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<b>Title</b>	<i>A is for Autism</i>
<b>Description</b>	Dame Stephanie gives a talk about her philanthropic work in autism, looking at the condition's history, its causes, the treatments, specialist education and society's position on autism
<b>Presenter(s)</b>	Stephanie Shirley
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**Contributor** Thank you very much. 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 has come to dominate my life. I have been long involved with support services and education and training and various strategic initiatives in the autism sector, and I will talk a little bit about them. Currently it is via Autism Speaks, which funds research into the causes of autism.

I'm also working with the World Health Organisation and peripherally a bit with the United Nations, who have recently set out a target slightly similar to my strategic, to understand the causes of autism. They've said in 10 years, so they are saying 2019. So, it is moving forward. All that really is grounded in the traumatic childhood, which the Chairman mentioned. I really - people say, "Well you've done a lot," and of course I do work very hard.

Started working at 18 and I'm still working flat out now but it's not really what I've done, it's all a matter of teamwork and I always think of myself as a gardener, sort of growing other people to do the other things that need doing. Now autism really brings into sharp focus what it means to be human. I was born in Germany at a time when Jewish families were described as subhuman. We moved around several countries of Europe looking for a safe place. My parents then did a very brave thing and organised for me to come to England on a kindertransport, into the arms of strangers who fostered me and brought me up as they would their own.

My birth parents never really expected see me again. I can just about remember when I was five years old, my weeping mother putting me on the train in Vienna and then let go. Professionals also have to learn to let go and to me the phrase captures the experience that parents have, of letting their children go, letting others help their vulnerable child. I grew up in England, studied mathematics at night school, became a systems engineer, founded an early software house which pioneered flexible working for woman.

The experience that I had there in outsourcing, I have now used very much in my philanthropic activities. I was the first woman this, the first woman that, always fighting for equal citizenship. People used to ask me, "Are you a feminist?" and I'd say, "No, I'm a humanist." I really believe in that equal citizenship and that applies for people with learning disabilities, it applies to people with physical disabilities and of course it applies, less so, to woman. My link with Balliol comes from the Oxford Internet Institute, where they have given me a Foundation Fellowship for the activities that I've done there, with the Internet Institute.

That is concerned with not the technical side of the internet, fascinating though that may be; but the social, economic, legal and ethical issues involved in the 21st century. Professor Margetts, from the Oxford Internet Institute, is speaking this afternoon on woman and the web, all these things are interconnected. One used to, in order to achieve something, have to focus very, very tightly on something. Digging down for some eternal truth but at the moment in science, it seems as if it is the cross discipline, the multidisciplinary things that are really helping society and certainly helping equal citizenship.

So, today I'm going to concentrate on autism and we will interweave the story of my son, Giles, with the autism story. It's a lifelong disorder, affecting over half a million people in the country. It varies in severity, so it is called a spectrum disorder. About 55% of the people affected are below the historic cut-off point of an IQ of 70. Others, often described as having Asperger's Syndrome, highly intelligent. All of them have difficulties with communicating, difficulties with forming relationships with others and find it hard to make sense of the world around them.

In our family, my husband always focused, you know, "If only he could speak," on the communication side and so on, but actually it was the inability to make relationships with others. Particularly a child that doesn't bond with his parents, that really made his life so impossible. He was a beautiful baby, I know all parents say that, but he was particularly lovely and it is almost a characteristic. We led a quiet life in the country and I deliberately made it quiet because I'd had such a turbulent childhood.

At first we seem to be doing rather well, I'm the mathematician, I really didn't know anything at all about children. So, we managed to bond, or at least I bonded to him, it was one-sided, and he physically thrived. I began to be worried at about eight and a half months, when I took him to the Doctor and sort of said, I said, "His head's a funny shape," which it was, it was sort of flat at the back. In fact I was worried about his social development.

Then, really like this changeling in the fairy story, he turned over in a matter of a few weeks, into a wild unmanageable toddler and he lost the speech that he had. Autism is one of those disorders, I think there are others but rare, where you actually regress. He was developing however slowly and then he lost it all. Not the terrible two's but he was later diagnosed as autistic. Autism was then, I am talking about the early 60s, considered to be a rare disorder. Today the latest estimates are that something like one in a hundred children are on that spectrum.

That increase being partly better diagnosis, partly, and again significantly, but partly a wider diagnosis of what it means to be on the autistic spectrum. Certainly in the 60s we didn't talk about a spectrum. Some of it may be real, so there is still a thought about is autism growing in numbers. There are no reliable figures available for adults because these things were not measured and monitored, nor is there any actuarial information. I have just started a project with the Mental Health Foundation to try and find out a little bit more about life expectation.

Which is, I was always told and every parent is told, is normal life expectation but I frankly have attended too many funerals of young people with autism, that it doesn't feel like a normal expectation. That rapid increase really explains some of the poor national funding because I lobby quite a lot for that and the unacceptable waiting times for services. There are an awful lot of things that we don't know but we are pretty sure the earlier you start to intervene with something like autism, the better the prognosis.

So, each year lost, each yet delayed, is not able to be recovered. Worldwide a new case of autism is diagnosed about every 20 minutes, so it is a significant thing. Although it has been separated out from learning disability for some 60 years now, the World Health Organisation has only this year naming autism specifically; and that is in an epidemiology study of learning disability including autism, in the low to mid income countries of the world. The incidence does not seem to vary by continent, by diet, by climate; it certainly varies by gender because autism is found four times more often in boys than girls.

One of the early studies found a significant link between autism and engineer parents; I'm a systems engineer! There has been a raft of studies linking autism with difficult births, to Jewish parents, to mercury from mobile phones, old iPod batteries and other products of the electronic age, to firstborn children. That is obvious what happens to the statistics there, like me, we decided not to have any more children, so the only child is then... None of those studies really add very much to the understanding of the disorder but many of them actually 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 might lead to something. The MMR study is not closed. We have spoken about the genetics and so far about 20 genes are thought to be associated, not so much with autism but with autism susceptibility, it's all getting a bit sort of mucky isn't it.

The clues come from the simpler single gene disorders, where there are also autism symptoms. It's been known for a long time to run in families, if you have a child with autism there is a 5% or 6% chance that a sibling would also be affected. Autism Speaks, my current charity, is investigating the incidents in cultures such as Saudi Arabia, a very interesting place to work in, where it doesn't just happen that close family members marry but it is the norm. Over 50% of parents are closely related by blood, usually first cousins.

Giles was diagnosed at the Park Hospital, here in Oxford, at about the age of three. We were advised to put him into an institution and start our family a fresh. We sought genetic counselling, again here in Oxford, 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 called mental handicap and many children were categorised as ineducable, it came under health rather than education. The only exception to that ineducable label was autism and so many parents actually pushed for diagnosis in autism because that would get their children into special schooling of some sort, rather than literally given up as far as education was concerned. That is a wonderful example of how statistics can get skewed, parents were pushing for this diagnosis.

As one of the so called refrigerator mums of the period, the implication was that we had somehow caused this disorder. I certainly - I was conscious that my maths degree wasn't good training to be a mother but I just could not believe that any mothering deficiencies could have affected my baby so dramatically, catastrophically. My guilt was not helped by terms such as, 'He's an elective mute,' which can be deeply hurtful, as if he's choosing not to communicate with me.

So, don't sneer at political correctness, a lot of changes - the big impact from when Mahatma Gandhi changed the name of the untouchables to Children of God. Today a diagnosis of autism covers such a range of disability, that we referred to or autisms. Some are aggressive, I used to think they all were and it was some time before I realised the other children were not like that. Some not, it's striking that they often co-occur in the same family. Some are associated with epilepsy, quite a lot, about a third. Some have no epileptic problems.

Some are 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 about an autism space, an autistic space. Whichever which way you look at it, we know very little. The ideal service for families with an autistic member would provide optimum medical, educational, social 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 and if there are enough professionals, if funding is targeted irrespective of coexisting problems and there is a national register of those requiring support. That's not my dream, that summary comes from what is now the NHS Scotland. We have

known what is needed for quite a long time. My husband and I got one period of respite care for Giles, we again let go. Actually it was fairly disastrous for him and I would never actually do it again but it was better for us and we were more able to cope after the break.

We had a comparable act of independence, when Attendance Allowance was first introduced, surely these benefits, Attendance Allowance were not intended for me, with my husband in full employment. I learnt to do away with guilt and take whatever help was available. We were desperate, reading anything that might be relevant, the then current fad was to pump vitamins into the children, mega vitamins. Even today there is a disturbing fringe on the web, offering conspiracy theories galore at the price. It's clear that certain interventions help certain children but no one knows which is going to assist who 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 of 40 hours a week, is not my mind respectful of that little person. There have been tragic examples of more extreme interventions and I am reminded of Florence Nightingale's stricture to, 'Do no harm'. Educators also need a Hippocratic oath because without 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, the lead charity in England, they spun off Research Autism, which compares and contrasts the many interventions, so as to give parents meaningful facts and figures. That charities is only a few years old, it is not very well funded and it is only just beginning to look at some of them. So, let me tell you what little we don't know.

There are whole schools of thought dedicated to something called applied behaviour analysis, ABA. It was devised by Ivar Lovaas in the mid 60s using rewards for the tiniest progress in social behaviour or academic learning. It is rewards; a smartie, a raisin, very specific rewards because just saying, "Well done," "Oh, I think that's good," doesn't work. What do I mean by a learn unit? Very simple; put the cup on the saucer rather than throwing it across the room or put the saucer on the cup, very specific learn units.

If a pupil has mastered a learn unit 18 out of 20 times over a period of three days, the pupil is credited with having learnt that learn unit. So, it is very painstaking, very labour intensive. Just because pupils can't speak and have problems with communication, doesn't mean that the national curriculum is necessarily closed to them, they are all learning to learn. Educators working one to one with pupils is an ABA hallmark and across the UK this one to one working model is used in many schools, not using totally ABA, one to one, very labour intensive.

Of course there's also speech and language therapy, some based on an ABA, to reinforce desired speech patterns and there are some films around showing people doing that. I always find them a bit demeaning but anyway some of them work. There is a lot of media hype about diet, so let's comment on that. There are two common treatments, removing grain especially wheat and removing dairy products from the diet. Those two treatments do work for some people but not for others.

If they work it's very dramatic, it's within weeks for children, months for adults, very dramatic. Correction, sorry; days for children, weeks for adults. That's pretty fast for anything to happen. Note though, as yet there is no scientific review of diet studies that have shown a positive result, although we think it works, it works dramatically, it works well, easy to do, or relatively easy to do. In *Who's Who* I give my recreation as wishful thinking and we shouldn't overlook wishful thinking when a new intervention is announced.

There is another intervention called TEACCH, spelt with a double C and that was the late Eric Schopler, who was another pioneer in the autism education. Not a name known to everyone but this kind and humane man, he founded TEACCH and is now used all over the world and one of the most widespread approaches to autistic children. He trained, Dr Schopler, with the

more famous old 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, cofounder of the Autism System of America, saw instead caring people who had frequently raised normal, and one learns political correctness talks about neuro-typical children in the same household. Those two first described autism as a brain disorder, not a mental illness.

The aging of so many autism pioneers has triggered one of my current projects, which is to commission a history of autism, conversations with the pioneers, it is going to be published by Wiley-Blackwell next spring. The history of medicine, there are things that we can learn from that and it's quite a scholarly work, I'm very pleased with it. Let me talk about another intervention, which is more extreme, facilitated communication. It's not in regular to use in the educational system, although it is widely used with apparent success in Germany.

It was originally from Australia and it was claimed that it allowed nonverbal individuals to communicate via a keyboard and a helper just sort of gave them a little bit of physical support to do it on the keyboard. Now, it's detractors insist that it's invalid because it's rather like the Ouija board, it is the helper that is actually communicating via the keyboard not the individual.

That was my belief and I'm trying to be open minded because I have read of a severely autistic boy, Jamie Burke, who is one of the earliest students and one of the most successful beneficiaries and he now has a lot to say, and only partly by keyboard. It sounds funny doesn't it? Even one such example, encourages parents to demand standard educational opportunities for all, if ever our dream or is it nightmare, that inside every child with autism, there is a normal child trying to get out. It is a nightmare.

I learned relatively recently to think of autism as a different way of living and that makes conductive education, in which teachers draw from their pupils, rather than impart knowledge more natural. Education has in any case changed its mission over the years. It has changed really from knowledge, to skills. Skills that last, rather than knowledge fades. That's dramatically true of special education. Like the sculptors chipping away at the block of stone, the teachers always trying to reach the child. A lot of longitudinal studies specific to autism concentrate really on children at risk.

I talked earlier about being in families but by tracking the development of babies born with an older sibling with autism. So, you have a family that has an older sibling, new baby coming along but by tracking that almost from pre-birth actually, researchers are able to spot potential problems, where development is starting to diverge from what is expected. So, spot problems, not necessarily make a diagnosis, as early as one year, perhaps even coming down to nine months. That is valuable time gained, in which to make an intervention.

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, to run after him, to keep him - it was just awful. I am intrigued to recently read of assistance dogs, which are used for precisely that sort of purpose. Chaos reigned in our family from the years of three to five but I could pick him up then, so avoid the worst disasters.

He was doubly difficult in puberty, which started far too early at the age of 11, think how difficult we all find puberty but he couldn't cope with it at all. Also at that time he developed epilepsy for the first time. About a third of people with autism are either born with epilepsy or develop it later. Brain research shows some 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. Next to nothing is known about the relationships.

At one time Giles was prescribed Lithium, on the basis of his possible manic depression, we did have good days and we did have bad days. Certainly depression is equally probable as existing alongside autism and the suicide statistics for Asperger's adults is a horrendous 6%. That is

nearing the 10% rate of the very severe mental illness such as schizophrenia. Asperger children usually realise that they are different to other children between the ages of six and eight, they themselves know that there is something.

It's important to help them fit in, perhaps by getting members of their peer group to help choose their clothes and sort out their haircuts. Bullying, I know it's common, but bullying is more common, something like four times more common than among their peers. In the teenage years an average of one in ten Asperger adults are actually victimised by their peers. Figures are probably conservative because with the demand for sameness and the acceptance and seeking out of sameness, children with autism accept the world, that's how it is.

What is undisputed is, that six out of every hundred adults with Asperger's succeed in taking their own lives. Given those facts, we really must learn more about the nature of autism spectrum disorders and investment in research is essential to further knowledge. Life is not just the one with autism. We decided to restrict our family but we all had ourselves to keep going, not least keep our own sanity. As I said earlier, what the family need is a sort of wrap around system of support, rapport.

Giles didn't sleep much, so my husband and I operated a shift system. No wonder that the separation rate among parents of autistic children is up to 80% compared to something like a third in other families. Looking back it was a terrible period. One of the practical research studies that my Shirley foundation funded, much later here at Oxford, was a comprehensive study of sleep patterns and parents perceptions of them.

That was at Oxford's Park Hospital, the very same hospital actually that Giles went to for diagnosis, he went back from Monday to Friday, for eight and a half months with me staying in the mothers unit there, to try and get a diagnosis, it was that rare at the time. It was Great Ormond Street Hospital who first used the A word to me and introduced a child therapist.

Too often I think researchers don't talk to clinicians, and clinicians don't talk to educators and nobody seems to listen to the parents, who are after all experts, not in much but in our children. It is important, I think, to trust in instincts and not let the professionals push the family into anything and I've been pretty stubborn about some things. 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 are still need.

Giles lost the few words he had, he never spoke again but for others with speech, and there are many, vocabulary and pronunciation seem to rely less on family conversations than the Americanism of TV and films. Giles had one term at the early old style training centre until he flinched when I waved him goodbye, somebody had been hitting him. Parents, indeed everyone, has to learn to listen. Listen very carefully, very hard, to non-communicating children. Later on he went to an excellent primary school but we never managed to find him any secondary schooling, he was after all then classed as an ineducable.

There were occasional day services that offered to help but often I would just get home after having settled him in somewhere to get a telephone call, with somebody speaking rather through gritted teeth, "Mrs Shirley, we cannot really cope. Could you come and get him." So, I had just about had one cigarette and I'd be turning around and having to go again. We got a bit of financial help from various grants, most of the application procedures socially irrelevant to autism.

There's a crying need for more and better partnerships to meet peoples needs, rather than trying to squeeze everybody into a framework of existing services. A quarter of pupils on the spectrum are excluded from school at sometime, 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 an appropriate service suitable to their needs and if that is poor, it's a lot better than the 3% of adults they estimate to be getting suitable services. 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 and I am a workaholic, so a year was quite a long time to be unable to work. Giles stayed in an old style sub-normality hospital for 11 years, he was in a locked upstairs ward of 12 adolescent boys. We took him home every weekend, then couldn't even manage even that, so we were reduced for taking him out for a weekly picnic within the grounds.

So, we would go for the day. That's fine in summer, I would take food and we would picnic out but awful in winter, when we cowered under heat reflecting sheet. It is very difficult to retain any sense of family. When I phoned midweek to find out how things were going, I was very frequently told that the activity for the day - we'd been hoping to go out. There were still lots of people leading such restricted lives. So, 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. Who was the lady I was talking to about that?

Giles was the first resident, in the first service and today that charity supports over 50 autistic adults, who are defined as the ones who's needs challenge services. It is a dynamic definition because as the services gets better, the people that come in are yet more difficult. Some are living in their own homes funded by housing benefits, some in parental homes, or a least one in a parental home, and a few in a small facility for five adults. We are managing to really support 50 adults who are living very well in the community.

Few adults who received a childhood diagnosis of autism are self-sufficient, less than 10% do well and the remainder are dependent on support in all aspects of life. The additional life time cost effecting, resulting from autism with learning disability and that is not all, as I explained, but it is estimated to average 4.6 million, lifetime cost. Only 7% educational, which you might expect to be there. Some in direct support but most of that is in lost employment because many people on the autistic spectrum, the 45% with the average or above average intellect, should be in work and they are not getting that.

The national cost of autism has been estimated at an astonishing 28 billion a year and if you remember 28 billion would just happen to be the cost of the Northern Rock. We never got anywhere near, considering even, paid or voluntary work for Giles but jobs are now achievable for some of his peer group, via work placements and support from organisations like the Disability Equality Scheme and the National Autistic Societies Prospects Service. Any work does seem to be best based on the child's specialist interest, obsessions if you like.

In Giles' case the only thing he was really interested in was jigsaws, very simple 20 piece jigsaws and he loved cats, we'd always had a cat and poor cat certainly earns its keep. So, perhaps I might have looked for some simple jobs in a toy shop or sweeping up in a cattery. Although they are university students here and elsewhere on the autistic spectrum, usually reading maths or computer sciences, they do need an understanding environment and most aren't really very happy students and a lot of them drop out.

We accept that it is discriminatory not to provide documents and keyboards and 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, our ways of living, rather than the conceitful reverse, expecting intelligent adults with autism to adapt to standard work environments.

They must be, according to equal citizenship, that is the theme of this weekend but at the moment they are - I made the analogy between subhuman, but they are not getting equal citizenship. A good strategy to help young people develop specialism's, is to direct them towards consultancy rather than employment because the sheer interview situation is just so difficult, that they don't get through and they get very depressed.

Now, my experience is of 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." My largest charitable project was Prior's Court School near Newbury, for pupils with both autism and learning disabilities. That made me think about what education is about. Certainly it has changed its mission, it used to be largely knowledge but now that each of us has access to so much information, education is much more about skills. Skills that last, rather than knowledge that fades.

That's especially true of special education, so hang on to that thought. Skills rather than knowledge. Prior's Court is a day and residential school and was the focus of my dream's and working life, working day, for five years. Three times I nearly gave up, all hope of making the school happen.

First, when the planned relationship with a Japanese and American school, well I knew nothing of education, when that relationship broke down. Secondly, when we had only two pupils signed up on opening and we already had 23 staff; and thirdly, when Giles died unexpectedly in the middle of that project and I lost all momentum. It is cruel that loss becomes ever more painful.

With most things it's easier the second or third, the next time, grief, the last gift, the expression, and proving of love is different. Our earlier sorrows, mourning the child that might've 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 rose to take over the bereaved persons life. I have now learned to live without Giles, without his need of me and bittersweet because, while it is a wonderful relief not to have him survive me, we miss him terribly because we used to spend a lot of time with an adult child.

The death of the child is unimaginably painful, for a long time his sheer absence was like losing a leg, lopsided and out of balance but eventually one does learn to live again and to walk with crutches. There is always an upside to difficult times, the newfound freedom from worry has energised me anew and autism has become my ongoing mission. A mission that makes sense of Giles' life and my life that was saved.

Nine years ago, I started to focus on the big question. What causes autism, what is autism, as distinct from what it looks like? Science has also moved on from behaviour to biology. So, let me talk a bit about what's happening in biomedical research. By measuring circumferences of heads, children with autism have been shown to average a normal head size at birth because these things are recorded, but increase above the population norm for the next three years, on average of course.

So, that on average young children with autism have larger head sizes. What can that mean? This then later evens out. What can that mean? Internally, imaging technologies show the difference in brain anatomy, so that full instance, you and I process faces when we are looking at faces. What are we looking at, how do we recognise it as a face, is it upside down? We process faces in a certain part of the brain but those with autism use of a different part, we can show that with imaging. What can that mean?

Recent research has shown that it's the cabling between different parts of the brain that is the central problem. What can that mean? My current charity is aiming really to determine the causes of this baffling disorder, the dream is for a practical biomarker, wouldn't it be wonderful if something as simple as head size... There are a number of major, major programs going on.

The international search for the genes that if not causing autism, rather confer susceptibility, is the Autism Genome project, led by Professor Tony Monaco here at Oxford. That's coming to the end of its second phase this year and there are exciting prospects for future work, that will support the diagnosis and treatment of autism. Even cold blooded scientists use expressions like, "We're at the tipping point of discovery." Maybe it's wishful thinking but anyway.

Professor Bishop was speaking yesterday about the role of genes in language disorders generally, we're really only starting in the 21st century to know what these genes are doing. Autism Speaks also funds mentored fellowships to increase the UK's research capacity. We have recently help fund a new Chair in autism at Cardiff University, a Professor Sue Leekam started in April. There are always people asking if we can't do more but as yet nobody has complained that we're doing too much. The next five to ten years really can be expected to deliver some significant advances.

Professor Tony Bailey's MEG Centre, here as part of Oxford Warnerford hospital, and progress is hampered though by not having enough post-mortem brain material and by the non-standardisation of imaging systems. So, you can't sometimes compare results taken from one image centre with those elsewhere. We started an Autism Brain Bank, again based here in Oxford. That was launched last year, funded by a single unrestricted donation to Autism Speaks.

It already has seven brains, each capable of providing material for some 50 researchers. You also need control samples there of people who are clearly not on the autistic spectrum because we really don't know which areas of the brain will become the focus of future research. So, samples are taken from all areas and I wear a bracelet that I can't take off, it's not soldered but it hasn't got a thing, and that records that my brain, indeed my body, is to go to Oxford University.

There's still no known cure for autism, although some interventions with people with a high intellect can result, due 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 my Giles. Despite everything we tried to do, the quality of his life was very poor.

As the Prime Minister found when he got involved with cystic fibrosis research, research is slow, research is expensive, it demands involvement, a can't be delegated very far, the best planning in the world gives perhaps only a one in ten chance of a particular research project finding anything that will make a difference. Progress depends on research, yes, but also vigorous information change among researchers and translation of their findings into service provision.

Chairman, many autism issues are similar to those discussed in the days before dyslexia became mainstream. Autism is no longer something that can remain on the fringes of policymaking provision and importantly knowledge. It should be a mainstream and very serious concern.

It has recently been rebranded as Autism Quotient, the autistic quotient, AQ. Implying that it is an inherent human condition. Autism strikes to the very heart of what we think of as being human. To understand the autistic mind and allow the possibility of equal citizenship, is a major and crucial problem. Thank you very much.

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