethical journey led me to not just look for recommendations for pedagogical practice, but to also consider the identity politics of teaching individuals with developmental disabilities. The ‘recovery movement’, which aims to ‘treat’ and ‘cure’ autism, surely diminishes an individual’s sense of self worth and the right to individuality and expression?

In a meeting with Todd Drezner, director of *Loving Lampposts*, a 2010 film that explores the tension between the ‘recovery’ movement and the neurodiversity movement, he tells me about the ‘Loud Hands Project’ – a blog in response to ABA methods and a platform from which to promote self-advocacy awareness. Drezner’s son, Sam, has autism and engages in stereotypy. One of his repetitive behaviours is visiting the same lampposts in Prospect Park, Brooklyn, New York. ‘Stereotypy can be helpful rather than harmful.’ For me, the filmmaker’s comment crystallizes the debate. How can we possibly intervene if the benefit is to us? It goes against all identity ethics to restrict the harmless habits and instincts of an individual so that they simply fit in and make others feel less uncomfortable. ABA practitioners would argue – and did argue at the conference in Atlantic City – that a child needs to be given every opportunity to develop skills that will allow them to lead a fulfilling

and independent life. Yet I fear, as does Drezner, that this does not contribute towards society's acceptance and understanding of autism. And it certainly does not allow for understanding or 'celebrating' the children affected.

My interview with Lindsay Webber, mother of Matthew who was diagnosed at 3, helped with this dilemma. 'Charlotte, it's great that there are lots of different methods. Because every child is different and will feel happy and learn effectively doing different things. Matthew didn't respond well to ABA but I still think it can be a great way to get children to manage their behaviour.' As a doctor and a mother, Lindsay had done years of research into autism and when I asked her to make a recommendation she spoke about the importance of having a supportive and empathetic team around the child.

So my recommendations for UK practitioners take a simpler form from that which I had envisaged. And, perhaps, a more achievable form. Because what needs to be put in place in our schools is a fundamental awareness and acceptance of autism. It is a complex disorder and this complexity needs to be shared with teaching professionals. It needs to be understood and accepted in our classrooms by both teachers and peers before we can even begin to improve provision and training and increase the number of specialist school places. All teachers in the US – even the mainstream teachers I met at Westchester Middle School in the Bronx, New York – have a thorough understanding of autism through their teacher training programmes. At one school I visited I even met an autism representative – someone with a background knowledge of autism and an interest in current methods and trends who could advise teachers and families. They may disagree over pedagogical approaches, but what I realized was of utmost importance was being informed and aware. This made teachers into the empathetic and considerate practitioners they need to be. I

recommend that all initial teacher training providers directly include autism in their training modules and incorporate visits or placements to special schools where trainees can meet young people with the disorder and experience a range of teaching methods. Autism is not a global disability and those affected can have a variety of skills and deficits. The tagline to *Loving Lampposts* is: 'if you've met one autistic person, you've met one autistic person' and, as Drezner explores the truth of this saying in his film, we realize how complex and individualized learning needs for autistic children are. The Teachers' Standards in the UK (the standards against which both trainees and qualified teachers are assessed since September 2012) require teachers to meet the special educational needs of learners in their classroom. But considering the complexity and individuality of autistic learners, and the fact that the prevalence is increasing in mainstream settings due to broader diagnoses, autism must be addressed discretely and directly in teacher training and performance management.

Eight weeks of observations and discussions with professionals, families and individuals with autism in the US has changed my teaching practice in many ways. This is why I place great importance in exposing UK practitioners to autism, its challenges and some helpful steps in the mainstream classroom. Some of these considerations seem small – warning an autistic pupil in my Year 9 class of an upcoming activity or a change in classroom layout to relieve anxiety, reconceptualising success in some activities so that social skills are deemed important and worth improving, placing more importance on routines and familiarity and modeling appropriate behaviours and expression. I saw that that these small considerations are making a difference to the pupils I met in the US. Reducing factors in the classroom that cause anxiety can improve learning outcomes, attitudes and behaviour. And fostering a spirit of acceptance and diversity in our schools is equally important.

Autism Awareness week is marked and celebrated with enthusiasm in the US and perhaps this acceptance and openness is making a difference to those affected by autism.

As the House of Commons report made clear, inclusion needs to become 'more than a rhetoric'. Teachers in the UK need to be more aware, better trained and more competent in their practice when teaching young people with autism. The Teachers' standards should include direct reference to autism and training providers would then need to address this area for development in their modules and qualifying requirements. Just as importantly, qualified teachers would also need to demonstrate professional commitment and competence in these areas. As Matthew's mother said to me, 'it's all about having a knowledgeable and caring team around the child. That's what will make a difference.' So I look forward to using the details of my report to influence not only my own school's teaching and learning methods but also other professionals through editorial publication and dissemination to the Department for Education. By influencing national teacher training programmes and adapting the Teachers' standards to acknowledge the absolute necessity of autism awareness we will move towards Matthew's mother's vision of supporting these young people.