

Celebrating the Shirley Foundation's contribution: 20 years of funding and research in autism (1996–2016)

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Editorial comment

Dame Steve Shirley is very well known in the autism world for the many projects and organisations that the Shirley Foundation has commissioned and funded. Of interest to readers, among these, was a sum of money to kick-start the founding and production of the *Good Autism Practice Journal* in 1999.

Steve Shirley's first career was in IT where she founded a software company for freelance programmers, a key aim of which was to provide employment for women with dependents who needed to work flexibly and often from home. This became a very successful company and when it was sold, Steve invested the vast majority of her own share (£150 million), together with enormous enthusiasm, energy, and commitment in a diverse range of projects in autism and some in IT. A key reason for choosing autism was that her son, Giles, had autism. In this paper, she describes the work which the Shirley Foundation has initiated and supported and comments on its governance, principles, successes and some failures. She has received numerous honours and awards for her work in IT and her philanthropy and her life and work is charted in the book, *Let IT Go* (Shirley and Askwith, 2012) where readers can learn more about her remarkable life and legacy.

Introduction

In January 2017, the National Autism Project, sponsored by the Shirley Foundation, published its report, *The Autism Dividend: Reaping the Rewards of Better Investment* (see a brief report on this on page 108). That title might well be shared by this 20-year review of autism projects funded by the Shirley Foundation, one of only four significant social investors in autism projects in the UK. An independent evaluation of all the foundation's grants in the period 1996 – 2016 is currently being carried out by *Philanthropy Impact*.

Over £50m (75 per cent of our total spend to date) has been invested in some 70 autism projects, primarily in the UK. Some £3m of projects were not autism specific but addressed learning disability including autism; or were oblique, such as communication and other hidden disorders (eg deafness, epilepsy) or Childhood Disintegrative Disorder.

The largest project cost £30m and a handful were into six figures, two at well over half a million pounds and dozens valued between £100,000 to £250,000; with a sprinkling of minor benefactions. Two of the largest grants were

unrelated to autism, but other gifts to the Kingwood Trust, Prior's Court Foundation and the universities of Cambridge and Edinburgh were also all in six figures.

There were some periods without significant activity such as when my attention was on the foundation's information technology (IT) projects such as the IT Livery Company (1996) and the Oxford Internet Institute (2001); when I lost momentum due to ill-health and when my autistic son died in 1998; in the financial downturn following the 2002 market crash; and during my year as the National Ambassador for Philanthropy in 2009 – 2010.

Governance of the Shirley Foundation

The corporate governance was simple. My business experience led to a strong board of three co-trustees. One had a legal background with much experience in the charitable sector, one had financial expertise and the third had a medical background (related to autism). The medical trustee retired and was replaced in 2003. The Board maintained a near-perfect attendance record and trustees also became directors when the Shirley Foundation became a limited liability company in 2003.

Rationale for setting up the Shirley Foundation

There are numerous reasons to set up a charitable foundation. The original impetus for the Shirley Foundation was to ensure that my giving was tax efficient. I had already set up the Kingwood organisation to pioneer long-term care for adults with severe autism. This started with my son Giles who, after 11 years in an old-style subnormality hospital, became the first resident in the first home of what became my first charity. But charitable status was only possible when Kingwood had two other residents (Shirley, 2004). The foundation's funding came from sales of shares in my software company and it has always been my intention, on the basis that current needs are so great, to distribute all of these funds. There are plenty of long-running dynasty foundations with lesser assets, but investing only income was not for me.

Staff within the Shirley Foundation

From 2001 to 2005, our busiest years, we employed a research director but generally relied on our medical trustee and the universities to provide due diligence. We

also engaged two consultants as project managers: one skilled in all aspects of care; and the other an experienced director who finished up chairing the trustee board of the Prior's Court Foundation. We also used various consultants on an ad hoc basis. My PA provided administrative support, including on occasion supervising a few projects. Everything happened from my study. We used professional accounting, legal and investment services.

Four charities established by the Shirley Foundation

We planned projects to be sustainable so set up four of the major ones as separate charities: Kingwood (long term care), Prior's Court Foundation (education), Autism Cymru (strategy and campaigning) and Autistica (research).

1 Kingwood

The first charity, Kingwood, had pre-existed as a not-for-profit enterprise for some years and became a registered charity in 1994. It took over £3m and 17 years to become financially and managerially independent of me. Today (2017), it is professionally managed, employs 260 staff, supports 118 adults with severe autism just like my son Giles and is contracted to keep an overview of 25 adults with Asperger syndrome who are able to live independently. I ran it for some years and then chaired the trustee board and eventually left in 1999. It went through a phase of having five different CEO's (Chief Executive Officers) over seven years before emerging as a professional success. It continues to pioneer best practice and has a small residential college teaching life skills.

2 Prior's Court Foundation

This was started on the eve of 1998 and turned into the foundation's largest consumer of both time and money. The available funds having increased dramatically by then, the whole project was carried out professionally. Over two years, we used a number of suppliers and engaged several specialists to set up Prior's Court as a state-of-the-art residential and day school for pupils aged 5 to 18 years with autism and moderate to severe learning disabilities. It was to be the quality school to which I would have been happy to entrust my own son's physical, intellectual and spiritual development.

Apart from recollections of our own schooldays, none of the Steering Group I set up had any educational expertise. The aim was to operate under licence from the Higashi School in Boston in the US which had originally inspired me. We contracted with an educational consultant to carry out a feasibility study (a discipline which suits my business culture and one which saved us more than one mistake); then with various consultants to find and help us acquire the property; then a host of contractors (with people to manage them) to make it suitable for purpose (eg knocking down and replacing one of the buildings and modernising the others). In addition, we had to recruit the initial staff. Today there are 600 staff (and one teaching robot) for a roll of 70 pupils plus 20 students in a Young Adult Centre. Following the completion of further site developments in September 2017, Prior's Court will increase its capacity to nearly 100 pupils, which will bring its turnover to £20m.

The Steering Group met frequently with the director and the full-time project manager because this was (and remains) our largest ever project: £30m in total including start-up losses. Trustees did not wish to transfer the £15m building out of the Shirley Foundation until we could see that the project was a success. So, initially it was on a 99-year lease for a rose rent – the annual bouquet was much nicer than the traditional peppercorn! The freehold was gifted in 2005. We also acquired, for £0.8m, six semi-detached cottages (one with an agricultural tenancy) and donated these to use first as staff accommodation, and later as the Young Adult Centre.

During its development, I was on-site several days each week. The responsibility for beautiful Grade 2* listed buildings and 50 acres of parkland – everything between earth and sky – was stimulating but onerous. After a hectic 22 months we opened in September, 1999 with two small pupils and 28 staff. A formal opening by the Princess Royal took place the next year. The business plan, to break even in five years, was achieved and this allowed me to leave it in the tender care of the founding principal, Robert Hubbard, who did the really difficult part, and gained his PhD for the project. In the middle of the project though, the

unexpected death of my autistic son, Giles, made me lose all momentum for several months.

Millennium honours: Dame Steve Shirley

People assume that my Dameship in the Millennium Honours was for charitable activities. In fact, it was for IT – as a pioneer of computing and featured in the National Museum of Computing. My software company of 45 years employed 8,500 people, men and memorably women, when it was acquired by another software house in 2007. That company should have been the legacy to justify my having been saved as a child from Nazi Europe. But it is now more likely that Prior's Court Foundation with its outstanding school and Young Adult Centre will be my personal legacy.

3 Autism Cymru

The Shirley Foundation took the initiative to head up a new organisation to develop policies, strategies and bi-lingual services for autism in Wales. Autism Cymru (2001 – 2014) led Wales to the first ever national strategy for autism, to the Celtic Nations Autism Partnership, and inspired some £16m of ring-fenced public funding to support the Wales autism strategic action plan. Its trustees took the brave step of closing the charity down in 2014 once its mission was achieved.

4 Autistica

The fourth charity is somewhat different to the three above. It was the culmination of a series of medical research projects starting in 2000 and leading, in 2004, to Autistica. This both funds (£9m to date) and campaigns for medical research to understand the causes of autism, to improve diagnosis and to develop new treatments and interventions. It funded the UK Brain Bank for Autism, now the largest in the world, which holds my son's brain. It is committed to working collaboratively with all autism charities.

Other organisations funded by the Shirley Foundation

As well as establishing these four charities we also supported existing not for profit organisations. In 1998, the legal trustee introduced me to The Mental Health

Foundation with whom we were later to do a number of projects, some of which were for learning disability generally. Together we commissioned some innovative work leading to a series of booklets focused on spirituality for people with learning disability with titles such as *What about faith?*, *Why are we here?*, *Religious expression: a fundamental right* and starting in 1999, the reference guide *The fundamental facts*, on all issues relevant to people with a learning disability.

We also funded the infrastructure costs for PACE (Parents Autism Campaign for Education) for three years which then successfully merged with Treehouse (now Ambitious about Autism). We similarly funded a National Advice and Expert Witness Service for the charity, Resources for Autism, for several years in the hope that it would become freestanding. However, this had to close down and we learned the lesson that it is never enough to 'do good', it has to be sustainable.

Mission

The Shirley Foundation gradually strengthened its plan and determined to focus on projects that were:

- pioneering – never more of the same, no matter how worthy; and
- strategic – by which I mean that, if successful, they would make a significant difference

and focused at that time on the two things I know and care about: IT (my professional discipline) which took some £17m; and autism which has taken over £50m.

In 2002, we realised that many people were starting to support IT projects and so revised the mission to be the: *facilitation and support of pioneering projects with strategic impact in the field of autism spectrum disorders with particular emphasis on medical research.*

Partners

Over the years we funded, directly or indirectly, projects at 12 universities, including a number of projects initiated and carried out by what is now the Autism Research Centre at the University of Cambridge. These included an epidemiological study of schoolchildren in Cambridgeshire (which first determined the high prevalence of autism), a research studentship and a

commercial venture teaching autistic children to recognise facial expression (acted out by Daniel Radcliffe, then unknown prior to his role as Harry Potter).

Working again with the Mental Health Foundation and its Foundation for People with Learning Disability, we started the first of what became a series of studies by the London School of Economics, focusing on the economics of autism. The 1997 initial study was updated in 2007, then again in 2014 (supported by the Simons Foundation in the United States) and is the major contributor to the Foundation's current National Autism Project (2014 – 2018) (Ragan, 2015).

As we largely operated without staff and initiated most of the projects, it was the norm for the Shirley Foundation to be the sole funder. Exceptions were for the Autism Awareness Year 2002, a highly successful awareness-raising campaign, which we co-funded with the Disabilities Trust and BIBIC (British Institute for Brain-Injured Children) and, at New Philanthropy Capital's request, its Autism Review in 2005. Both relationships worked to everyone's advantage.

Autism and IT

Some projects linked both my interests - Autism and IT. A 1998 project was a web conference on autism attended by over 65,000 people from around the world. This was a first in the disability field and links to the Global Health Network for Autism (targeted to low- and middle-income countries) which we funded in 2014–16.

In 2002, funding was given to the University of Birmingham to develop and create an online, web-based, Level 1 course for professionals, parents and autistic individuals to gain an accredited qualification in autism. This has been a real success. The course is now in its 15th year and many students have developed their careers in autism as a result and continued their studies to gain higher qualifications.

My visit to the Wirral Autistic Society (now Autism Together) to consider its request for computer equipment valued at £15,000 led to our funding the £0.8m conversion of a derelict building into a care home for 12 young autistic people (who later formed the Beathovens

music group). The building now also houses a computer centre and community facility for the area. It seemed in tune with Port Sunlight's history of 'prosperity sharing'.

Another significant project for both IT and autism started in 1999 at the University of Nottingham and used Virtual Reality to develop independence skills for adults with autism (eg finding their way around the city; how to choose a seat on the bus). This pioneering work was developed by others and remains relevant today.

A professional foundation: linking groups together

Parliamentary groups

Many of our projects aimed to bring the fragmented sector together. Whenever we found a gap in services, we tried to help, and were responsible for the setting up of a number of autism projects. 1999 was particularly significant because, once I'd recovered from Giles' death that was a year of fantastic innovation and drive. I initiated some 30 autism projects that year, including the successful All-Party Parliamentary Group for Autism at Westminster which led to similar work with the Scottish Society for Autism to launch a Scottish Parliament Cross-Party Parliamentary Group on autism, including a Parliamentary and Policy Officer for an initial three years.

Schools and interventions

We provided a £130k grant to a school for 100 autistic pupils in Wales which was in need of assistance. A band of active parents managed to raise its political profile and the Welsh Assembly granted it £2m. When I last visited, the school was unrecognisable and wholly successful. Among many other projects, such as music therapy, sleep disorders, and the development of Lovaas methods, one small project is worthy of special mention. Though it did not lead to anything strategic, this provided an experienced fundraiser for six months to assist autism not-for-profit organisations. It was a different sort of infrastructure and was part of trying to get the sector more professional and collegiate.

Evaluation of the work of the Shirley Foundation

It took six years to develop our skills and knowledge so that forecasts were met and there were no surprises. To

mark our 10th anniversary, we did an evaluation survey to try and get meaningful scores on projects. The process was helpful and clearly showed that the larger projects were 'better'. Perhaps the scoring system reflected my belief that giving is best as a reciprocal activity, with neither party finishing in the red, and smaller projects do tend to disappear without trace as far as the donor is concerned.

Grants were strictly time limited. So that, for example, one project was £120k but because they did not get going soon enough they underspent and only got about half that sum. For a number of reasons, some projects were funded anonymously.

Our 2012 support of Pre-School Autism Communication Therapy (PACT) led, four years later, to some positive conclusions on the long term value of early intervention. Indeed it does seem that many of our projects show public benefit over a period of years, not months.

We only supported not-for-profit organisations but made an exception for a first class graduate diagnosed with Asperger syndrome to do a PhD on the ethics of autism. It took years for my interests to extend from my son's regressive autism to the somewhat different problems associated with Asperger syndrome and our first actual Asperger syndrome project was not until 2013.

Medical research

Around 2002, I began to target medical research via a series of projects triggered by the review of autism by the Medical Research Council (MRC, 2001). These led inexorably to Autistica which I founded in 2004. I had previously spent two years on the trustee board of the National Alliance for Autism Research in the United States (now Autism Speaks) to learn what was needed and what to avoid. Now on its third name, Autistica is the largest charitable funder of autism research in Europe, is Deutsche Bank's Charity of the Year (2016 – 2017) and raised over £3m in 2016.

We also supported the Patrick Wild Centre for Research into Autism, Fragile X Syndrome and Intellectual Disabilities at the University of Edinburgh starting with a mock scanner in 2007, complemented by work on

functional imaging biomarkers in 2012 and followed by a £1m grant in 2011 for an imaging suite of microscopy equipment, research operator and 'consumables' (in this case rats). This was formally opened, again by the Princess Royal then the Chancellor of the University. The centre leveraged additional and significant support from the university and others, including Autistica.

International Work

We seriously considered major support of some autism work in India (where my software company had three thriving centres) but eventually rejected the idea. We also contemplated major support of a US charity ICare4Autism for a proposed international autism centre in Israel. But governance issues meant I merely spoke at its inaugural conference. The project never went ahead. We initiated and sponsored three autism projects for the World Health Organisation (who were then grouping autism under Substance Abuse!) and supported overseas attendances at the World Autism Organisation. We made two small gifts to America and Australia, but otherwise concentrated on the UK. There were exceptions, but in the main the Shirley Foundation stuck to its aim of supporting pioneering work which, if successful, would make a strategic difference in the 'autistic sea of need'.

Where do funding ideas come from?

The ideas mostly came from me. But the steady stream of unsolicited requests for funding had to be trawled through to pick out anything relevant. I started by responding to them all, then only those linked to autism and learning disability. There was the occasional standard response but I found myself providing advice and guidance on a range of topics and setting up a number of introductions. This advice varied (eg in the next county there's some similar work going on; here is a list from my directory of grant-giving foundations which support projects such as yours; your budget is unreasonable because you are paying for activities that donors expect to be done by volunteers or that are correctly the responsibility of the state; or your budget is unrealistically low with no possibility of success). We often suggested a more pertinent donor for a good application that did not happen to fit our mission.

My style is always to give a positive input, and to thank the writer for whatever it is that they are doing. By always quoting the Shirley Foundation's mission, the word gradually got out that the foundation strictly applied its focus on autism. Unsolicited requests came down from the hundreds we used to receive and as the number reduced the quality and relevance improved. One of the three projects we initiated in 2016 came from an outside approach.

Acknowledgements from recipients of funding

We do not ask for acknowledgement but over the years I have been persuaded to allow The Patrick Wild Centre to call its imaging suite The Shirley Laboratory; Autism Together to have Giles Shirley Hall; and Prior's Court School to have its Giles, Millington and Shirley residential Houses.

Themes of the work, projects funded and publications

Looking back, one can perceive strings of related projects – on economics, taking a good idea out to the devolved nations, topping up major projects, and of course, medical research. There were also three sponsored books, for which we waived our Intellectual Property Rights. These were:

Harker, M and King, N (2002) *Designing for Special Needs: Architects Guide to Briefing and Designing Options for People with Learning Disabilities* Newcastle: RIBA enterprises

Feinstein, A (2012) *A History of Autism: Conversations with the Pioneers* London: Wiley. This has since been translated into six languages.

Feinstein, A (in press) *Autism Works* (Routledge 2018). This built on our 2000 support of inclusive employment.

We have also explored conditions that commonly co-occur with autism such as deafness, epilepsy, mental health issues and allergies (see below). Over the years, I have opened schools and buildings, launched charities and projects and promoted autism at every opportunity.

Some failures

The Foundation is proud of the impact of its 20 years' work but there were inevitably some failures. The most dramatic was the support given in 1999 to the later discredited Dr Andrew Wakefield via the Allergy Induced Autism Group. He was then a Senior Lecturer and Consultant at the Royal Free Hospital of Medicine (now UCL Medical School). He was in the middle of a study on Crohn's disease and autism which needed further investment to get to its conclusion, positive or negative. He was fervent in his commitment to autism, the amount needed was not huge (£50k) and I happily agreed to support this work.

The support for this work was abandoned once he left the Royal Free Hospital. Dramatic projects are always likely to get exaggerated attention, while solid, staid work can get ignored.

There were some administrative failures also. Philanthropists do not give to be thanked but I certainly noticed when one gift was not even acknowledged. I discovered years later that, although the cheque had been cashed, it had been misdirected to a linked, not-for-profit organisation and had never reached its intended recipient.

We arranged for a university to evaluate the work at Prior's Court school but this study was terminated prematurely. I also cancelled midway into a three-year project at another university as it became clear that the sample sizes were too small to provide anything useful.

The Shirley Foundation was business-like although we did not always adequately check the financial viability of charities we gave to. One charity became insolvent in the middle of our project with them.

Recent activities: the National Autism Project (NAP)

Recently we have provided support to extend the World Health Organisation Quality of Life metrics to apply to autism but otherwise we are now focused on the National Autism Project (Ragan, 2015). This is the project of which I am most proud. It started in late 2014 and is due to finish in 2018. Its original purpose

was to map the existing research base on autism and provide authoritative recommendations on what further research was needed, with the ultimate aim of attracting significantly more funding, in line with the national cost of autism. The London School of Economics found the evidence base for many activities and practices to be of limited or poor quality. However, there were others proven to be beneficial, some of which were also cost-effective. NAP is now focused on identifying and promoting the best of these.

The work of NAP led to a debate on autism in the House of Commons and to the Westminster Commission on Autism which made the first of its several reports in 2016. NAP's Autism Dividend report, published in January 2017, addresses all four UK nations, as will the ongoing campaign throughout 2017.

Concluding comments: the Shirley Foundation's legacy

As stated earlier, the foundation never had dynastic aims and in October 2016 it decided to close down with a target date of the end of 2018. Autistica, having developed over 12 years with professional management, strong corporate governance and a wildly impressive Scientific Advisory Board, clearly meets all the foundation's criteria and is the obvious candidate to receive the foundation's residual gift.

The Shirley Foundation has had a strategic impact on the autism sector and it is now a 'mere' administrative matter to arrange to pay all the committed grants, collect all debts, transfer the investments to Autistica and close everything down as a job well done.

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