THE SHIRLEY FOUNDATION

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FOSTERING SOCIAL SECTOR INNOVATION
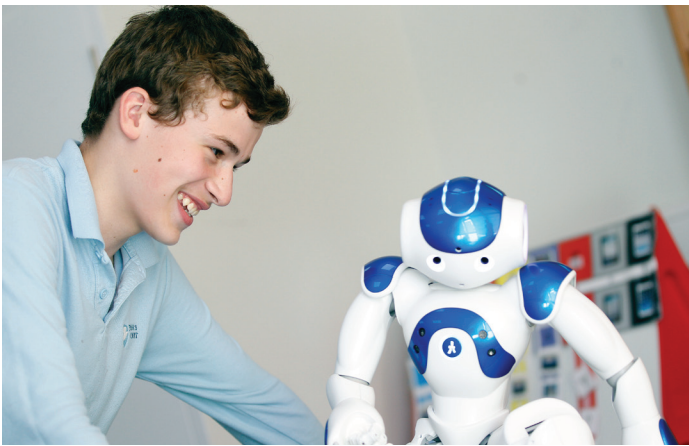
1996-2016
Twenty Years of Grant Making

Autism and Information Technology
An Overview of The Foundation's
Impact

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Cover photos courtesy of Prior's Court School.

1.0   Executive Summary

'The return when investing in yourself is negative; there's a huge win when you invest socially – the benefit to other people and also, ultimately, to the donor. When you measure philanthropy against the difference it makes, it's indecent not to help.'[1]

The Shirley Foundation has invested over £68m the past 20 years, £50m on autism projects and £15m on information technology projects; the remainder on a variety of arts and culture projects. Donations ranged from minor amounts to those of over seven figures. This was done with the motivation to pioneer and disrupt, innovate and to make a significant difference. The approach combines elements of venture philanthropy[2] and the application of an emergent strategy[3].

The Shirley Foundation commissioned an evaluation[4] of the projects funded over the past 20 years by The Foundation. The process to carry out the evaluation included interviews with Dame Stephanie Shirley, a documentation review and a survey to key grantees.

Note the response rate to the survey was very positive; that is 60% or 18 out of 30 surveys (totalling 85% of the funds donated) were completed.

In summary the respondents to the survey clearly indicated that the funding achieved their purposes but also those of The Shirley Foundation – making a great difference. Not only were the results impressive but the processes on the whole were efficient. For example:

- The reported measures of outcomes and methodology appeared well thought out.
- Survey respondents reported that project aims and outcome measures were agreed in advance with The Foundation.
- For the autism funded projects:
  - 94% (N=15) of the respondents reported that the intended results were achieved.
  - 88% (N=14) reported that the primary underlying assumptions held true for the expected results.
- The two funded information technology projects achieved their intended results and the underlying assumptions held true – accomplishing significant impact.
- There were a number of reported unintended outcomes which added value to the grants.
- Respondents reported that the results of their work could be generalised to other situations including research and service provision.
- Overall the organisations involved benefited from their involvement with The Shirley Foundation.

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[1] (There's a huge win when you invest socially: Dame Stephanie Shirley, Philanthropy Impact Magazine: 10 – WINTER 2015–16)

[2] 'Venture philanthropy and social investment are about matching the soul of philanthropy with the spirit of investment, resulting in high engagement and a long term approach to creating social impact.' http://evpa.eu.com/about-us/what-is-venture-philanthropy

[3] https://ssir.org/up_for_debate/article/strategic_philanthropy

[4] Not included in the evaluation there were 102 autism projects, their funding equalling £5m or 10% of the total autism projects funded; and the miscellaneous grants of £3m.

With the exception of the application for a medical research grant where there is a detailed Application for a Medical Research Grant Guidance form, the non-medical research grant application process is very informal. For the latter, there is no application form or detailed written criteria; although The Foundation's website does state that projects must be within The Foundation's mission and be 'innovative in nature with the potential projects to have a strategic impact in the field of Autism Spectrum Disorders'. This informal approach reflects the style and values of Dame Stephanie.

With reference to application criteria and process and to grantee support from The Foundation:

- The application criteria average rating was 2.4 out of 3.
- The application process average rating was 4.1 out of 5
- 53% (N=9) responded that they needed support or follow up from The Foundation. All but one indicated the support was given. The quality of the support was: very high quality 67% (N=6), high quality 11% (N=1), neither high nor low quality 11% (N=1), and very low quality 11% (N=1).
- 14 out of the 16 projects indicated that reporting of key milestones and results were required. Of those reporting that milestones and results were required the average rating on a scale from 1 (not helpful) to 3 (very helpful) was 2.2 concerning who found the process helpful. No one reported it as not helpful.

Reflecting the strong value given to a hands-on venture philanthropy approach bringing to grantee the experience and expertise of Dame Stephanie it is important to note that the ongoing support from Dame Stephanie and The Foundation was reported as 'inspirational'.

Of note is the application of emergent strategy by The Foundation, rather than just a focus on strategic philanthropy. It reflects the complexity of the issues being addressed by The Foundation; supporting evolving solutions that emerge over time. Its process is co-creative and with a special emphasis on adding value to and reinforcing systems, organisations and people who generate solutions.

It is very clear from the respondents that the assumptions underpinning the work of The Shirley Foundation - to make a real difference, to be pioneering and disruptive - are wholly reflected in the projects supported by The Foundation. 100% of the respondents agreed that their projects met this criteria. This can be seen in a number of ways:

- Successfully influencing policy makers with evidence.
- Raising profile contributing to meeting their organisational vision and mission.
- Leveraging additional funding and impact.
- Replicating successful and tested methods leading to change in government policies and strategies; transforming the lives of people with autism and their families.
- Creating, developing and applying innovative interventions.

"…the ongoing support from Dame Stephanie and The Foundation was reported as 'inspirational'."

Not only were the results impressive but the processes on the whole were efficient. The work of The Shirley Foundation over the past 20 years has achieved the ambitious goals of The Foundation, achieving impact - making a great difference to the lives of people with autism and their families.

Lastly, in a report issued in April 2017 entitled 'Smarter Grants Initiative'[5] respondents identified issues facing the charitable grant-making process. It is important to note that The Shirley Foundation has in place practices that have already addressed grantee main concerns – for example: not having an overly complex application process; strong communication with grantees; big grants without grantees facing a disproportionally harder time, mutual expectations agreed re outcomes and impact; and The Foundation outperforming the expectations of grantees. This would indicate that The Shirley Foundation, based on this research, is a positive example of best practice in giving.

In summary, if Dame Shirley was doing it again, could she have achieved more? A difficult question, but based on the evaluation results The Shirley Foundation would be hard pressed to achieve more. As Aristotle wrote: "To give away money is an easy matter. But to decide to whom to give it and how much and when, for what purpose and how, is neither in every man's power, nor an easy matter.'" [6]

"...The Shirley Foundation, based on this research, is a positive example of best practice in giving."

The Shirley Foundation's current mission is the 'facilitation and support of pioneering projects with strategic impact in the field of autism spectrum disorders with particular emphasis on medical research.'

It does so by proactive and engaged philanthropic support of projects (a form of venture philanthropy) related to autism as well as information technology; including adding value by applying business and entrepreneurial skills as well as funding. The Foundation's intention is to make a real difference, to be innovative, pioneering and disruptive. Based on the evaluation results it has done so for 20 years.

In light of the 20 years of strategic philanthropic giving The Foundation has evaluated the efficacy of its work. The following is a summary of the evaluation along with recommendations.

'Giles Shirley House'
Autism Together

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[5] LocalGiving www.localgiving.org
[6] (There's a huge win when you invest socially: Dame Stephanie Shirley, Philanthropy Impact Magazine: 10 – WINTER 2015–16)

2.0   The Evaluation

2.1   Purpose

In order to achieve the highest possible return on The Shirley Foundation's investment it is essential that there is a clear understanding of what the funding does, its underlying assumptions, its intention and impact.

This reflects the major change in philanthropic giving where measuring return on societal investment is a vital element of strategic giving.

'At this time, theory and art combine. Science and logic work alongside intuition and creativity, but with a shifting emphasis towards evidence. Social impact measurement is the discipline of understanding and reporting on social, environmental and other changes effected by organisations for their stakeholders. Whether you are engaging in philanthropy or social investment, understanding social impact and how it is measured is important, and the only way we can truly understand the relationship between money and mission.' (The Relationship Between Money and Mission Philanthropy Impact: Editor, Magazine: 10 – WINTER 2015–16).

The purpose of this evaluation is to assess the impact of The Shirley Foundation's £68m donations to the autism and information technology sectors over the last twenty years and to help improve the work of The Foundation.

'World Autism Awareness Day, Giles Shirley House'
Autism Together

"The Foundation's intention is to make a real difference, to be innovative, pioneering and disruptive. Based on the evaluation results it has done so for 20 years."

2.2   Methodology

The Shirley Foundation has commissioned an evaluation of the projects funded over the past 20 years by The Foundation.

2.2.1   Limitations

The Shirley Foundation has invested £68m in autism (£50m), information technology projects (£15m) and the remainder on a variety of arts and culture projects – the donations ranging from minor amounts to those of over seven figures.

Not included in the evaluation were small to medium grants to organisations and individuals directed at autism issues as well as to arts and cultural projects - 102 autism projects, their funding equalling £5m, and £3m on arts and cultural projects, ie 12% of the total donations. This limits the conclusions to about 88% (or £60m in grants) of the work of The Foundation.

Applications and detailed Foundation decisions, reports from funded applicants and internal files were not reviewed as part of the evaluation**. It is recommended that internal files be reviewed as part of the evaluation process.** However the former was addressed in the survey to grantees and are therefore self-reported.

The data, findings and recommendations are limited to survey respondents only. **To develop a complete picture of The Foundation and its impact it is recommended that all projects that are funded by The Foundation be evaluated.**

Note the response rate to the survey was positive; that is 60% or 18 out of 30 surveys (totalling 85% of the funds donated to the target respondents) were completed.

2.2.2   Evaluation Process and Methodology

The process to carry out the evaluation was:

1. Initial meetings/interviews with Dame Stephanie Shirley.
2. Documentation review.
3. Development and testing of the survey questionnaire. The survey (a copy of which is in appendix 1) was emailed out to the selected list of grantees, with follow-up emails and telephone calls for those not responding. It focused on such questions as:
   a. What was the project and its intended results?
   b. Were the intended results/outcomes/impact of the project achieved?
      i. What were the underlying assumptions and the intended outcomes?
      ii. Were these outcomes achieved?
      iii. Were there any unexpected outcomes and what are they?
      iv. What is the evidence?
   c. What lessons were learned?
   d. Did the project meet The Foundation's criteria to make a real difference, to be pioneering and disruptive?
   e. To what extent can the results be generalised to other situations?
   f. How would you rate the application criteria and process, support and reporting?

4. Distribution of the survey and follow-up.
5. Analysis of the survey and preparation of a report with recommendations.
6. Presentation to The Foundation to discuss preliminary findings and recommendations.
7. Finalisation of recommendations and creation of this report.

Students 2011 - MSc in Social Science of the Internet 2011 students, some of the many people who have benefited from The Shirley Foundation's contribution to the Oxford Internet Institute.

3.0   Survey Results

3.1   Theory of Change and Projects' Presenting Problems

3.1.1   Theory of Change

There were a wide range of projects supported by The Foundation, all with the purpose of positively affecting the lives of people dealing with autism or with information technology.

Underpinning this is the funding of research into the causes of autism including improving diagnoses of autism and supporting new treatments. In addition a number of projects had the added goal of supporting the long term sustainability of a number of charities who are responding to this issue.

With reference to information technology the purpose of the grants were to:
- Act as a catalyst for the creation of a multi-disciplinary institute, the Oxford Internet Institute. Its intent is to coordinate and strengthen internet research in and around Oxford, to foster public policy debate and to create an online community.
- Establish the Worshipful Company of Information Technologists to use information technology to provide improved quality of life for the disadvantaged.

As reported by the survey respondents the underlying theory of change assumptions varied according to the autism project. In summary they consisted of the following.

- Belief in supporting autistic people in all cases including in their efforts to flourish on their own.
- Change can happen based on the efficiency and effectiveness of autism interventions.
- Parents and families are key elements supporting autism.
- An evidence based approach is highly valued.
- The importance of applying scientific approaches to developing and testing.
- The importance of research and of growing funding for research.
- Agreement that there should be a theory of change model underpinning research and interventions.
- An emphasis on policy development, an evidence based approach, raising profile of issues related to autism, campaigning, and joint working are valued.
- Shared expertise and collaboration are essential.
- Training of people is needed at all levels.
- Measuring outcomes and impact is essential to assessing progress and to reporting.

For the information technology projects the assumptions were related to:

- Co-ordination and joint efforts creates efficiency and stronger results.
- Drivers of change that are systemic in nature, to nurture leadership and to meet need for information technology to help the disadvantage.
- The broader applicability of the lessons learned.

3.1.2 Funded Projects' Presenting Problems

Funded projects addressed a number of presenting problems.

1. There is very little known about what works and is evidence based, as opposed to what is assumed to work. The project mapped the whole area of research in autism and seeking to identify the interventions with the best outcomes, both in terms of the views of autistic people themselves and in cost/benefit terms.
2. Childhood-disintegrative-disorder mapping of this rare condition.
3. There is an urgent need to identify non-invasive repeatable measure as a marker to aid diagnosis and therapy.   The new measurements created using MRI scanning offer the exciting prospect of an aid to detection of autism. The goals of the project were to validate these measurements using direct comparison of brain imaging and post-mortem microscopy on brains from within the autism brain bank. Subsequently the signal should be detectable in living volunteers using non-specialist, clinical MRI scanners.
4. To establish The Shirley Imaging Suites at the University of Edinburgh. To establish a new rat model of Fragile X Syndrome.   Both of these aims were designed to increase the fundamental knowledge of the autisms as well as improving our platforms for translating this knowledge to real clinical impact.
5. To establish a first national autism charity for Wales. A small but uniquely Welsh national autism charity led and staffed by people of Wales from 2001-2014 sought to try to change the face of autism.
6. Developing and evaluating a DVD to teach emotions to children with autism dealing with the disability in emotional recognition.
7. Addressing a lack of reliable evidence, the project attempted to evaluate both economically and qualitatively autism interventions.
8. A knowledge sharing hub to facilitate research and develop research tools and resources in the area of autism and neurodevelopment in low-resource regions of the world.
9. ASD consultant Shirley Foundation
10. Prior's Court was purchased and the school was set up by The Shirley Foundation in 1998. The project was initiated by Dame Stephanie Shirley whose vision was to create "the school to which I would have been only too happy to entrust my own autistic son's physical, intellectual and spiritual development – if only such a school had existed at the time." The 50 acre site and existing buildings were renovated and new facilities added to create an autism-specific residential special school for young people up to the age of 19 with autism, severe learning difficulties and complex needs. Based in Berkshire, the severity of the needs of the young people meant that they would come from local authorities across the UK.
11. There has been no academic work on the notion of autistic flourishing. The project addressed the notion of 'autistic flourishing'. In contrast to viewing Asperger's syndrome/high-functioning autism as a medical condition that requires therapy, it was analyse as a neurocognitive difference that requires one to re-think what the notion of the good life, or human flourishing, might mean. Rather than there just being a species-standard notion of flourishing that neurological minorities fall outside of, there may be different kinds of flourishing that have hitherto been overlooked. The project explored what autistic flourishing might look like, how we might make sense of the concept, and how it might be achieved.

12. Core funding over five years to take new artworks into a loan collection, manage them, and develop a new loan scheme of art specific to the needs of people on the autistic spectrum (as well as generally strengthening and growing the other activities of the charity); all to benefit children and adults with autism

13. Although around 50% of people with autism have a learning disability (IQ<70), the existing research literature primarily focuses on only those of much greater intellectual ability and relatively mild autism. While this is understandable in practical terms it does mean that the current literature is unrepresentative of the broader population of people with autism. The project aimed to develop methodology to allow the magnetic resonance imaging scanning of the brain function in people with autism and learning disability. In order to do this The Shirley Foundation funded the development of a mock MRI scanner to allow severely affected people to gradually acclimatise to the scanning environment and satisfactory scans to be obtained.

14. To address the lack of awareness at policy levels of the distinct needs of children with autism, the under-provision of specialist schools and teachers and a lack of early intervention The Foundation supported a parent-led campaigning umbrella charity, aimed at raising awareness of the educational needs of children with autism in the UK.

15. To meet the needs of people working directly with autistic individuals who were not eligible for specialist training due to a lack of professional qualification The Shirley Foundation covered the set-up costs of an on-line accredited training programme in ASD for parents and direct 'hands-on' professionals under the auspices of the University of Birmingham.

16. There is a need to communicate the study of autism up to the present day to help a wide variety of people understand its range and growth; and there is a need to help people with Autism, their families, employers and others understand how to offer or find employment for those with Autism. The Foundation commissioned two books, one on the History of Autism, which has been published, and one on employing people with Autism which is underway.

17. At the time of creating the Oxford Internet Institute there was no university based research body devoted to the internet.

18. The Worshipful Company of Information Technologists vision was to be the leading facilitator of IT related charitable activities.

"Change can happen based on the efficiency and effectiveness of autism interventions."

3.2   Intended Outcomes and Impact

Survey respondents identified intended/measurable outcomes[7] and impact that would be achieved as a result of the funded project. These could be used to test the efficacy of the grants. Examples included:

- Outlining evidence based interventions that could be used to identify, influence and change policy.
- Identifying the incidence of CDD, presenting features, investigative and management approaches, and short-term outcome.
- Using the post-mortem brain collection in the autism brain bank to validate a new method of MRI analysis that could then be applied to living participants, in order to aid the detection and understanding of ASD. A new analysis method will be developed in further research projects for potential use in a clinical setting or in the development of improvements in care and therapies.
- Establishing a world-class imaging suite to recruit world-class scientists in the field of autism. The long-term impact is to translate the information gained from our preclinical models into rational, science-led treatment strategies.
- Developing and implementing a national autism strategy for Wales and to have the Welsh Government take far greater responsibility for autism through strategy and policy development. This was successfully achieved.

> "…creating a better appreciation of the understanding of Autism publishing a history on the topic, published around the world, translated into five languages."

- Improving emotion recognition and in the long term have teaching materials for schools.
- Reporting a listing of possible interventions with advantages and disadvantages. The impact of this will be reviews of policy across a number of sectors and, where evidence is still lacking, further research in these areas.
- Building an awareness and community of practice to enable information, methods and knowledge sharing.
- Improving the lives of individuals and their families, strengthening their support networks to enable long term care and better outcomes for individuals with ASD.
- Specialist training and support for professionals and families in support of services for young people with autism, severe learning difficulties and complex needs creating safe, fulfilling and happy lives for the young people; as well setting up a young adult provision with onsite college and residential homes for students aged 19-25.
- Laying the academic groundwork for thinking about autistic flourishing, to inspire more research in this area, and to help autistic people practically and other relevant persons achieve greater well-being leading to changing perceptions regarding autism and challenging long-held assumptions in ethical theory.

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[7] An outcome is the effect a project produces on the people or issues that are being addressed, that is, the change that occurs as a result of the project. Impact is the long term deeper changes that are a result of or correlated with the project. As Robert Penna says in *The Non-profit Outcomes Toolbox*, "…**impacts are what we hope for**, but **outcomes are what we work for**."

- Supporting a greater number of new social and educational care sites (and their beneficiaries) gaining the therapeutic benefits of art; as well as a greater (researched) understanding of the likes and dislikes of art for those on the autistic spectrum including creating a new loan collection that reflects these. Achieving societal acceptance of the benefits of the visual arts to health and general wellbeing.

- Scanning people with severe autism and intellectual disability to create a better understanding of an under investigated group.

- Empowering parents to become effective 'influencers' with regard to autism research, practice and policy. Improved awareness of distinct needs of children with autism amongst; politicians, civil servants, local authorities, teachers and the general public.

- Providing access to those living and working with people on the autism spectrum to training that builds on their experience and gives them a way of understanding the individuals they work and/or care for and understanding how they could improve and develop their practice.

- Creating a better appreciation of the understanding of Autism publishing a history on the topic, published around the world, translated into five languages.

- Enhance opportunity for young people, improve their quality of life, support charities to effectively use IT, and to improve understanding of IT and its capabilities to the wider public.

- Coordinate and strengthen internet research in Oxford and foster public policy debate.

However, it appears that identifying impact was not part of a small number of the grant applications. **It is recommended that this be part of future grant applications, that the impact of past grants be analysed to get a better sense of the broader influence of the funding.**

'Thames Reach is one of the UK's leading homelessness charities, they are using IT sessions to educate, train and then aspire to support service users into work through the Digital Pathway Project. The WCIT Charity has dedicated 3-year funding towards the Digital Skills Pathway Project.'
The Worshipful Company of Information Technology.

3.3 Measures, Methodology and Reported Outcomes

3.3.1 Approaches to Measuring Outcomes

There are various approaches that could be used to measure outcomes and impact. **It is recommended that The Shirley Foundation develop rigorous methodological approaches for measuring outcomes and impact, these in order to evaluate effectiveness and efficiency of the interventions supported by The Foundation.** This would reinforce external messaging of The Foundation, supporting its aims.

Numerous approaches to evaluations exist. They should be assessed as to their applicability to The Foundation, its grantees and to contributing to its broad aim. Some example of approaches to measuring outcomes and impact:

- Randomised control trials www.educationendowmentfoundation.org.uk
- General information on measuring impact including social return on investment http://socialvalueint.org/
- New economics Foundation **www.nef-consulting.co.uk** has reports on its site covering outcome evaluation and impact assessment.
- New Philanthropy Capital www.thinknpc.org studies on impact on its web site.
- European Venture Philanthropy Association www.evpa.eu.com
- Inspiring Scotland VP organisation www.inspiringscotland.org
- Pro Bono Economics www.probonoeconomics.com
- Bridges Ventures www.bridgesventures.co.uk
- Nesta www.nesta.org.uk

3.3.2 Respondents' Responses

3.3.2.1 Measures Well Thought Out

Survey respondents' approach to measurement as self-reported varied considerably with some focusing on outcomes, a few on impact and some on outputs. The reported measures and methodology reported in the survey appeared well thought out.

3.3.2.2 Project Aims Were Agreed With The Foundation

94% (N=17) of the survey respondents reported that project aims and outcome measures were agreed with The Foundation. Concerning those answering 'no' it was reported that the aims of the project were part of the proposal but The Foundation felt that second year funding was not realistic.

3.3.2.3 Intended Results Achieved

94% (N=17) of the respondents reported that the intended results were achieved. **It is recommended that an analysis of project progress reports be undertaken to test respondents' perceptions.**

3.3.2.4 Underlying Assumptions Hold True

88% (N=16) reported that the primary underlying assumptions held true for the expected results. With reference to the remainder one project is still in progress and the other adjusted assumptions based initial research. Other respondees indicated that:

- The project opened the way to looking to find research funding for many common but largely non-empirically validated interventions.
- The new methods have yet to be proven that there will be widespread utility with consequent beneficial social impact.
- The initial goals of the grant were achieved, however the goal of translating fundamental knowledge into useful treatments can only be achieved over a longer time period.
- There is still a lack of clarity on the qualitative result on many standard interventions
- It had not anticipated how some local authorities would not respond in a collaborative manner no matter how constructive the parental approach.
- The respondent was only been able to collect 'soft data' on impact having failed to get funding for a more robust measure of impact.
- The project surpassed the original objectives.
  - The Institute has developed into a full-fledged university department, with a large programme of externally funded research; an extensive and innovative postgraduate teaching programme; a vibrant programme of events and policy-related activities; an extensive network spanning international policy-making and business communities, with an annual budget of around £5 million.
  - Attracted world-class research faculty: our research faculty comprises over 50 researchers across the whole range of university academic posts, from research assistant to statutory professor, all engaged in a range of research projects and producing a regular stream of high quality research outputs and publications.
  - In the 2014 Research Excellence Framework evaluation exercise, Institute faculty were submitted with world-leading departments in 9 units of assessment spanning all four divisions of the university – a story of successful multi-disciplinarity that no other university in the country can tell. In turn, research projects and the evaluation exercise (on which central government funding is based) have played a major role in ensuring the financial viability and sustainability of the Institute.
  - The Institute's extensive networks and relationships with policy-makers ensure that OII research shapes policy, a key aim articulated in the original documentation.
  - With respect to teaching, the Institute has gone beyond the original aims and set itself the goal of 'educating the next generation of internet-literate policy-makers'. With an MSc in the Social Science of the Internet and a DPhil programme in Information, Communication and the Social Sciences, OII has educated over 200 students from all over the world who have gone on to careers across public, private (including Google, Facebook, McKinsey and Cisco), university (including LSE, Princeton and Harvard) and voluntary sectors.
  - The £5m endowment is still intact and has increased to £5.99m. The Charity grants over £200k per year as well as covering core costs. 100% of donations goes into charitable projects. Substantial pro bono outputs have been achieved.

3.3.2.5 Unintended or Unexpected Outcomes.

In 12 of the projects there were no unintended outcomes. The remainder indicated there were unexpected outcomes, for example:

- Respondents were surprised that the most commonly practised interventions had little or no evidence base.
- A negative outcome was that the intention to acquire new brain tissue from new donors was frustrated largely due to delays by the existing brain bank organisers. Positively the profile of the need for brain donations was raised. An additional positive outcome was that the frustration of not receiving sufficient new post-mortem material resulted in a shift of emphasis to begin development of a more automated analysis of living subject scans.
- Positive collaborative relationship with government 2003-2012; thereafter approach to delivery did not actively involve the respondent organisation.
- While under investigation the science developed such that the importance of single gene causes of ASD was recognised and new treatments were developed for certain of these. Most of these have very severe phenotypes and respondents have now been able to conduct scans in these groups within the context of treatment trials.
- Positive results included reaching out internationally; the extent of policy and campaigning became the central work of two key charities in the UK (i.e. NAS and Ambitious about Autism); networking introducing key players to each other leading to long-term working relationships; and bridge-building across conflicting or disparate sectors, individuals and organisations.
- Respondents had not recognised the number of those on the spectrum who were able to take advantage of the programme and the great contribution they were able to make to the development of the programme as they participated.

> **"It is important to continue to learn and extend the scope of provision, responding to the needs of our people with autism and to share expertise and lessons learnt with other professionals and organisations."**

3.3.2.6 Processes Leading to the Outcomes: Lessons Learned

The following summarises lessons learned in the processes leading to the outcomes (designing, developing and delivering the project) and suggested improvements.

- Problems were encountered in the delivery of the project, which indicate that alternative strategies should be considered and incorporated at the project planning stage.
- Develop from the beginning a fuller understanding of the parties involved, dependence on collaborators should be clarified at the beginning, and strategies agreed to enhance the effectiveness of working with collaborators.
- Ensure the time taken in specifying the remit of the research was essential and to learn during the process which is inevitable given the expertise around the table and the necessity of taking outside advice.
- It is important to continue to learn and extend the scope of provision, responding to the needs of our people with autism and to share expertise and lessons learnt with other professionals and organisations.
- There appears to be little work done on the philosophy and ethics of autism and there is a need for more research on autism carried out in the humanities and social sciences.

- Learnings led to the development of a whole new scheme and programme of activities. This should have formalised more thoroughly at the start.
- There is a need for patience, highly trained staff with experience and a consistent environment for implementation of the project.
- It is important to recognise when an organisation's unique work could be taken up and developed by others.
- It is important to address the difficulties in getting people with very different backgrounds to understand and appreciate different points of view including the long-term value of developing an integrative approach.
- Intellectual rigour, good project management are essential to achieving on time and on budget performance.
- The experience of setting up and growing the Institute has provided rich understanding of what is important in establishing an institute at a world-leading university. For example, it was set up as a department – which turned out to be completely critical for being permitted to create a teaching programme, without which it would have been difficult to gain financial sustainability and security. The Institute also demonstrates how important is a permanent faculty with the security to conduct cutting-edge, risky, innovative research – something that could not have been achieved with some kind of virtual institute that relied on part-time participation from members of other departments.
- A well thought plan was essential in achieving the project goals.

3.3.2.7 Generalisation of Results

A positive outcome of The Shirley Foundation supported projects is that respondents, with the exception of one grant[8], unanimously reported that the results of their work could be generalised to other situations including research and service provision.

3.3.2.8 Benefit to Organisation Receiving the Funding

Overall the organisations involved benefited from their involvement with The Shirley Foundation. For example funding from The Foundation:

- Allowed the organisation to collaborate with charities without them feeling there may be competition for funding.
- Raised profile of the organisation and its aims.
- Supported the development of brain imaging methods that may also be relevant to other neuropsychiatric conditions and the retention of expertise in this area, and enabled the development of an autism research seminar series and the gathering of collaborators.
- Increased the quality and number of PhD and postdoctoral applications.
- Effected a major cultural shift for the benefit of people with autism and their families.
- Allowed the organisation to undertake research adding value to clinical research.
- Extended an organisation's activities into autism and neurological development leading to a strong engagement in the wider field of mental health especially in low income countries.
- Leveraged to receive further grants.
- Enable the long-term development and implementation of a school.
- Allowed fundees to achieve personal research goals.

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[8] This organisation indicated that it was unique and operates differently from all similar organisations; therefore their challenges 'we experienced are distinctive'.

- Improved ways of engaging with the organisation's beneficiaries.
- Gained the confidence to grow and begin new areas of programming and research.
- Allowed the organisation to conduct studies that would otherwise have been unable to do and has enabled two PhDs and an MD to be completed.
- Supported organisational infrastructure development as essential support for organisational development and growth
- Established a successful programme that attracts a large number of students from the UK and overseas
- Increased the diversity of students by including those with poor initial qualifications and those with autism.
- Enabled research and policy initiatives helping to build the international reputation of the organisation
- Improved and developed the programme providing a model for involving those with ASD in autism training and research and the mixed design used in the programme has been used to develop Continued Professional Development in other areas of special need and in course development more widely.
- The donation was completely critical to creating the Institute. The grant has allowed members to work synergistically.
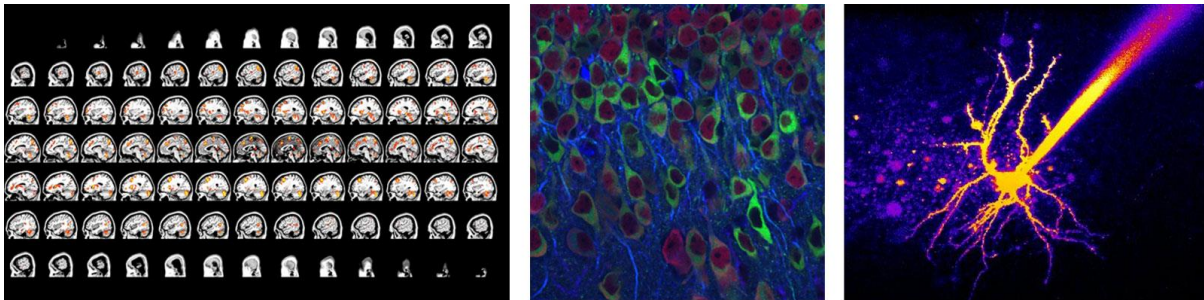
'The first image shows fMRI images from a human subject with Fragile X Syndrome (FXS) - a leading genetic cause of Autism.   This project, led by Andrew Stanfield, would not have been possible without the mock scanner purchased with a generous grant from The Shirley Foundation. The second and third images were taken using 2 photon microscopes purchased as part of The Shirley Imaging Suites.'
The Patrick Wild Centre, University of Edinburgh.

4.0   Application Process and Criteria and Support

4.1   Application Criteria and Process

With the exception of the application for a medical research grant where there is a detailed Application for a Medical Research Grant Guidance form, the non-medical research grant application process is very informal. There is no application form or detailed written criteria; although The Foundation's website does state that projects must be within The Foundation's mission and be 'innovative in nature with the potential projects to have a strategic impact in the field of Autism Spectrum Disorders'.

Potential grantees may be identified by Dame Stephanie Shirley or individuals and organisations may apply by email or by sending a letter. The initial screening process is informal led by Dame Stephanie Shirley with final grant decisions made by the Board.

The application criteria was rated on a scale of 1 (not clear) to 3 (very clear). The average rating was 2.4. It is important to note 18% (N=3) of the respondents reported the process as 'not clear', 23% (N=4) clear and 59% very clear (N=10) . There were no recommendations re the criteria.

The application process was rated on a scale of 1 (very low quality) to 5 (very high quality). The average rating was 4.1. 41% (N=7) rated the process a very high quality, 29% (N=5) as high quality, and 29% neither high or low quality (N=5). None of the applicants rated the process as low quality or very low quality.

Recommendations from survey respondents to improve the process included:

- Although the process was informal for applicants it is important it could lead to a lack of understanding of the process and a potential lack of clarity.
- Ensure all applicants have equal access.
- It would be helpful for The Foundation to give formal feedback about the application and decisions.

Although the vast majority rated the application criteria and process as very positive it is recommended that feedback about the criteria and its clarity and the process be obtained from each applicant for all applications including those that were not approved and feedback be given to all applicants about their application and the funding decision.

The OII - The founding of The Oxford Internet Institute in 2001 was made possible by the benefaction of The Shirley Foundation.

4.2   Support from The Foundation

53% (N=9) responded that they needed support or follow up from The Foundation. All but one indicated the support was given. The quality of the support was: very high quality 67% (N=6), high quality 11% (N=1), neither high nor low quality 11% (N=1), and very low quality 11% (N=1).

Comments included that the ongoing support from Dame Stephanie and The Foundation was 'inspirational'.

It was suggested that support, as appropriate, should be a condition of the grant.

'Baby from the Baby Sibling research at Birkbeck'
Autistica

4.3   Reporting of Key Milestones

14 out of the 16 projects indicated that reporting of key milestones and results were required, 3 not required. **It is recommended that grant files be reviewed to assess what the issues are concerning reporting and that a clear policy of reporting and criteria be established.**

Of those reporting that milestones and results were required the average rating on a scale from 1 (not helpful) to 3 (very helpful) was 2.2 concerning who found the process helpful. No one reported it as not helpful. **Although the rating is positive it is recommended that follow up re the process of reporting and improvements that could be made should be a normal part of the grant process.**

Respondents did not have any recommendations to strengthen the process.

'Leona at Bluebell Wood. Courtesy of Lifelites. Lifelites provides specialist entertainment, educational and assistive technology packages to over 10,000 children and young people with life-limiting, life-threatening and disabling conditions in children's hospices across the UK. Leona is using Magic Carpet Technology, a sensory learning tool with the capacity to engage children of all abilities. The system projects interactive games and images onto the floor that users can play with, simply by moving on or over the projected image. The technology allows a child in bed with little or no mobility to have an image or game projected on a sheet over them which they can play with, or a child with limited mobility having a game projected on a wheelchair table.'
The Worshipful Company of Information Technology

5.0   Make a Real Difference, Be Pioneering and Disruptive

It is very clear from the respondents that the assumptions underpinning the work of The Shirley Foundation - to make a real difference, to be pioneering and disruptive - are wholly reflected in the projects supported by The Foundation.

100% of the respondents agreed that their projects met these criteria. This can be seen in a number of ways – successfully influencing policy makers with evidence; raising profile contributing to meeting their organisational vision and mission; leveraging additional funding and impact; replicating successful and tested methods leading to change in government policies and strategies; transforming the lives of people with autism and their families; and creating, developing and applying innovative interventions.

The above reflects the strong value given to a hands-on venture philanthropy approach bringing to grantees the experience and expertise of Dame Stephanie in support of the grantees as well as application of an emergent strategy, rather than just a focus on strategic philanthropy. The latter respects the complexity of the issues being addressed by The Foundation; supporting evolving solutions that emerge over time. Its process is co-creative and with a special emphasis on adding value to and reinforcing systems, organisations and people who generate solutions.
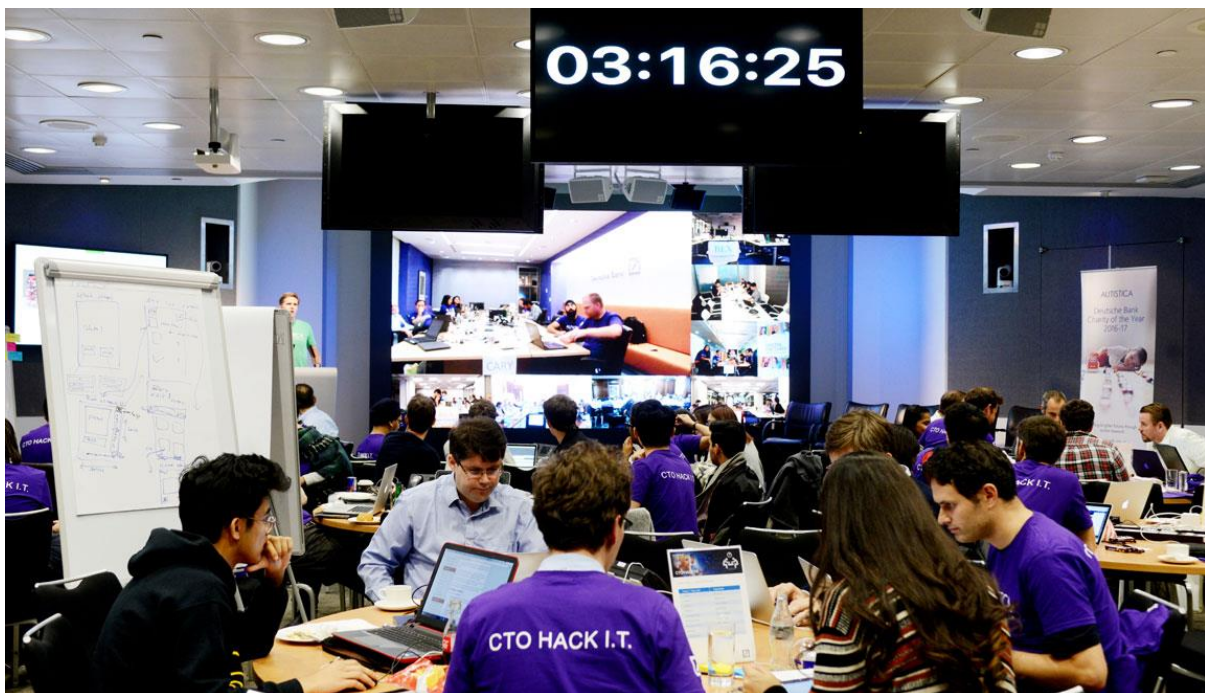
'Deutsche Bank 24hr 'hackathon' where tech staff worked with autism researchers to develop a prototype mobile app to aid anxiety'
Autistica

"It is important to continue to learn and extend the scope of provision, responding to the needs of our people with autism and to share expertise and lessons learnt with other professionals and organisations."

6.0   Conclusion and Recommendations

6.1   Summary

In summary the respondents to the survey clearly indicated that the funding achieved their purposes but also those of The Shirley Foundation – making a great difference.

Not only were the results impressive but the processes on the whole were efficient.

Final comments from respondents says it all. They found The Foundation's team engaged, a pleasure to work with, and inspirational. There was excitement about improving early detection, achieving leaps in autism research, pioneering a charity and closing it as it had successfully achieved its mission, establishing a well-respected highly accredited organisation that impacted positively on people with autism and their families, reinforcing long term financial viability of organisations.

Lastly, as stated by a survey respondent and reflecting the essence of the responses: 'It provides with great hope for the future.'

Autism at Kingwood

"Final comments from respondents says it all. They found The Foundation's team engaged, a pleasure to work with, and inspirational."

6.2   Best Practice

Smarter Grants Initiative Report
The report issued in April 2017 entitled 'Smarter Grants Initiative'[9] identified issues facing grantees during the charitable grant-making process. It is important to note that The Shirley Foundation has in place practices that have already addressed the main concerns of the above grantees – for example The Shirley Foundation:

- Does not having an overly complex application process.
- Has strong communication with grantees, this as a result of its venture philanthropy approach.
- Has realistic expectations – with mutual expectations agreed re outcomes and impact.
- Outperforms the expectations of grantees.

This would indicate that The Shirley Foundation, based on this research, is a positive example of best practice in giving.

Awards - Dame Stephanie Shirley, the OII's founding donor, becomes the recipient of an "OII Lifetime Achievement Award"
Oxford Internet Institute

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[9] LocalGiving www.localgiving.org

6.3   Recommendations

In summary the recommendations are:

Recommendations	Section
1. It is recommended that internal files be reviewed as part of the evaluation process.	2.2.1
2. The data, findings and recommendations are limited to survey respondents only. To develop a complete picture of The Foundation and its impact it is recommended that all projects that are funded by The Foundation be evaluated.	2.2.1
3. It appears that identifying impact was not part of a small number of the grant applications. It is recommended that this be part of future grant applications that the impact of past grants be analysed to get a better sense of the broader influence of the funding.	3.2
4. There are various approaches that could be used to measure outcomes and impact. It is recommended that The Shirley Foundation develop rigorous methodological approaches for measuring outcomes and impact, these in order to evaluate effectiveness and efficiency of the interventions supported by The Foundation.	3.3.1
5. It is recommended that an analysis of project reports be undertaken to test respondents' perceptions	3.3.2.3
6. Although the vast majority rated the application criteria and process as very positive it is recommended that feedback about the criteria and its clarity and the process be obtained from each applicant for all applications including those that were not approved and feedback be given to all applicants about their application and the funding decision.	4.1
7. It is recommended that grant files be reviewed to assess what the issues are concerning reporting and that a clear policy of reporting and criteria be established.	4.3
8. Although the milestones and results ratings are positive, it is recommended that follow-up re the process of reporting and improvements that could be made should be a normal part of the grant process.	4.3