

**Scottish Autism Service Network
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Keynote Address: A Lifetime of Networking

Dame Stephanie Shirley

Good morning Chairman, Ladies and Gentlemen.

The great Rabbinic 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.

My long involvement with support services, education and training and various strategic initiatives in the autism sector (currently via *Autism Speaks* 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, became a systems engineer and founded the software house now called Xansa. That's been in Scotland for 25 years, working with customers such as BSkyB and Scottish Widows.

I've been asked to tell you about my son and I will interweave his story with the autism story. When he was young autism was considered a rare disorder. Today the latest estimates are 1 in every 166 children, the increase being partly accounted for by redefinition and better diagnosis. But not wholly so. Worldwide a new case of autism is diagnosed nearly every 20 minutes. The General Register Office for Scotland's latest figures, latest that I've seen anyway, are 2114 children under 19 with autism and another 5600 categorised as having an autistic spectrum disorder. There are no 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.

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 is not closed.

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 is found four times more often in boys than girls and 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. *Autism Speaks* is investigating the incidence in cultures such as Saudi Arabia where it doesn't just happen that for close family members to marry but it is the NORM. More than ½ the couples are close blood relative.

Diagnosis

Giles was diagnosed at the age of three and we were advised to put him into an institution and start again. 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 my 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 which way, 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. In the second half of this new decade, Scotland can only aspire to such ideal services if agencies work together, if there are enough professionals, if funding is targeted irrespective of co-existing problems and there's a jointly shared register of those requiring support. That summary is not mine. It comes from the 2001 Needs Assessment Report from the Public Health Institute of Scotland. 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 and very active also here), spun off Research Autism which is planning to compare and contrast the many different interventions so as to give parents meaningful facts and figures.

ABA

There are whole schools dedicated to Applied Behavioural Analysis – ABA devised by Ivar Lovaas in the mid 60s using rewards 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.

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

Dr Eric Schopler, a pioneer in the field of autism education, died in July. 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 Dr Bernard Rimland co-founder of the Autism Society of America, who died last week, 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 my latest project: to capture the history. This should include a Wellcome Witness Seminar next year.

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, not the subject, doing the communicating. Certainly that was my belief; I am trying to be open-minded because of a 19-year-old 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.

Giles was profoundly disabled intellectually. 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.

Glasgow’s philosophy (that’s the City Council and NHS Glasgow) for service provision is to make autism the responsibility of the mainstream rather than sidelining it in a separate little world of its own. The strong points are the long established Scottish Centre for Autism, the Community Autism team at Yorkhill’s children’s hospital, and ARC (the Autism Research Centre) which focuses on adult services.

ARC itself has its staff drawn from the City Council and NHS Glasgow, the three charities (National, Scottish and Strathclyde) and the new National Centre for Autism Studies. A network indeed!

Scotland’s research

The Scottish Antenatal Birth Cohort Development Study (ABCD) is still in its very early review stages. It aims to recruit mothers before their child is born and then follow up and document the children over time, seeking out what affects social relationships, early onset mental health or developmental problems, how problems overlap and how early one can identify children and families who need support.

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 am intrigued to recently 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 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, on average of one in ten Asperger adolescents are victimised by their peers. Figures are probably conservative, 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 and all organisations must continue to press for investment in research to further our knowledge.

The largest single organisation representing learning disability and autism in Scotland is Enable. The Scottish Charity Regulator lists ten area-specific charities starting with Autism Argyll and Action Against Autism and including the leading Scottish Society for Autism. Sense Scotland (originally for the blind and deaf and learning disabled) has changed markedly over the past few years and helps people with severe behavioural problems, including those associated with autism.

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. 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 is a comprehensive study of sleep patterns and parents' perceptions of them. Solitude can help in developmental learning. It's also a most effective restorative for someone with Asperger's. The child's bedroom should be a refuge that is sacrosanct.

It was Great Ormond Street hospital who first used the A word to me and introduced a child therapist. 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 TV and films. Do many Scottish children speak with an American accent?

Giles had 1 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. There were occasional services that wanted to help but often I'd just get home after settling him in somewhere to get a phone call saying they couldn't manage, would I come and collect him? It was an awful, ghastly period. We got a bit of financial help from various grants, most of whose applications procedures were not relevant to autism. [I'm told that the Disability Living Allowance has been affected by last year's job cuts in the Dept. for Work and Pensions.] 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. It was Strathclyde University which first described the passage of people with ASD through services as "snakes and ladders". Apt metaphor.

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 this autumn 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 estimated to be getting suitable services.

But things have hugely improved. For example, 15 years ago The Strathclyde Regional Council's Education Department ran a school for pupils with autism, but they called it Communication Disorder; autism was just another learning disability. That Department now has Autism Units attached to four primary schools and two secondary schools as well as supporting mainstreamed pupils with ASD. The original autism school is still there, pupils are sent to independent special schools such as Struan House and Daldorch House, and there are two FE colleges in Glasgow with specialist provision for young people on the spectrum.

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 a year. Giles stayed in an old-style subnormality hospital for 11 years. He was in a locked upstairs ward for 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 covered 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 25 years of Care in the Community, there still remain thousands of people living such restricted lives.

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 £3m – only 7% education, all the rest is direct support. What one doesn't want is a failing child becoming a failing adult and ending up in institutional care, having broken the health of a parent. My experience is with a profoundly affected child in days long past. But a recent Scottish survey showed that both parents and professionals still feel that there is, and I quote: "very little available indeed".

Adulthood

Giles became institutionalised 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 an adult service *Kingwood*. Giles was the first resident; today *Kingwood* supports 50 autistic adults whose needs challenge existing services.

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 organisations such as the Disability Equality Scheme. Here in Scotland, boards and local authorities have worked collaboratively with NAS Scotland with its Prospects service based in Glasgow, and the Scottish Society for Autism. 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. (Hugh Morgan will be addressing more of the adult issues in his Keynote this afternoon).

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 Asperger adults to adapt to standard work environments.

A good strategy is to help young adults develop specialisms where customers seek them out as a consultant rather than aim for employment with its difficult interview to be got through. I hardly dare suggest on this St Andrew's Day, that perhaps young adults could move to a part of the world where any bizarre behaviour would be accepted as due to the Scottishness rather than autism!

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At the age of 35 Giles died suddenly in an epileptic fit 8 years ago and I have learnt to live without him, without his need of me, to slowly let his memory go – perhaps fade would describe it better. I am restored in mind and spirit. Love transcends death and my life is dedicated to the autism sector, perhaps to make sense of Giles' life, perhaps to give significance to my life, the life that was saved.

The Big Question

Six 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 have 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. 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?

My current charity *Autism Speaks* (Dr Walter Muir from Edinburgh is a trustee) aims to determine the causes of this baffling disorder. My dream is for a practical biomarker. We plan a number of programmes including: the Autism Genome Project, bringing together 170 of the world's leading genetics researchers; we've offered to support fundraising for the ABCD study I mentioned earlier; and have well established links with researchers and practitioners at the universities of Edinburgh, Glasgow and here at Strathclyde. *Autism Speaks* is funding Dr Pollock at Glasgow with a 2 year functional Magnetic Resonance Imaging study of adults with high functioning autism who operate at a high intellectual level.

Autism Speaks also funds lots of pilot studies and mentored Fellowships to increase the UK's research capacity. An immediate aim is for three Scottish Fellowships. People are always asking if we can't do more. No one has ever complained that we do too much!

The next 5-15 years can be expected to deliver significant advances in genetics and brain imaging. Progress is hampered by not having enough *post-mortem* brain material and non-standardisation of imaging systems. Will Edinburgh's new imaging system be able to share its results?

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 Aspergers 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 the Chancellor will find if he gets involved with cystic fibrosis 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.

Today's conference is a showcase of good practice in Scotland and has as its focus the huge importance of everyone working together. Let me conclude by asking you to concentrate your ideas on the big current needs: firstly improving awareness; secondly to ease the different transitions – difficult for children with autism to move between playground and classroom; it's the transition not the destination that is troublesome. And the children need specific support with life's transitions: from home to pre-five, from pre-five to primary, then to secondary, and to the adult world. Three. There are next to no specialist special schools, or special units in mainstream schools for Asperger pupils, the very ones who realistically aspire to independence and, altho' I know the numbers are small, the services for Black and Minority Ethnic children are awful – somewhere between awful and appalling. Finally, The Big Question of what causes the disorder.

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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 needs confronting, it requires resources and we have to get closer and work together.

So please, Ladies and Gentlemen, be persistent, be resolute. Work together in asking the right questions, ask the Big Question.

Thank you.

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