

**Address for
correspondence**
E-mail: [ian@
nationalautismproject.
org.uk](mailto:ian@nationalautismproject.org.uk)

The National Autism Project: aims and objectives

C Ian Ragan, London

Editorial comment

Dr Ian Ragan is the director of the National Autism Project (NAP), launched in April 2015 and funded by The Shirley Foundation. In this paper, he describes the key aims of the project and the advisers and organisations who are contributing to this work. He makes the case that the spending on autism, relative to other conditions, is very low and that this has limited the progress on identifying the most effective interventions. It is hoped that data will be gathered on the cost-benefit of different services and strategies which can then be used strategically to inform future practice in health, education and social care and the voluntary sector. Readers of the *GAP Journal* who would like to read more about NAP or contribute to its work can visit the website www.nationalautismproject.org.uk.

Note: The term autism is used throughout this paper to denote all individuals on the autism spectrum, including those with Asperger syndrome.

Introduction

All charities face the issue of deciding how best to spend their money and to justify their existence to their donors, supporters and beneficiaries. They can augment their in-house expertise with the opinions of independent experts but every organisation still needs to develop its own strategy, its future direction, and its goals and ambitions. The Shirley Foundation is no stranger to this problem. As one of autism's greatest benefactors, the foundation routinely faces requests for funding for research and for support for organisations and interventions across the whole range of activities that impact on the lives of autistic people, their families and carers. Is money best spent on basic research which one day might have a dramatic effect on the quality of life of autistic people? Or should money be spent on things of more immediate benefit such as timely diagnosis, earlier intervention and better employment prospects

for young people and adults? Can we be sure that 'benefits', as normally defined by the neurotypical majority, are really meeting the needs of the autistic minority? It was to try and find answers to such questions that Dame Stephanie (Steve) Shirley with others developed the idea of the National Autism Project (NAP) which was officially launched in April this year.

The economics of autism

One thing that is clear is that autism can be very costly. Calculating the actual costs for an autistic individual and his or her family is complex. Studies which have attempted to estimate these suggest that the economic impact on the UK is about £32 billion per year (Buescher et al, 2014), divided mainly between the additional costs of accommodation, productivity loss, health and social care services, and education. This sum greatly

exceeds equivalent estimates for dementia (£26 billion per annum) (Prince et al, 2014) and cancer (£14 billion per annum) (Luengo-Fernandez et al, 2013) and yet spending on research in the UK bears no relation to these numbers. The research spend per person with the condition is over £100 per annum for dementia (Prince et al, 2014; Luengo-Fernandez et al, 2015), around £250 per annum for cancer (Luengo-Fernandez et al, 2013, 2015); but for adults with autism, only about £1 per annum (Buescher et al, 2014; Pellicano et al, 2013).

The world of autism therefore faces two central issues – how can the total research spend on autism be increased and how can decisions be made to allocate funding for the maximum benefit, both now and in the future? The latter is particularly important for autism because of the prevalence of misinformation on treatments and interventions which are not only ineffective but sometimes even harmful.

At its inception, the National Autism Project aimed to tackle these questions in the context of research into autism, much of which in the UK has focused on its causes and the effects of behavioural and educational interventions in children. It is clear that the present research agenda in the UK is at odds with the issues that the autism community identify as important to them. For example, the report from the Centre for Research in Autism and Education, entitled, *A Future Made Together* (Pellicano et al, 2013), concluded that a more balanced research profile was needed with greater emphasis on research which had a direct impact on the daily lives of autistic people in areas such as public services, life skills, cognition and learning and the place of autistic individuals in society. Similarly, *Autistica's* publication, *One in a Hundred*, emphasised the enthusiasm for research that exists in the autistic community and the desire of those on the spectrum and their families to be more involved in the research process (Wallace et al, 2013). A key point which emerged from the survey was the need for research into interventions which address problems which occur throughout the life of autistic people; namely, the comorbidities such as epilepsy, sleep disorder and mental illness.

As a result of further discussions, NAP therefore widened its remit to include all activities that affect or might affect the quality of life of the autistic community, and set out to answer the basic questions posed above, which can be restated as follows:

1. What kind of research and interventions in autism are effective, and benefit or could benefit the health and wellbeing of autistic people and their families and carers?
2. How can funders be persuaded to increase their spend on effective activities and to reduce their expenditure on resources which are ineffective?

These two questions correspond to the two phases of NAP: the first, to produce an expert report with recommendations for action; and the second, to conduct a campaign to make sure that these recommendations are put into practice.

What is the National Autism Project (NAP)?

NAP is a project fully funded by The Shirley Foundation for its proposed lifespan of three years. It does not have to raise funds from external sources, in competition with existing organisations, in order to support its activities. On the contrary, it aims to help all the autism organisations, whose support is in fact vital to NAP's success, by increasing the size of the research spend in the area. NAP's financial independence in this respect is certainly an attractive feature of the organisation and helps open doors and build relationships. But the unique aspect of NAP is its analysis of the economic benefits, actual and potential, of research and interventions in autism. That is, it aims to show that investment in research and interventions is, or can be, economically as well as socially beneficial and, therefore, that further investment would reduce the enormous economic impact of autism.

The concept of cost is a complex one in autism, much more so than for diseases such as cancer, which self-evidently require treatment, and which have no positive aspects (Knapp and Buescher, 2014). Access to effective services that improve the wellbeing of

autistic people should be encouraged not minimised, in order to reduce, for example, lifelong dependence on family and other forms of support, interaction with the criminal justice system and the development of mental health issues that can be seen as costs that arise from shortcomings in earlier services and interventions. NAP is aware that the use of language which labels autism as a disorder, in need of treatment or even cure, is greatly resented by some sections of the autistic community (Lorcan et al, 2015). NAP's stance on terminology is to use whatever form of language is most appropriate for the target audience and to consider including in our expert report a glossary of terms with justification for our choice of words. However, while governments are more likely to listen to economic arguments than those based solely on quality of life benefit, and when, as now, there is financial competition with advocates of those with other conditions, we must use at times the same vocabulary as these others, and, in this context, demonstrating the economic value of research and interventions will be our strongest weapon.

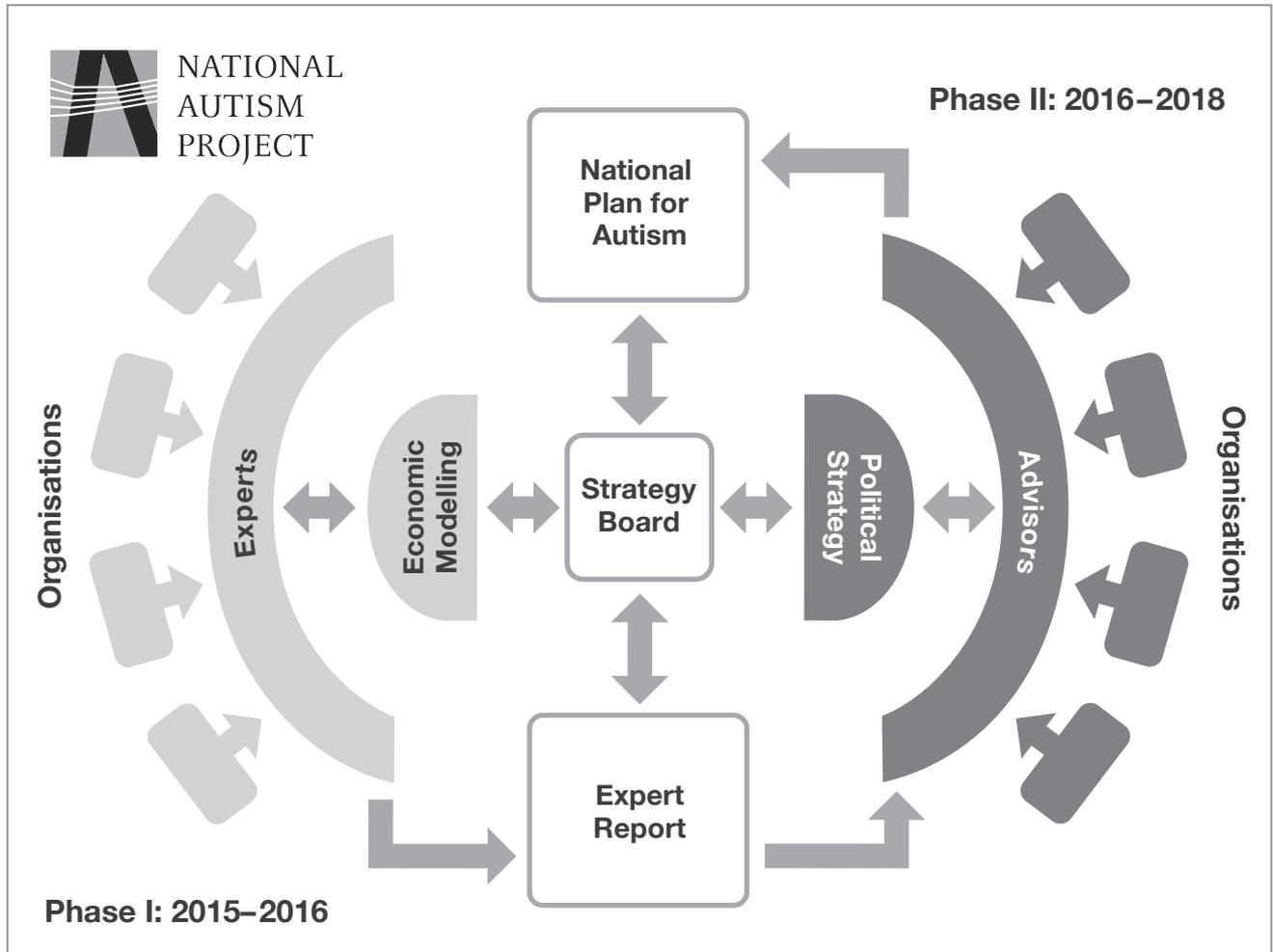
The economic case will be explored by a team led by Professor Martin Knapp of the London School of Economics and Political Science (LSE) whose work is described in more detail below. The economic analyses will be informed by a large number of experts recruited to the project, including those with personal experience of autism, whose opinions will be crucial in ensuring that NAP's recommendations are as well-based as possible. In some cases, the evidence base will be robust enough to enable clear conclusions to be drawn on the positive societal and economic outcomes of current investment, and to make strong recommendations for the future. In other cases, the evidence base may be less robust, but our experts' considered opinion could be that further research is merited to determine the benefit to people with autism and the economic case. In some cases, of course, the evidence may be negative, in which case this will be clearly stated.

Who is involved with NAP and how does it work?

NAP's recently launched website (www.nationalautismproject.org.uk) contains much information about the people involved with the project. The Strategy Board is chaired by Lady Elizabeth Vallance, JP, PhD. It is a unitary board composed of individuals distinguished in their own fields which often lie outside autism. They are well connected scientifically and politically. It was felt to be important for the board to have a member from the autism community, but we wished to avoid accusations of tokenism or of placing the burden of being the 'representative' of autism on one person's shoulders. Dr Dinah Murray was asked to join the board and she proposed inviting a panel of fellow autistic people to advise her and to act as a sounding board for proposals and decisions coming from the Strategy Board itself. The membership of this Autistic Advisory Panel is described in more detail on our website.

The roles of the Strategy Board are to review progress of the project, especially, at this time, the work ongoing at LSE; to oversee the writing of the expert report to be completed and published in Autumn 2016; and most importantly, to plan and implement a campaign to bring the conclusions of the report to the attention of funders and policy makers. Since the Strategy Board is not, for the most part, expert in autism, over 20 UK experts have been recruited whose knowledge and experience covers the wide range of NAP's remit (www.nationalautismproject.org.uk/experts). They function as consultants to the team at LSE, acting as a reality check on the conclusions of the economic analyses, offering expert opinion where evidence or data are lacking and ultimately lending their authority to the expert report. The experts provide their input as individuals rather than as representatives of their respective organisations, but, of course, they will be able to draw on the knowledge of these organisations as needed. The relationship between these various bodies is illustrated in *Figure 1*.

Figure 1: The organisation and goals of the National Autism Project



The right hand side of *Figure 1* is more speculative as a detailed strategy has not yet been formulated for the campaign to ensure that the recommendations of the report are taken up in practice. This phase of the work is shown as following on from the current phase leading to the expert report, but of course, in reality, the groundwork is being laid for the second phase, in discussion with many organisations which are planning to support the work. The advisory group consists of individuals representing major UK bodies involved, for example, in research and provision of services to the autistic community. They include the major UK charities such as the National Autistic Society, Research Autism, the Autism Alliance and Autistica, and those of the

devolved nations, Autism NI, Scottish Autism and Autism Spectrum Connections Cymru. But other bodies are also being consulted (eg ,the National Institute for Health and Care Excellence (NICE), Specialisterne, Sense About Science and MQ Transforming Mental Health).

There are good reasons for involving these organisations. First, they are hugely knowledgeable about the real issues affecting the lives of the autistic community. Secondly, they are already involved in the provision of services and/or funding research. Thirdly, without their support, the expert report and the subsequent campaign will have little validity. Fourthly, many of these organisations have a long history of influencing

policy at the highest level. With their active support, it can be ensured that NAP does not make recommendations for actions that are already being undertaken by other organisations, that their work is built upon and that value is added, wherever possible. It will also be important to work in partnership in the campaigning phase. Even at this early stage, the help provided by many of these organisations has been extremely useful and they will help in the development of our strategy in the coming months.

What has NAP achieved so far?

The official launch of NAP in the House of Lords on 28 April 2015, was a major event as the culmination of several months of work to establish the structure of the organisation and to define the short term goals. Around 150 people attended the occasion, many of whom were from the groups and organisations mentioned above. The launch had been preceded by the first meeting of the Strategy Board, on 23 April 2015, and descriptions of these events can be found on the NAP website, the creation of which has been one of the main achievements to date.

Work at LSE started in March 2015 and is progressing well. Currently, the team is conducting rapid literature reviews on the effectiveness and cost-effectiveness of interventions for both children and adults with autism. In particular, they are starting to gather evidence on multidisciplinary diagnostic assessment teams, early interventions, psychosocial interventions, vocational interventions and interventions for parents and carers. The evidence is being organised into tables to summarise key information: the name of the intervention, the country where the evaluation has been conducted, who the intervention is for (eg type of autism diagnosis, level of learning disability, age), description of the intervention itself, setting (eg school, health clinic, at home), components of the intervention (eg different therapy types), evidence on effectiveness, evidence on cost-effectiveness and information on the costs of delivery.

These tables will support discussion of the evidence with the experts to facilitate the selection of promising interventions for which the economic case will be explored. Such discussions with the experts have been crucial in

helping to understand the preliminary results from the literature reviews and the broader context. The team is also mining datasets from previous evaluations (eg effectiveness trials or observational studies) that may help inform the analyses for interventions lacking economic evidence. These data would be used in simulation modelling or to examine economic questions in other ways. One example is the Scottish Autism dataset that includes data on sociodemographic and clinical characteristics, and service use for children and adults with different types of autism diagnoses (MacKay et al, 2013).

We are sensitive to the difficulty of comparing research and interventions that have short term versus long term economic impact. While it would be valuable to present to policy makers recommendations that are easy to implement and which have immediate cost benefits, some valuable activities may only have an economic impact in the longer term. Emphasis on immediate benefits must not be at the expense, for example, of basic research into autism, which interestingly is greatly supported by the autistic community, but its impact is difficult to estimate and rarely occurs in the short term.

Referring back to the earlier question about what constitutes 'benefit', the team is exploring ethical issues in the area of autism and their economic implications. The identification of ethical issues would inform not only the selection of promising interventions for which the economic case will be explored, but also the design of the economic models, and the interpretation of results. These could be, for example, ethical issues around early interventions for autism (when is early 'too early'?), around intervention effectiveness (which dimensions of health or quality of life matter?), around intervention efficiency (are clinical and economic gains today more important than gains in the future?), and around fairness (are interventions accessible to all socio-economic groups?).

The autism spectrum contains within it a wide range of opinion on the definition of needs and therefore of the definition of effectiveness of interventions. While it is fair to say that these definitions have for too long been dominated by the opinions of the neurotypical population, it is necessary that the views of the entire

autism spectrum are fairly represented, of those with higher needs and dependence on services, as well as those with lower levels of need.

Consultation with the experts is ongoing to find out about research currently underway, to understand the relevance and significance of the preliminary findings of the literature reviews, to explore the relevance of emerging interventions, and later to identify some of the parameters needed for the analyses.

What about the future?

The Strategy Board at its next meeting this autumn has some important issues to consider. It is important to define our three-year goal, to identify something ambitious but realistic and quantifiable. It might take the form of a significant increase in funding for autism research and interventions based on the recommendations of our report. It could also be about establishing a new structure for integrating and managing all the various aspects affecting the lives of the autism community, a UK National Plan, say, that seeks to eliminate the current gaps in provision of services that leave people stranded without proper support, but one for which an economic case can be made through improving employment chances and independence.

Concluding comments

With some ideas of our future goal, it is also important to address the issue of how this is achieved, and for that the experiences of others will be drawn upon, not only in the field of autism but outside, with organisations that have already achieved some political (and therefore financial) prominence in areas such as Alzheimer's disease and cancer. New partners may be needed to help drive the campaign phase but in the meantime much effort will be made to raise the profile of NAP and the awareness of its ambitions. NAP is pleased to support the proposal from Barry Sheerman MP to launch a Parliamentary Commission on Autism (www.nationalautismproject.org.uk/progress-report-may-june-2015) which, while independent of NAP, could give a tremendous boost, in both Houses of Parliament and beyond, to understanding of the issues surrounding autism, and could complement the work being undertaken in the NAP project. Similarly, NAP is very happy to be involved in the work of the

All-Party Parliamentary Group on Autism (www.appga.org.uk), recently relaunched after the General Election.

Those involved in NAP feel that it is on the right track. Many individuals and organisations have said that what NAP is trying to do is long overdue and those involved in NAP have been enormously encouraged by their enthusiasm for NAP. There is much to do in a short time but confidence is growing that NAP will have an important impact and will answer the questions that Steve Shirley posed over a year ago to the real benefit of all those in the autism community.

References

- Buescher, AVS, Cidav, Z, Knapp, M and Mandell, DS (2014) Costs of autism spectrum disorders in the United Kingdom and the United States, *JAMA Pediatr*, 168(8), 721–728.
- Knapp, M, and Buescher, A (2014) Economic aspects of autism, in F Volkmar, R Paul, S J Rogers and K A Pelphrey (Eds) *Handbook of autism and pervasive developmental disorders* (Fourth Edition), New Jersey: John Wiley and Sons.
- Lorcan, K, Hattersley, C, Molins, B, Buckley, C, Povey, C and Pellicano, L (2015) Which terms should be used to describe autism? Perspectives from the UK autism community, *Autism*, doi: 10.1177/1362361315588200.
- Luengo-Fernandez, R, Leal, J, Gray, A and Sullivan, R (2013) Economic burden of cancer across the European Union: a population-based cost analysis, *Lancet Oncol*. 14(12), 116–74 .
- Luengo-Fernandez, R, Leal, J and Gray, A (2015) UK research spend in 2008 and 2012: comparing stroke, cancer, coronary heart disease and dementia, *BMJ Open*, 5 (4).
- MacKay, T, Boyle, J, Knapp, M and Connolly, M (2013) A multi-strand investigation of microsegmentation of the autism spectrum to enhance the data on the economic costs and benefits of provision, *Good Autism Practice*, 14 (Supplement 1), 99–104.
- Pellicano, L, Dinsmore, A and Charman, T (2013) *A future made together: shaping autism research in the UK*, London: Centre for Research in Autism and Education.
- Prince, M, Knapp, M, Guerchet, M, McCrone, P, Prina, M, Comas-Herrera, A, Wittenberg, R, Adelaja, B, Hu, B, King, D, Rehill, A, Salimkumar, D (2014) *Dementia UK: The second edition*, London: Alzheimer's Society.
- Wallace, S, Parr, J and Hardy, A (2013) *One in a hundred: Putting families at the heart of autism research*, London: Autistica.