

The Shirley Foundation Chairman's Report for the year ending 31 March 2005

It is my pleasure to report on our ninth year of operation, which saw the conclusion of a number of major projects and included the emergence of a new charity, National Alliance for Autism Research (UK), in line with our Mission

Facilitation and support of pioneering projects with strategic impact in the field of Autism Spectrum Disorders, with particular emphasis on medical research

We also commissioned a review of published material "Autism: State of the Global Science" and committed to part-fund **New Philanthropy Capital** to review European social investment in Autism Spectrum Disorders (ASD). These small but strategic expenditures were the foundation's first such initiatives for nearly three years.

Projects Concluded

Our largest-ever project culminated this year with our grant of the freehold of **Prior's Court School** and its twelve associated individual houses to the Trustees of the school's foundation.



Prior's Court provides quality education to 59 day and residential pupils (from 5 to 19), all with both autism and moderate to severe learning disabilities. It also provides a resource for research into interventions, serves as a beacon of excellence to UK and overseas schools and is planning a Further Education college with capacity for an additional 12 students.

The trustees would like formally to acknowledge the crucial contributions made by Founding Principal Robert Hubbard; Project Director John Kinder, now chairing the school's Trustees; the initial Project Director Kate Luker; Educational Consultant John Woodhouse; and the many others involved in delivering this success. We are delighted to report that Robert Hubbard was gazetted with an OBE in the New Year 2005 honours.

Our three-year support of **Resources for Autism's Expert Witness Service** came to an end in Summer 2004. This service supported parents trying to obtain a Statement of Special Educational Needs for their child. It provided both helpline and expert support in presenting to Tribunals and was extremely successful, with 86% of appeals either won or partially won. Both the tribunal service and the helpline filled an important niche, addressing the most complex needs and it was in many respects a service of last resort with many referrals coming from other organisations in the field of autism that lacked the expertise (and time) to accept such cases. We were therefore very sad to learn that Resources for Autism had been unable to secure follow up funding from any source and, as our funding ran out, had to wind up the service.

The long-term impact of the work we funded in **Cambridge University's Autism Research Centre assessing the prevalence of Asperger's Syndrome** amongst primary school children seems to be more certain as the results are to be extrapolated nationally to assess need and plan services. The project has also included an element of teacher and parent training and information and has assisted the parents of those children identified as a result of the study as having an autistic spectrum disorder, to access services for their child. Final results and an evaluation of the project, which finished in March 2005, are due shortly.

Another research project will also finish soon. The **Department of Child Psychiatry at Oxford University** has been looking at the efficacy of behavioural (i.e. non-drug) treatment for **severe sleep disorders in children with autism**. The interim results are very encouraging and overall parents have rated the new treatments/interventions positively and reported their child's sleep to be better and they are less disturbed by and anxious about their child's sleeping patterns as a result. Sleeping problems are one of the most exhausting aspects of their child's autism that families have to contend with and these results could greatly improve the quality of life of children with ASD and their families.

Presentations of the findings of this research to clinicians and researchers are planned not only in the UK but also in Europe and the United States.

We have for many years been supporting **Brondyffryn**, a school and resource centre for children and young people (from 3 to 19) with autism in North Wales. Our support has not only been through a grant but also in terms of expertise and advice. Our commitment and support to this struggling school initially helped to secure the interests of the Welsh Assembly and to set up an independent charitable trust. The plans were to redevelop the school, residential provision and related services with financial support from the Welsh Assembly, The Shirley Foundation and other charities and for the new charitable trust to enter into a joint agreement with the school to manage all the services.



The long term outcome in terms of structure is not as we planned and first expected but the much-needed services are still being put in place and the headway is dramatic. Parents agree that although there is still a way to go to complete the full range of services, the improvements to their children's educational environment have already been immense. Guided by Project Director June McKerrow, The Shirley Foundation is very pleased to have played a vital part in bringing that about.

Ongoing Support

A further year's funding of **Autism Cymru** continues to improve the lives of people on the autistic spectrum and those who care for them. Over 3000 people have now attended the programme of training opportunities in Wales, and the charity is co-ordinating the development of a new Welsh Centre for ASD Research, and has been chosen for Channel S4C's "Charity of the Year, 2006".



Autism Cymru's contribution to the development of autism strategy in Wales and, by extension, other European countries, has been exemplary. Chief Executive Hugh Morgan has developed a 6-strong management team and Autism Cymru is moving towards financial independence over the next few years.

The foundation's sole commitment outside the autism sector is to the **Oxford Internet Institute** with its focus on social, economic, legal and ethical issues. The Institute, part of the Social Science Division of the University, has grown rapidly to a staff of thirty including three established chairs and a three-year fixed term chair. In addition, the OII benefits from a strong team of twelve research staff and three research officers on fixed term contracts. The Oxford Internet Institute makes an important contribution to higher education and to information technology.

Following on last year's positive developments with the 10-year established **National Alliance for Autism Research**, The Shirley Foundation also supported the incorporation of the affiliated UK charity and is funding its initial costs, apart from the (sponsored) Inaugural Walk.

The aims and objectives of the **National Alliance for Autism Research (UK)** are

To raise funds to accelerate biomedical research to determine and understand the causes and biological basis of autism spectrum disorders. And through that understanding, discover and promote new ways of improving the quality of life for all those affected.

Professor Sir Michael Rutter is Patron.

Walks are NAAR's signature events and serve several purposes. They are community events bonding together families affected by autism; they raise awareness; if the US pattern transfers successfully they raise funds; and they will bring forward volunteers to lobby Parliament and others, guided by lobbying professionals from LLM Communications.



The Windsor Walk



During this year NAAR (UK) put its multi-talented Advisory and Corporate Boards in place, engaged Consultant Hilary Gilfoy as Project Director, and employed (via this foundation) an experienced fundraiser Dr Stephen Humble as half-time Administrator to the Advisory Board. The first unsolicited contributions were received, some initial proposals submitted and a number of policies and strategies developed, including an outline of the Business Plan.

Acknowledgements

On behalf of the millions of potential beneficiaries worldwide, I should like to acknowledge the commitment and work of Trustees Professor Eve Johnstone CBE, Michael Macfadyen and Anne Menzies; Project Directors John Kinder and June McKerrow; part-time Administrator Elizabeth Lake and consultants Roberta d'Eustachio, Peter Galsworthy and Dr Stephen Humble for their paid and voluntary services during the year. It is a balanced and quality team.

Summary

Aside from the £2m annual grant to the Oxford Internet Institute, the year was totally committed to Autism Spectrum Disorders. The foundation has successfully concluded a number of positive developments in the sector and now concentrates on biomedical research to determine the causes of autism and halve the costs of the disorder worldwide.

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