

EXECUTIVE SUMMARY

Background

In 2007, research led by Professor Martin Knapp from the London School of Economics and Political Science demonstrated that the economic consequences of autism in the UK totalled £28 billion per annum. The study, financed by The Shirley Foundation, stimulated other work such as the National Audit Office report in 2009, *Supporting People with Autism through Adulthood*, which showed that effective support could substantially reduce costs. The Autism Act (2009) aimed to improve diagnosis and support for autistic adults in England, while in Wales the first ever national strategy for autism was published in 2008, and other political initiatives followed in Scotland (the Scottish Strategy for Autism launched in 2011) and Northern Ireland (the wide-ranging Autism Act (NI) 2011). These initiatives in all four nations led to further development of action plans, revised strategies and new guidance. It looked as though a new era of more effective recognition and support for autistic people was beginning. Yet nearly a decade on, the needs of autistic people are still unmet and the expected economic dividend never materialised. When the LSE revisited the figures for 2014 using more accurate information the total came to £32 billion. Something is clearly not working.

Concerned that this situation could not continue, The Shirley Foundation established the National Autism Project in early 2015 and asked Professor Knapp and his team to map the existing evidence base and identify clear research gaps. The discovery that the evidence base for the effectiveness of many support practices and interventions in current use was limited or of poor quality led to a shift in focus to whether these offerings were effective and, if effective, whether they made economic sense.

The Shirley Foundation believes that a focus on actions that the evidence shows are both effective and cost-effective will benefit the autistic community and contribute to a reduction in the huge impact of autism on the UK economy. This is the Autism Dividend.

The analysis of evidence was carried out over a period of 21 months. It was based on an extensive literature search of priority areas and topics which were selected with the advice of a team of external experts recruited to the project. These included an Autistic Advisory Panel composed of autistic adults. The experts were also important in helping understanding of the practical and conceptual challenges to developing the economic evaluations and models that underpin the analyses.

The work identified many gaps in the evidence base, leading us to conclude that most policy and practice is not supported by evaluation of effectiveness and cost-effectiveness in studies of good quality. This is hardly surprising in view of the very small sums of money spent on autism research (only £4m per year in the UK) compared with other societal issues of comparable size and importance.

From these gaps, we have selected some of the areas of particular relevance to the lives of autistic people as topics for further research to support good practice. The recommendations of this report therefore fall into two categories: those in policy and practice for which we have made a case based on the existing evidence of effectiveness and cost-effectiveness; and those where research is needed to build the evidence base.

The Four Principles

In considering the wide range of possible interventions in areas such as education, health, social care and employment, we came across consistent themes or principles that underlie both our recommendations and the challenges most commonly faced by autistic people.

Principle 1: Personalised actions

Recognising people's individual characteristics and circumstances, different needs and individual preferences.

Principle 2: Choice and control

Balancing the wish of many autistic people for greater autonomy with effective support structures to meet their needs.

Principle 3: Addressing inequalities

Providing support and building better understanding and tolerance of difference to address inequalities in access to healthcare, education and employment.

Principle 4: A life-long perspective

Ensuring early identification and evidence-based interventions during childhood or adolescence, and at all stages of life.

The Policy Recommendations

Each of the recommendations listed below encompasses very broad areas of policy and practice. To illustrate the evidence base on which they are founded, we have included case studies in the report that contain detailed evidence on reported effectiveness and, where available, cost-effectiveness.

The recommendations are:

1. Ensure timely identification and diagnosis
2. Provide evidence-supported interventions
3. Make the economic case for intervention
4. Remove barriers to access
5. Tackle environmental and other stressors
6. Fight stigma and discrimination
7. Ensure better transitions (for example between child and adult services)
8. Coordinate action across sectors
9. Build better information systems

We are not the first to call on policy makers to implement recommendations of this type. However, our approach has been a rigorous evaluation of evidence backed by expert opinion which we hope will strengthen the case and encourage and support responsible authorities to take action.

The National Workshops

We recognised that any implementation of the policy recommendations will take different pathways in England, Northern Ireland, Scotland and Wales because of the continuing process of devolution of powers from central government. In order to understand what policies were already in place in the four nations, how present policy is addressing our recommendations and how changing policy might affect their future implementation, workshops were held in London, Belfast, Alloa and Cardiff with charities, professionals, policy makers and autistic people and parents. The outputs of these workshops together with descriptions of national policy and policy initiatives are included in the Appendices of this report.

The Research Recommendations

A number of research areas emerged from the analysis of the evidence-base where knowledge is currently weak. With stronger supporting evidence though, these areas could have significant impact on the lives of autistic people. Other ideas came from proposals made in the national workshops.

Many of these proposals have been identified by others as important topics for research and some are already under investigation. We hope, however, that the approach we have taken to identify these topics will spur further effort and encourage funders to look at some different areas for research. Most importantly we hope that there will be recognition of the current inadequacy of autism research funding, and understanding that such research is a good investment, one that is vital for the wellbeing of autistic people.

Conclusions

Our work has found that a great deal more could and should be done to generate evidence to shape policy and improve practice in autism. Too often, the evidence base was found to be weak on benefit and even weaker on cost-effectiveness. Efforts to collect data to substantiate the effectiveness of interventions are inadequate and research to underpin practice is woefully underfunded. The result is a UK economic impact of £32 billion per annum while the needs of autistic people remain unmet. This is an unsustainable state of affairs and must be addressed.

We call on national governments to acknowledge our findings and recommendations on evidence-based practice, to empower and resource service providers in all areas of autism provision to implement the recommendations, and to take our findings into account in their own future planning.

We also call on national governments and research funders to increase investment in autism research from its current low base in order that future decision-making is properly knowledge-based.

Over the next year we will be campaigning to promote the Autism Dividend described in this report so that not only autistic people but society as a whole can reap the rewards of better investment. We will be inviting people associated with the project and others, to write about the “future they would like to see” on our website.