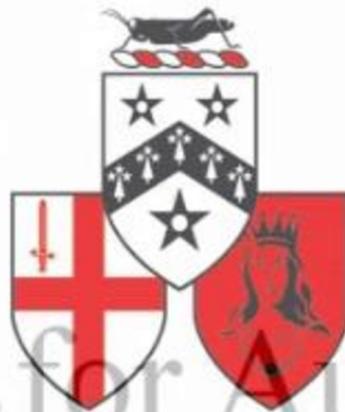


GRESHAM COLLEGE
Founded 1597

A is for Autism Transcript

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A is for Autism

GRESHAM COLLEGE

by

Dame Stephanie Shirley

Director, The Shirley Foundation

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A is for Autism

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Chair, The Shirley Foundation

Good evening Provost, ladies and gentlemen. Thank you for coming.

Gresham College and its Lectures were founded in 1597 to bring new learning to the City of London. Today, its educational programme is disseminated electronically and includes a number of voluntary sector activities, to which I hope this talk makes a strategic contribution. There should be time for some discussion afterwards.

The great Rabbie Burns wrote that "The purpose of life is a life of purpose". The experience of caring for my autistic son Giles was my life for 35 years and – like many parents of a child with autism – the disorder came to dominate my life.

My long involvement with support services, education and training and various strategic initiatives in the autism sector (currently via the *Autistica* charity concentrating on medical research into causes) is grounded in my traumatic childhood. But I've done nothing by myself, it's all been from networked team effort.

Autism brings into sharp focus what it is to be human. I was born in Germany at a time when Jewish families were described as subhuman and we moved around seven countries in Europe looking for safety. My parents then did a very brave thing: they organised for me to come to Britain on a Kindertransport, into the arms of strangers, thinking never to see me again. I was only five when my weeping mother put me on a train of 1000 children with two adults and "let go".

Professionals also have to learn to "let go" but for me the phrase captures the experience that parents have of letting others help their vulnerable child.

I grew up in England, studied mathematics at night school, (Sir John Cass College, now part of Metropolitan University) became a systems engineer and founded an early software house, that in 1962 pioneered flexible working for women with domestic responsibilities. I was the first woman this, the only woman that, always fighting for equal citizenship.

Today I'm going to tell you about autism and shall interweave the story of my son Giles with the autism story. Autism is a lifelong disorder affecting over ½ million people in the UK. It varies in severity so is called a spectrum disorder. Many (55%) are below the historic cutoff point of 70 IQ. Others, often described as having Asperger's syndrome, are highly intelligent. All of them have difficulties in communicating and forming relationships with others and find it hard to make sense of the world around them.

Giles was a beautiful baby. We led a quiet, stable life in the country and at first he seemed to be doing rather well. Then, like the changeling in the fairy story, he lost the little speech had and turned into a wild unmanageable toddler. Not the Terrible Twos but he was autistic.

Autism was at that time (early 60's) considered a rare disorder. Today the latest estimates are around one in every 100 children, the increase being partly accounted for by redefinition and better diagnosis. But not wholly so. There are no reliable figures available for adults. Nor is there any actuarial information. The rapid increase explains the poor national funding and the unacceptable waiting times for services that spell lost opportunity.

Worldwide, a new case of autism is diagnosed nearly every 20 minutes. Altho' it's been separated out from learning disability for some 60 years now, the World Health Organisation is only last year naming autism specifically. That's an epidemiological study of learning disability in low to mid income countries. The incidence does not seem to vary by continent, by climate, by diet. It certainly varies by gender. Autism is found four times more often in boys than girls. It presents itself somewhat differently. So there may be an element of underdiagnosis for girls.

One of the early studies found a statistically significant link between autism and engineer parents – there have been a raft of studies linking autism to difficult births, to Jewish parents, to mercury from mobile phones, old iPod batteries and other products of the electronic age, to first born children ... none adding very much to understanding but the many adding to confusion.

Equally, there's no evidence that vaccines are contributing to the increase in autism but rather like the occasional child for whom eating part of a tiny nut can bring on a life threatening reaction, it's possible that some children's immune system can't deal with toxins and so vaccinations may lead them to autism. The MMR case should have finished when Andrew Wakefield was struck off the medical register. But its serious repercussions linger on.

Genetics

So far, about 20 genes are thought to be associated with autism susceptibility. Clues also come from simpler, single gene disorders where there are autism symptoms.

Autism has been known for a long time to run in families. If you have a child with autism, there's a 5 or 6% chance a sibling would also be affected. *Autistica* is investigating the incidence in cultures such as Saudi Arabia where it doesn't just happen that close family members marry but it is the norm. More than half the couples are close blood relatives.

Diagnosis

Giles was diagnosed at the Park Hospital in Oxford, at the age of three and we were advised to put him into an institution and start our family anew. We sought genetic counselling but there was then little understanding of what is now recognised to be one of the most heritable disorders. In any event we decided to concentrate on the child we had, though mourning the child who might have been.

In that dark age, learning disability was termed mental handicap and many children were categorised as ineducable and came under Health rather than Education. Early exceptions were those with autism so parents pressed for an autism diagnosis – an example of how statistics can get skewed.

As one of the so-called refrigerator mums of that period, I was conscious that my maths degree was not good training to be a mother but could not believe that any mothering deficiencies could have affected my baby so catastrophically. My guilt was not helped by terms such as “elective mute” which can be deeply hurtful. So don't sneer at political correctness. Think of the impact of Mahatma Gandhi changing the name of the “untouchables” to “children of god”.

Today, a diagnosis of autism covers such a wide range of disability that we refer to autisms. Some are regressive, some not; (it's striking that both often co-occur in the same family); some are associated with epilepsy; some not; the high functioning end, Asperger's syndrome; we say autistic spectrum but since it ranges in at least three dimensions – language, social, obsession with order – we should perhaps talk of an autistic space. Whichever whichway, we know very little.

The ideal service would provide optimum medical, educational, social and support services for people with Autism Spectrum Disorders and their families and carers ... a holistic approach to autism. That's only possible if agencies work together, if there are enough professionals, if funding is targeted irrespective of co-existing problems and there's a national register of those requiring support. That summary is not mine. It comes from what is now NHS Scotland.

Respite

We got one period of respite care for Giles, we “let go” and were certainly more able to cope after the break. We had a comparable attack of independence when Attendance Allowance was first announced. Surely that was not for us with my husband in full employment? But I learnt to do away with guilt and accept whatever help was available.

Interventions

We were desperate – reading anything that might be relevant (the then current fad was for megavitamins). And even today there is a disturbing fringe on the Web offering conspiracy theories galore and at a price. It is clear that certain interventions help certain children, but no one knows which is going to help whom and in what circumstances. So parents can bankrupt themselves (emotionally, financially) for treatments having absolutely no effect – sometimes to an abusive level: a strict training regime of a young child for 40 hours a week is not to my mind respectful of that little person. There have been tragic examples of more severe interventions and I'm reminded of Florence Nightingale's stricture to “do no harm”. Educators also need a Hippocratic oath. Without that, we're acting as if the child is indeed ineducable. We need to distinguish between child assent, parental permission, legal authorisation and moral responsibility.

The National Autistic Society (lead charity in England) spun off Research Autism which compares and contrasts the many different interventions so as to give parents meaningful facts and figures about some of the seven hundred interventions it lists.

ABA

There are whole schools dedicated to Applied Behavioural Analysis – ABA devised by Ivar Lovaas in the mid 60s using rewards (a Smartie, a raisin) for the tiniest progress in social, behavioural or academic learn-units. If achieved 18 times out of 20 over 3 days, the child is credited with having mastered the learn unit. Put the cup on the saucer.

Just because pupils can't speak doesn't mean the National Curriculum is closed to them. They are all learning to learn. Educators working 1:1 are an ABA hallmark and across the UK this 1:1 working model is used in many schools not adopting a totally ABA approach.

Of course there's also speech and language therapy, some based on ABA to reinforce desired speech patterns.

Diet

Given the media hype in relation to diet, I'd like to make a brief comment. Removing grain, especially wheat, and dairy products from the diet are two common treatments which work for some – but not others. If they work it's very dramatic: only days for children, weeks for adults. Note though that as yet no scientific review of diet studies has shown a positive result. In *Who's Who*, I give my recreation as “wishful thinking”. We shouldn't overlook wishful thinking when a new intervention is heralded.

TEACCH

The late Dr Eric Schopler was another pioneer in the field of autism education. Not a name known to everyone but this kind and humane man founded TEACCH, used all over the world and one of the most widespread approaches to autistic children.

Dr Schopler trained with the more famous, to me infamous, psychoanalyst Bruno Bettelheim who compared the parents of autistic children to concentration camp guards.

Eric Schopler together with the late Dr Bernard Rimland co-founder of the Autism Society of America, saw instead caring people who had frequently raised “normal” children in the same household. These two first described autism as a brain disorder, not a mental illness. The aging of so many autism pioneers has triggered one of my recent projects to commission Adam Feinstein to research and write *A History of Autism: Conversations with the Pioneers*. This was published last year by Wiley/Blackwell.

Son-Rise

Last year there was also a first ever study of Son-Rise (Son as in Daughter not Sun as in Moon) by Lancaster University teamed with Northwestern in the States. As yet unpublished, this recorded some improved (child-initiated social interaction and communication) behaviour after a 40 hour intensive Son-Rise intervention with six children with autism (matched with six control children). It would be interesting to have had a larger sample size and also to compare with other 40-hour interventions, both for the subject children and for the control group who received no intervention.

I say this because the earliest autism research project the Shirley Foundation ever sponsored was very like this – tho' the sample sizes were larger – and we cancelled it one year in.

Facilitated Communication

Facilitated Communication is not in regular use in the educational system here though widely used with apparent success in Germany. This is the controversial system – originally from Australia – which it is claimed allows non-verbal individuals to communicate via a keyboard. Its detractors insist it is invalid because – like the ouija board – it is the assistant supporting the arm, not the subject, doing the communicating. Certainly that was my belief; I am trying to be open-minded because of a severely autistic boy Jamie Burke who was one of the earliest students and one of the most successful beneficiaries. He now has a lot to say, only partly by keyboard, about his years of silence.

Even one such example encourages parents to demand standard educational opportunities for all. It's ever our dream, or is it nightmare, that inside every child with autism there's a “normal” child trying to get out.

I've learnt relatively recently to consider autism as a different way of living. Which makes conductive education, in which teachers draw from their pupils rather than impart knowledge, more natural. Education has in any case changed its mission from knowledge to skills – skills that last rather than knowledge that fades. That's dramatically true of special education. Like the sculptor chipping away at the block of stone, teachers reach out to educate the child within.

Longitudinal studies specific to autism concentrate on children at risk: by tracking the development of babies born with an older sibling with autism, researchers are able to spot potential problems (not necessarily make accurate diagnoses) at 1 year, sometimes as early as 9 months. Valuable time gained in which to intervene.

I made many mistakes trying to raise Giles; even with all the love in the world it was not a pretty story. Huge amounts of energy and effort. At one time I seriously thought of getting a sheepdog to help me with Giles. And was intrigued later to read of “assistance dogs” trained for that precise function. Chaos reigned in the years 3-5, but I could pick him up then and so avoid the worst disasters. He was doubly difficult in puberty which started (far too early) at age 11, when he also developed epilepsy. About a third of people with autism are either born with or develop epilepsy. Brain research shows the closeness of the abnormalities.

The associations between autism, epilepsy and learning disabilities such as Tuberous Sclerosis, Fragile X and Down's Syndrome are important in meeting affected people's needs. But next to nothing is known about the nature of the links.

At one time, Giles was prescribed Lithium on the basis of his possible manic-depression. Depression is equally probable as existing alongside autism and the suicide statistics for Asperger adults is an horrendous 6% -- nearing the 10% rate of the very severe mental illnesses such as schizophrenia.

Asperger children usually realise that they are different to other children between the ages of 6 and 8. It's important to help them fit in - perhaps by getting someone from their own age group to choose their clothes and supervise their haircuts. Bullying is four times higher than for their peers and in the teenage years, an average of one in ten Asperger adolescents are victimised by their peers. Figures are probably conservative, the children accepting bullying as "this is the way it is". What is undisputed is that six out of every hundred adults with Aspergers succeed in taking their own lives.

Given these facts we must learn more about the nature of Autism Spectrum Disorders. Investment in research to further knowledge is essential.

Life is not just the one with autism. We'd decided to restrict our family but we had always to keep going, not least keep our own sanity. As I said earlier, what the family needed was a wraparound programme of support.

Giles did not sleep much so my husband and I operated a shift system. No wonder the divorce rate in parents of autistic children is 80%. Looking back, it was a terrible period. One of the practical research studies my Shirley Foundation funded much later was a comprehensive study of sleep patterns and parents' perceptions of them. That was at Oxford's Park Hospital - the very same hospital that Giles went for diagnosis - 8½ months Monday to Friday - with me in the associated Mother's Unit .

It was Great Ormond Street hospital who first used the A word to me and introduced a child therapist.

There's now a national Centre for High Functioning Autism Spectrum Disorder at Great Ormond Street Hospital. It sees children 3-16 in mainstream education, offering diagnosis and recommending bespoke intervention for each child. They also train professionals. One of their current research aims is to reduce mental health problems.

Always to the fore, last year they started a study into transitions, transition to the adult world, as pupils with high functioning autism move from primary to secondary education. A training pack for teachers and families is in planning and the plan is to have trained support workers to help patients with autism. Too often researchers don't talk to clinicians and clinicians don't talk to educators. And nobody seems to listen to the parents - experts in their own children. It's important to trust in instincts and not let the professionals push the family into anything. There is a crying need to train mainstream teachers to make the term "inclusive" more meaningful, to have associated specialist units and indeed special schools.

Giles lost the few words he had as a toddler and never spoke again. For others, vocabulary and pronunciation seem to rely less on family conversation than the Americanisms of TV and films.

Giles had one term at an old style training centre - until he flinched when I waved. Someone had been hitting him. Parents, indeed everyone, have to learn to listen, listen hard to these non-communicating children. Later Giles went to an excellent weekly boarding school.

We never managed to find any secondary schooling for Giles. He was after all (then classed as) ineducable. There were occasional day services that wanted to help but often I'd just get home after settling him in somewhere to get a phone call saying, through gritted teeth that they couldn't manage and would I come and collect him? It was indeed an awful, ghastly period. We got a bit of financial help from various grants, most of whose applications procedures were not relevant to autism. There's a crying need for more and better partnerships to meet people's needs rather than trying to squeeze people into the framework of existing services

A quarter of pupils on the spectrum are excluded from school at some time, two thirds of those more than once, with others being bullied and ostracised in inappropriate settings. The National Autistic Society reported that only 40% receive a service that is suitable to their needs. But if that's poor, it's a lot better than the 3% of adults they estimate to be getting suitable services.

But things are improving.

Eventually when Giles was 13 I cracked up and both of us finished up in hospital. I came out of mine after a month and was back at work within the year. Giles stayed in an old-style subnormality hospital for 11 years. He was in a locked upstairs ward with a dozen adolescent boys. We took him home every weekend, then couldn't manage even that so were reduced to taking him out for a weekly picnic in the grounds. Fine in summer. Awful in winter when we cowered under a heat reflecting sheet. Very difficult to retain any sense of family. When I phoned midweek to learn how things were going, the activity for the day was too often described as "we have been hoping to go out". After over 25 years of Care in the Community, there still remain people living such restricted lives.

Adulthood

Giles became institutionalised in hospital and, as can so often happen, lost most of his human rights. The abuses made us determined to get him back into the community and so we set up the *Kingwood* Charity. Giles was the first resident in the first service. Today *Kingwood* supports over 50 autistic adults whose needs challenge existing services. Some in their own homes (funded by Housing Benefit) some in parental homes, a few in a small facility for five residents. *Kingwood* is just starting to use assistance dogs.

Few adults who received a childhood diagnosis of typical autism are self-sufficient. Less than 10% do well and the remainder are dependent on support in all aspects of life. The average additional lifetime cost resulting from autism with learning disability is estimated to average £4.6m – only 7% education, some in direct support most of it in lost employment. The national cost averages an astonishing £28bn a year (£28bn was the cost of Northern Rock).

We never got anywhere near considering paid or voluntary work for Giles but jobs are now achievable for some of his peer group via work placements and support from various organisations notably the NAS Prospects service. Any work seems to be best based on a child's specialist interest. In Giles' case that was only jigsaws and cats – so perhaps I might have looked for simple tasks in a toyshop or sweeping up in a cattery.

University students on the autistic spectrum, (usually reading maths or computer science) need an understanding environment and a lot of them drop out.

Several City organisations committed to diversity, employ staff on the autism spectrum, often starting as interns. This is true even in today's straitened economic times. Managers have commented that learning to understand the communication difficulties of those with ASD has helped them to communicate with their whole team more effectively.

Let me tell you about one such organisation. The investment bank Goldman Sachs has had an Asperger syndrome initiative since 2003.

Working with the National Autistic Society, they started with one man with Asperger's syndrome on work experience. Although well qualified, he'd never worked before. Now he's permanently employed, not with them as it happens, but with another company.

Their second Asperger's syndrome worker after a five week placement, secured a position with the Royal Courts of Justice in the Strand. So they went ahead with paid interns – and have now developed good disability practice throughout the firm. So far this has given 26 people the opportunity of an internship – a good start to ongoing employment. They've committed to at least four paid placements a year.

BT has comparable policies and practice.

Of the 300k people of working age in this country on the autistic spectrum, 78% are of average or above average intelligence. Only 15% are in full time paid employment – far less than the proportion of disabled people generally.

There's no doubt that people with Asperger's may provide accurate loyal, hardworking, honest staff who perform well on repetitive, factual tasks [enquiry systems is the one which is always quoted]. Their approach is straight forward and honest. They may have excellent technical skills, and a good knowledge of facts and figures. Those staring-at-the-screen type of jobs are well suited to people with Asperger's syndrome.

But equally they can create difficulties. They can be negative, undermining everything. Quiet, know-it-all thinking of all the reasons not to. People are paid to do a certain job and may have to be shown how to present a positive face. Large groups may be too stressful. One-to-one working is ideal. A designated workspace, not a hot desk! Facing the wall perhaps, perhaps with special lighting or tinted lenses to filter out the frequencies that cause problems. Or headphones to block out the noises that wouldn't worry me but are excruciating for them.

People with autism relate better to the consistency of computers than to unpredictable human beings. So IT enables them to work better and faster. As it can do for us all.

We accept that it is discriminatory not to provide documents and keyboards in Braille for people who are blind. But few understand that social inclusion can be actively discriminatory in the case of Asperger's syndrome. Perhaps we all need to adapt our ways of working rather than the conceitful reverse: expecting intelligent adults with autism to adapt to standard work environments. They must be accorded equal citizenship.

Another strategy is to help young adults develop specialisms in tasks such as graphic arts where customers seek them out as a consultant. Pattern cutting in Saville Row is another highly skilled task that proved successful.

Caring for autistic people is hard. But autism can also mean originality and creativity. And innocence. My experience is with a profoundly affected child in days long past. But a recent survey showed that both parents and professionals still feel that there is, and I quote: "very little available indeed".

One of the Shirley Foundation's smaller projects was the £20,000 (matched by the Disabilities Trust) to support

Autism Awareness Year 2002. This brought 800 autism charities and not for profit groups together for the first time and led to a number of standing partnerships. Nobody does anything by themselves anymore; and I believe in partnerships and alliances of all shapes and sizes. There's so much to do that reinventing the wheel makes me see red. Only by getting everyone together to lobby on shared points are we likely to make anything happen in time for today's children.

Autism Awareness Day led to some groups coordinating a bit, starting with the day itself April 2nd each year. The 730 responses of an annual survey carried out this year are just being analysed.

My largest charitable project was Prior's Court School, near Newbury for pupils with both autism and learning disabilities. It made me think about what education was all about. Certainly education has changed its mission. Education used to be largely knowledge. Now that each of us has access to so much information, education is more about skills, skills that last rather than knowledge that fades. Especially true of special education.

Prior's Court is a day and residential school and was the focus of both my dreams and waking hours for five years. Three times I nearly gave up all hope of making the school happen. First when the planned relationship with the twin schools in America and Japan which had originally inspired me broke down. Secondly when we only had two pupils signed up on opening. With 28 staff! And thirdly when Giles died unexpectedly in the middle of the project and I lost all momentum.

It's cruel that loss becomes ever more painful - with most things it's easier the second, the third, the next time. Grief - the last gift - the expression and proving of love - is different. Our earlier sorrows - mourning the child who might have been, mourning the grandchildren we were not going to have - each loss seemed to sharpen the pain of his death.

But love transcends death and grows to take over the bereaved person's life. I have now learnt to live without Giles, without his need of me. Bittersweet but it is a wonderful relief not to have him survive us. The death of a child is unimaginably painful. For a long time his sheer absence was like losing a leg; life became lopsided and out of balance. But sooner or later one learns to walk with crutches.

But there's always an upside to difficult times: the newfound freedom from worry has energised me anew. Autism has become an ongoing mission, a mission that makes sense of Giles' life and puts value on mine, the life that was saved.

The Big Question

Ten years ago I started to focus on The Big Question: what causes autism, indeed what autism is as distinct from what it looks like. Science has also moved on from behaviour to biology. So let me talk a bit about what is happening in biomedical research:

By measuring heads, children with autism have been shown to average a normal head size at birth but increase above the population norm for the next three years so that on average children with autism have larger heads. But this evens out. What can that mean? Internally, imaging technologies show differences in brain anatomy so that, for instance, we "normal" people process faces in a certain part of the brain; those with autism use a different part. What can that mean? Recent research indicates that it's the abnormality of the cabling between different parts of the brain that is the central problem. What can that mean?

The *Autistica* charity aims to determine the causes of this baffling disorder. The dream is for a practical biomarker. There are a number of programmes. The international search for the genes that if not causing autism but rather confer susceptibility, is The Autism Genome Project led by Professor Tony Monaco at Oxford. There are exciting prospects for future work that will support the diagnosis and treatment of autism.

Autistica also funds pilot studies and mentored Fellowships to increase the UK's research capacity. It led the funding of a new Chair in autism at Cardiff University. Currently doing the same for a Fellowship in Autism for Scotland. Also international Fellowships, to date with Saudi Arabia and India..... People are always asking if we can't do more. No one has ever complained that we do too much!

The next 5-10 years can also be expected to deliver significant advances in brain imaging. Progress is hampered by not having enough *post-mortem* brain material and by the non-standardisation of imaging systems. The Autism Brain Bank was funded a few years ago by a single unrestricted donation to *Autistica*. Already it has 15 brains - each capable of providing material for several research projects. 855 projects have now been approved to use donated brain tissue and the tissue of some individuals - tiny slivers of brain - have been used by over 30 laboratories. Control samples are also needed. We don't know which areas of the brain will become the focus of future research, so samples are taken from all areas. My own brain, indeed also whole body, is to go to medical research.

There is still no known cure for autism although some interventions with people of high intellect can result, do result after many years, in a few people learning to lose their mannerisms and becoming seemingly "normal".

Certainly I have learnt to view autism as a different way of living but there is no way in which I would ever choose to have a child as profoundly handicapped as Giles. Despite everything we tried to do, his quality of life was very poor.

But as many people have found: Research is slow. Research is expensive. It demands involvement and cannot be delegated very far. The best planning in the world gives perhaps only a 1 in 10 chance of a particular research project finding anything that will make a difference. Progress depends on research, yes, but also vigorous information exchange among researchers; and translation of their findings into service provision.

Mercers (which supports Gresham College) and the Girdlers' and Clothworker livery companies are among City organisations that provide charitable support for autism.

But chairman, autism is no longer on the fringes of policymaking, provision and importantly knowledge. It is a mainstream and very serious concern. It has recently been rebranded as AQ, the autistic quotient, implying that it is an inherent human condition. Autism strikes at the very centre of what we think of as being human. To understand the autistic mind and allow lives of equal citizenship is a major and crucial problem.

Ladies and gentlemen, I hope that, by telling you my personal story, to have spread new learning in a way that Sir Thomas Gresham would have approved.

I thank you for listening to me.

And am very happy to take questions.

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