Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Executive Summary

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The term Autistic Spectrum Disorder (ASD) is used to cover a broad range of conditions defined as pervasive developmental disorders. In April 2008, the Welsh Government published the Autistic Spectrum Disorder Strategic Action Plan (ASD SAP), an all-age strategy intended to improve understanding and provision of services for individuals with ASD in Wales (WAG, 2008).

At the end of 2012 the Welsh Government commissioned the People and Work Unit to undertake an external evaluation of the ASD SAP. This evaluation has two main objectives:

- to undertake a comprehensive assessment of data availability and gaps to inform the development of indicators to measure progress; and
- to undertake an assessment of how the ASD SAP is meeting its original aims.

This report outlines the evaluation methodology, the progress made against key areas of the ASD SAP and the conclusions of the evaluation in relation to the outcomes in each of these areas.

Approach and methodology

This is a theory-based evaluation. It is structured around the development of a series of logic models for the ASD SAP, a depiction of different elements of the strategy outlining the intended implementation of the strategy (inputs, activities and outputs) and its expected impact (including short- and longer-term outcomes). The logic models were tested

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and refined by drawing upon data from a number of sources, including:

- a desk-based review of literature and data;
- interviews and discussions with people with ASD, parents and carers of people with ASD and a range of key stakeholders from public, academic and voluntary sectors; and
- interviews and discussions with, and a survey of, ASD leads/co-ordinators.

Key findings

Wales has led the way in the UK in developing policies to support people with an ASD, and their families. Since the launch of the ASD SAP in 2008, a national and local ASD infrastructure has been developed. This includes a national co-ordinator, ASD leads and co-ordinating groups in each of the 22 Welsh local authorities (LAs) and an all-Wales diagnostic and pre/ post counselling network for adults. The strategy and the infrastructure have helped raise the policy profile of ASD, empowered individuals to develop and improve services and provided a focus for developments across Wales.

Training and awareness-raising are a key focus of the national and local ASD infrastructure. A wide range and large number of services and people have been reached and the improved training and awareness is reported to have had positive outcomes. Nevertheless, coverage has been uneven across services and groups and more work is needed.

Increased awareness of ASD has contributed to increased rates of identification. This in turn has contributed to sharply increased rates of diagnosis among school age pupils in Wales, from approximately 0.2 per cent in 2003/2004 to 1 per cent by 2012/13 (Holtom et al., forthcoming). This represents a key outcome. It has improved the support that children and young people can access in education, increased the likelihood that the needs of young adults will be recognised, and is valued by parents and carers. However, greater awareness has also increased the pressure upon children's diagnostic services, contributing to lengthy waiting times in many parts of Wales.

Improvements in assessment and in diagnosis of ASD for adults are also key outcomes. New services have been established in some areas, including pre- and post-diagnosis counselling, and existing services consolidated in others, increasing capacity and improving the quality of the diagnostic process. However, the number of adults getting a diagnosis remains small and there are gaps and weaknesses in adult diagnostic and pre/post counselling services in some parts of Wales. Moreover, the impact of increasing rates of diagnosis upon outcomes for adults has been limited by high thresholds of eligibility for adult services and by a lack of specialist services for adults with ASD who do not have a learning disability.

There have been improvements in transition services since 2008. These have contributed to improvements in experiences of transition, although transitions from school to further education (FE) and higher education (HE) are generally much more successful than transitions from FE or HE into employment. The lack of services for adults with ASD (discussed below) can limit the impact of transition planning, and qualitative evidence indicates that many adults with ASD struggle to make a transition into employment and independent living and continue to be supported by their parents. In some cases, they lose independence and their social skills deteriorate, making them increasingly disabled as a consequence.

Rises in rates of diagnosis in childhood have led to an increase in the number of young adults with a diagnosis; having a diagnosis means that people are much more likely to have their needs understood and supported in FE and HE and by employment services. The number of adults with ASD in FE and HE has increased markedly; for example, the number of Welsh learners in FE with ASD recorded as their primary disability increased from 70 in 2004/5 to 465 in 2011/12 (Holtom et al., forthcoming).

ASD awareness-raising and training has improved capacity in some employment services and a number of projects have been established specifically targeted at supporting transition to, and sustaining of, employment. Despite this, adults with ASD still struggle to access effective support to find employment, and employment rates remain low.

In order to support adults with high-functioning autism or Asperger syndrome, community monitoring and support (CMS) worker posts were established and a number of projects developed. The CMS posts were intended to provide a signposting service for adults with ASD and, by providing low-level support, were intended to help stop problems escalating. The lack of services for adults has blunted the impact of this work as there are few statutory services to which people can be signposted. Overall, there has been little change in a situation where most adults with ASD and a learning disability can access a statutory service, while those without a learning disability cannot. The extent to which learning disability services can meet the needs of adults with ASD has also been questioned.

The establishment of the local and national ASD infrastructure, which contributed to service mapping and the development of service directories and websites, means that parents' and carers' access to information has improved. Nevertheless, parents and carers consistently report that it remains difficult to identify support and services and that they experience high levels of stress and anxiety as a consequence.

Conclusions

Stakeholders welcomed the ASD SAP. It was widely felt to have directly contributed to raising the profile and awareness of ASD, it has enabled the development of a local infrastructure and it is perceived to have had a positive impact upon people with ASD, on their families and on professionals.

However, the ASD SAP has a number of weaknesses, including a lack of explicit priorities, a lack of detail on what was required, and weak governance and accountability structures, making it difficult to direct developments across Wales. This all contributed to an uneven impact across Wales, so that the strategy helped create "islands" of good practice across Wales, but struggled to create systemic change.

In assessing the impact of the ASD SAP it is important to distinguish between outcomes – what changed, and the impact the strategy made – the extent to which the strategy caused or contributed to those changes. Many of the changes, such as increases in awareness (discussed above), were not solely caused by the strategy – although the strategy did contribute to them.

It is not possible to definitively isolate the impact of having a strategic action plan and the focus of this report is primarily upon whether the ASD SAP achieved its aims or not; that is whether the intended *outcomes* were achieved - rather than trying to isolate the contribution of the ASD SAP to these outcomes (that is, the *impact* of the ASD SAP). Nevertheless, the logic models developed for this study highlight some key strengths and weaknesses, which cast light on the difference the strategy made (its impact), in particular:

- local and regional projects played a key role in creating change and improving outcomes, but contributed to an uneven impact across Wales because they were local or regional rather than national projects;
- the impact of the local ASD infrastructure upon commissioning was limited because it has tended to focus upon services or projects it has commissioned itself, rather than those commissioned by LAs and local health boards(LHBs);
- new national standards and guidance were intended to drive improvements in areas like education and young people's transitions. The failure to develop or implement these limited the ASD SAP's impact; and
- in many areas, the ASD SAP defined the standard to be reached, but did not articulate an effective means for reaching it and much therefore depended upon local initiatives and priorities.

Overall, progress has been made in all the key areas that the SAP focused upon, and the strategy has contributed to improving the experiences of both individuals with ASD and their families. Nevertheless, it has not fully achieved its aims, particularly in relation to services for adults with ASD, and there is a need to continue and refresh the ASD SAP.

Key priorities for any refreshed strategy are likely to include:

- improving assessment and diagnosis of ASD, particularly for children;
- ensuring that the skills and independence that many children and young people develop through education are sustained into adulthood (while ASD is a lifelong condition, people's levels of disability are not fixed);
- improving adults with ASD's access to support (particularly for those who cannot access learning disability (LD) or mental health (MH) services);
- improving access to information and support for parents and carers of people with ASD; and
- improving data on the impact and effectiveness of the refreshed strategy (enabling greater accountability and improving the identification of both the strengths and weakness of any refreshed strategy).

Key challenges for any refreshed strategy are likely to include:

- consolidating and developing ASD-specific specialist services where appropriate (such as ASD assessment and diagnosis services and ASD-specific employment support services) and integrating ASD awareness and support into “mainstream” policy and practice, in areas such as education, mental health, social care and employment services (through for example, workforce development and the development of mechanisms to share expertise);
- sustaining the important improvements in both mainstream and specialist services that have been made to date, in what is expected to be a challenging context, characterised by increasing demand for services, alongside cuts in resources (Williams, 2014);
- scaling up those local and regional initiatives that have made a difference, in order to improve support and services across Wales; and
- developing more person-, rather than service-, centred services[1] which are better able to meet the complex needs of people with ASD who do not fit easily into existing service structures or teams.

Recommendations for improving outcomes for people with ASD and their families

Increasing awareness and understanding of ASD

R1. The ASD national development lead to work with the Welsh Government and local ASD leads to ensure that ASD awareness is integrated into workforce development strategies (e.g. as part of initial training) in careers, education, health, housing, employment and social care services.

R2. The ASD national development lead to work with the Welsh Government and local ASD leads to maintain and develop ASD networks, or “hubs” of expertise, such as the ASD diagnostic and pre/post counselling network for adults (Holtom and Watkins, forthcoming) and ASD-specific employment services (Townsley et al., 2014). Support should focus upon not only sustaining this expertise, but also on ensuring that it is shared with others.

R3.The Welsh Government to continue to fund national resources, such as the ASD info Wales website.

Improving assessment and diagnosis of ASD for children and adults

R4. The Welsh Government to invest in an all-Wales children’s ASD diagnostic and

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[1] This is key aim of the Social Services and Well-being Act.

pre/post counselling network, and to continue to support the all-Wales ASD diagnostic and pre/post counselling network for adults.

R5. The Welsh Government to require LHBs to provide annual reports on the performance of children's and adults' ASD diagnostic services (see, for example, the proposed measures in tables four and five).

Improving the education of children and young people with ASD

R6. The Welsh Government to continue work to reform the system for identifying, assessing and supporting children and young people with additional learning needs (ALN), in preparation for the forthcoming Additional Learning Needs and Education Tribunal (Wales) Bill. This should include, for example, workforce development in order to better meet the needs of all learners, including those with ASD.

R7. The Welsh Government to require LA education services to provide annual reports on the performance of pupils with ASD in their area (see examples in table six).

Improving the transitions of young people with ASD

R8. The Welsh Government, LAs, schools and post-16 providers to implement the recommendations of the study to identify transition arrangements from school to post-16 FE and HE and training for young people with learning difficulties and/or disabilities (LDD) (Holtom and Lloyd-Jones, forthcoming).

R9. The Welsh Government to require LAs to provide annual reports on the performance of post-16 learners with ASD in their area (see examples in table seven).

Improving employment outcomes for people with ASD

R10. The Welsh Government to implement the recommendations of the research into employment outcomes for young people with ASD (Townsley et al., 2014). This could include identifying how additional employment support, such as job coaching for people with ASD could be funded (e.g. through the use of Dormant Account funds and European Social Fund (ESF) monies).

R11. The Welsh Government to work with LAs and Careers Wales to improve integration of support for young people who are at risk of disengagement from education or training or who have disengaged, under the Youth Engagement and Progression Framework, with support for young people with LDD (see e.g. Holtom and Lloyd-Jones., forthcoming).

R12. The Welsh Government to explore the scope for the ASD Employment Ambassador to work with employers' human resource departments to ensure recruitment and support meets the needs of people with ASD. Initial efforts could focus upon public sector employers, such as the Welsh Government, NHS and LAs.

R13. The Welsh Government to request data on outcomes for people with ASD supported by Jobcentre Plus and work programme providers, from the Department for Work and Pensions (DWP).

Improving adult services for people with ASD

R14. The Welsh Government to require the all-Wales ASD diagnostic and pre/post counselling network for adults to develop stronger links between assessment and diagnostic services and adult services, and to report on these.

R15. The Welsh Government to evaluate the impact of the Social Services and Well-being Bill upon people with ASD. This should include its impact upon assessments of need; the impact of national eligibility criteria on access to care and support; and its impact upon the provision of information to people with ASD identified as "in need" and to their carers, about the care and support that is available in their area.

R16. The Welsh Government to consider the case for developing more integrated services for adults with ASD (Holtom and Watkins, forthcoming). This should include evaluating the cost-effectiveness of existing integrated service models, such as the Cardiff One Stop Shop and CMS workers.

Improving information and support for people with ASD and their parents and carers

R17. Local ASD leads to work with the voluntary sector to help ensure that people with ASD and their parents and carers can access informal support (e.g. through support groups).

R18. Local ASD leads to work with local services and the voluntary sector to explore the scope to develop local ASD information and advisory services that could act as a first point of contact for advice to people with ASD and their parents and carers.

Consolidating the ASD infrastructure and sustaining progress across Wales

R19. The Welsh Government to require LAs to report on an annual basis on the use of funding for ASD rolled into the Revenue Support Grant.

R20. The Welsh Government to continue to fund an ASD national development lead post, working with the ASD Stakeholder Advisory Group to review and, if appropriate, revise the role in line with the findings and recommendations of this report and the revised SAP.

R21. The Welsh Government to strengthen the role of the ASD Stakeholder Advisory Group, so that it can both provide expert advice and hold stakeholders, such as the Welsh Government and LAs, to account (e.g. by sharing data on outcomes with the ASD Stakeholder Advisory Group).

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