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Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report

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Glossary of Acronyms

ADOS	Autism Observation Diagnostic Schedule
ALN	Additional Learning Needs
ASC	Autism Spectrum Conditions
ASD	Autistic Spectrum Disorder
BME	Black and Minority Ethnic
CAMHS	Children and Adolescent Mental Health Services
CMS	Community Monitoring and Support
COP	Code of Practice
CSSIW	Care and Social Services Inspectorate Wales
CYPP	Children and Young People’s Partnership
DEA	Disability Employment Adviser
DISCO	Diagnostic Interview for Social and Communication Disorders
DWP	Department for Work and Pensions
ESF	European Social Fund
FE	Further Education
HE	Higher Education
HESA	Higher Education Statistics Agency
HSCWB	Health, Social Care and Well-being
IDP	Individual Development Plan
IQ	Intelligence Quotient
JCP	Job Centre Plus
LA	Local Authority
LD	Learning Disability
LDD	Learning Difficulties or Disabilities
LGDU	Local Government Data Unit
LHB	Local Health Board
LLWR	Lifelong Learning Wales Record
MH	Mental Health

NAfW	National Assembly for Wales
NAS	National Autistic Society
NCCHD	National Community Child Health Database
NDC	National Data Collection
NEET	Not in Education, Employment or Training
NICE	National Institute for Health and Care Excellence
NOS	Not Otherwise Specified
NSF	National Service Framework
OT	Occupational Therapy
PCP	Person-centred Planning
PDD	Pervasive Development Disorders
PLASC	Pupil Level Annual School Census
SAP	Strategic Action Plan
SCAT	Social Communication Assessment Team
SEN	Special Educational Needs
SSIA	Social Services Improvement Agency
TKW	Transition Key Worker
UAP	Unified Assessment Process
WAG	Welsh Assembly Government
WARC	Wales Autism Research Centre
WBL	Work-Based Learning
WG	Welsh Government
WLGA	Welsh Local Government Association

Executive Summary

Introduction

1. 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).

The evaluation of the ASD Strategic Action Plan

2. 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.

3. 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

4. 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 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

5. 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.

6. 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.

7. 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.

8. 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.

9. 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.

10. 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).

11. 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.

12. 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

13. 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.

14. 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.

15. 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.

16. 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.

17. 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.

18. 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).

19. 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 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).

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

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[2] 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[3].

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[2] Eligibility criteria will be detailed in forthcoming regulations.

[3] LAs will be under an enhanced duty to provide people in need, and their carers, with information 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).

1. Introduction

1.1. The term Autistic Spectrum Disorder (ASD) is used to cover a broad range of conditions defined as pervasive developmental disorders (PDD). Such disorders include autism, Asperger syndrome and pervasive developmental disorder - not otherwise specified (PDD-NOS). “Spectrum” has been adopted to describe these conditions, as although the variance and severity of their symptoms is broad, the conditions share some common traits. Shared symptoms include qualitative impairments in social interaction, communication and imagination as well as restricted or repetitive patterns of thought, behaviours and routines. Whilst IQ amongst those with Asperger syndrome is at least average and language development is normal, in classic autism IQ can be anywhere on the scale and language development is delayed (Baron-Cohen, 2008, p.1). Given the range of problems covered by the spectrum, and in recognition of its neurobiological basis, some researchers refer to autism spectrum conditions (ASC), rather than disorders (Baron-Cohen, 2008, p.14).

The ASD Strategic Action Plan

1.2. Wales is pioneering work in the UK in relation to ASD and 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). The strategy led to the establishment of a local and national ASD infrastructure (discussed in section three), including ASD leads in each local authority (LA), local co-ordinating groups and the development of local action plans.

1.3. In 2010, the Adult Task and Finish Group Report (WAG, 2010a) was published and the ASD SAP was effectively extended, with additional actions to improve outcomes for adults with ASD. These are also considered as part of the evaluation.

The evaluation of the ASD Strategic Action Plan

1.4. 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:

i) to undertake a comprehensive assessment of data availability and gaps to inform the development of indicators to measure progress, including:

- using a logic model to identify ongoing activity and how the ASD SAP contributes to short-, intermediate- and long-term outcomes;
- developing potential measures to assess the impact of the ASD SAP in future years and the feasibility of data collection for LAs and local health boards (LHBs);
- collection of available data from LAs and LHBs and appropriate analysis thereof;

and, in liaison with the pilot North Wales Database development staff;

- identification of any problems with current data collection methods, the impact on LAs and LHBs and recommendations as to how these could be resolved;

then to:

- work with a sample of LAs and LHBs to propose and trial improvements to data collection; and
- develop and pilot guidance for ASD leads based on the trialling work.

ii) building on the first objective and using the logic model, undertaking an assessment of how the ASD SAP is meeting its original aims, using routinely collected data and the views of individuals, families and professionals to provide:

- a map of advancements in ASD infrastructure, services and projects across Wales;
- a review of the number of individuals with ASD in Wales;
- a broad assessment of impact on the experiences of individuals with ASD, their families and carers and professionals; and

- an assessment of the impact of awareness-raising, including the distribution of awareness-raising materials and training.

1.5. This study complements a discrete study of the employment outcomes for young people with ASD, also commissioned by the Welsh Government and undertaken by Ruth Townsley Research (Townsley et al., 2014).

1.6. In 2014, an extension to the contract was agreed, to enable the study to undertake further research to:

- assess the extent to which the needs of people with ASD are not being met by either community monitoring and support (CMS) services or by social services;
- assess, as far as possible, the number of people with ASD whose needs are not being met by either CMS services or by social services; and
- appraise options for meeting unmet needs.

1.7. Findings on the extent to which the needs of people with ASD are being met by existing services are included in this report and in a supporting report (Holtom et al., forthcoming). Findings from the review of options for meeting unmet needs are included in this report and in a supporting paper, Options for Meeting Unmet Needs (Holtom and Watkins, forthcoming).

Structure of the report

1.8. The report focuses upon assessing outcomes and impact across Wales in nine thematic areas:

- commissioning services for people with ASD;
- increasing awareness and understanding of ASD;
- assessment and diagnosis of ASD for children (0-17);
- assessment and diagnosis of ASD for adults (18+);
- compulsory education;
- transitions for young people;

- post-16 education, training and employment;
- services for adults; and
- services for parents and carers.

1.9. These provide the focus for sections three to ten and for each theme/section, the report:

- outlines the aim in the SAP, highlighting the key issues identified in the SAP, the desired changes/outcomes and the strategy (how the outcomes were intended to be achieved[4]);
- provides illustrative examples of the type of projects and initiatives undertaken;
- discusses the extent to which the strategy in the ASD SAP was implemented and outcomes achieved, using logic models outlining the strategy's theories of change (discussed below); and
- outlines the development of indicators to measure progress. The approach was informed by "results-based accountability" and focuses upon three broad areas: effort or quantity (how much was done?), quality (how well was it done?) and effect or impact (what difference did it make, what changed as a result?).

Impact pathways

1.10. As illustrated in the example below, for each of these impact pathways the report outlines:

- the key **issues** identified in the ASD SAP, such as unmet needs of people with ASD or weaknesses in services for people with ASD, which are presented in the column on the left;

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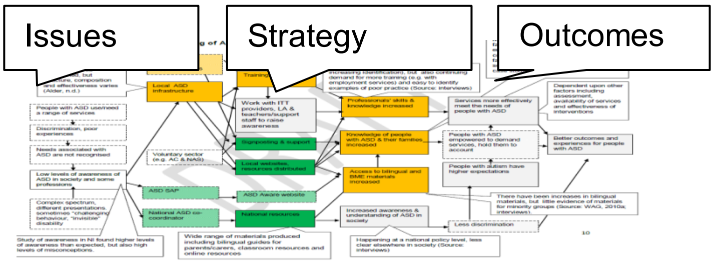
[4] The study focuses upon the SAP's strategy, including elements of the strategy that were not new (or "caused" by the ASD SAP) but represented existing policy, such as proposals for reform of the Statutory Framework for Special Educational Needs.

- the **strategy** proposals; the way in which issues identified in the SAP (such as unmet needs) are to be addressed (e.g. by changing provision for people with ASD), which are presented in the middle columns; and
- the intended **outcomes** of the strategy; the changes expected to flow from the strategy, which are presented in the columns on the right.



Sample table showing layout only

1.11. The report outlines the expected relationship between issues, the strategy and the outcomes, by using arrows. The report distinguishes between “outcomes” - what changed - and “impact” - the cause of the change. It also identifies issues such as aspects of the strategy or outcomes which were not identified in the SAP, but which are important in understanding the impact of the ASD SAP. This includes, for example, projects established after the ASD SAP was published in 2008. These are indicated by boxes with a dashed line.

1.12. The report summarises the evidence gathered to date - and this is used to make judgments using a traffic light system, illustrated by the keys below.

Implementation of the strategy

Not known (no/lack of data)	Data on implementation is generally positive	Data on implementation is mixed	Data on implementation is generally negative

Impact of the strategy (i.e. outcomes)

Not known (no/lack of data)	Data on change is generally positive	Data on change is mixed	Data indicates no change	Data indicates negative change

2. Approach and methodology

2.1. 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 the strategy outlining its intended implementation (inputs, activities and outputs) and its expected impact (including short- and longer-term outcomes) (HM Treasury, 2011). These logic models were tested and refined by drawing upon data from three key sources:

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

Desk-based review of secondary data

2.2. The desk-based review served two key purposes. It was crucial in helping identify the baseline position when the ASD SAP was launched in 2008 (four years before the evaluation started). It also enabled research findings from, for example, interviews with stakeholders to be triangulated to help judge whether the views and experiences expressed were representative.

Purposive literature review

2.3. The purposive literature review focused upon:

- key policy documents, including the ASD SAP itself (WAG, 2008) and the Adult Task and Finish Group report (WG, 2010a);
- plans, such as local ASD action plans, children and young people's plans and health, social care and wellbeing strategies; and
- research and evaluation, including studies which :

- focused specifically upon people (of all ages) with ASD (such as the study of employment outcomes for young people with ASD (Townsley et al., 2014), the interim evaluation of the ASD SAP (WAG, 2010b) and a National Autistic Society (NAS) Cymru survey of 415 people with ASD and their family members (NAS, 2011); and
- focused upon provision, experiences and outcomes for people with a disability or additional learning needs (ALN) (such as reviews of special educational needs (SEN) provision (NAfW, 2004, 2006a, 2007) and evaluation of provision for transitions for young people with additional needs (LGDU, 2011).

Systematic literature review

2.4. The purposive review was enriched by a systematic literature review focused upon seven key research questions which were discussed and agreed with the Welsh Government. The review looked at what evidence there is in the literature:

I. of what is working well, what is not working well and what could be developed in relation to: current data collection on the incidence of ASD amongst different groups of people in Wales; data collection on their needs; data collection on provision to meet those needs and data collection on outcomes for people with ASD in Wales;
II. of how provision for people with ASD in Wales (including the identification, assessment, planning and review of provision, and the underpinning infrastructure, such as commissioning arrangements) has changed since the ASD SAP was launched in 2008;
III. of the needs of people with ASD in Wales;
IV. of the needs of the families and carers of people with ASD in Wales;
V. of the key determinants of outcomes (excluding employment outcomes for 16-25 year olds) for people with ASD;
VI. of the key determinants of outcomes for families of people with ASD;

VII. of how outcomes for people with ASD in Wales, with the exception of employment outcomes for 16-25 year olds, have changed since the ASD SAP was launched in 2008.

Data

2.5. The primarily qualitative data on changes in provision, experiences and outcomes provided by the purposive and systematic literature reviews was enriched and triangulated with quantitative data drawn from a number of sources including:

- education data drawn from the National Pupil Database[5], the Lifelong Learning Wales Record (LLWR) (covering FE) and the Higher Education Statistics Agency (HESA);
- health data drawn from individual services and the North Wales Regional Database pilot; and
- data on working age benefits provide by the Department for Work and Pensions (DWP).

Case studies and action research studies

Case studies

2.6. The purpose of the case studies was to contribute to the assessment of the ASD SAP's progress against its original aims, and to the development of indicators to assess its impact. The case study approach enabled key areas of interest to the study to be explored in depth and provided scope to include the experiences of a range of stakeholders on a specific issue. The case studies included:

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[5] The National Pupil Database links the data collected through both the Pupil Level Annual School Census (PLASC) and National Data Collection (NDC) of pupil attainments.

- local infrastructure development (Caerphilly and Rhondda Cynon Taf);

- support services and service mapping (Flintshire and Rhondda Cynon Taf);
- young people's transitions (Conwy and Carmarthenshire[6]);
- assessment and diagnosis pathways for children (Betsi Cadwaladr, Hywel Dda and Powys LHBs);
- diagnostic and pre/post counselling network for adults (all Wales);
- training and awareness-raising (Monmouthshire);
- education and outreach (the Caerphilly Autism Spectrum Service);
- employment (Cardiff and Bridgend);
- CMS (Cardiff and the Vale of Glamorgan; Powys and Neath Port Talbot);
- services to meet the needs of adults with ASD, but no learning difficulty (Carmarthenshire[7], Ceredigion, Newport, Neath Port Talbot and Powys);
- parents' and carers' experiences (Blaenau Gwent, Carmarthenshire and Caerphilly).

Action research studies

2.7. The purpose of the action research studies was to contribute to the assessment of data availability and gaps and to inform the development of indicators to measure progress. The action research approach was intended to enable problems to be identified and options for development to be identified and trialled. The action research studies included work with:

- the North Wales ASD database pilot;
- the disability index used by Newport;
- the provision map being developed by Caerphilly Education Service;

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[6] This included work as part of a separate study to draw up a position statement for Carmarthenshire.
[7] This included work as part of a separate study to draw up a position statement for Carmarthenshire.

- the CMS database;
- Carmarthenshire social services[8]; and
- the all-Wales ASD diagnostic and pre/post counselling network for adults.

2.8. The research was important in identifying the issues, challenges and opportunities around the use of data. However, only two opportunities to develop tools in partnership with others were identified (for the CMS projects[9] and the all-Wales diagnostic and pre/post counselling network for adults). Crucially, as outlined in section eleven, an evaluation of the data needs identified that the objective of developing a single database or range of databases of children, young people and/or adults with ASD, was in many ways misplaced and the focus shifted from trying to predict the need for services, to developing indicators to measure the effectiveness of services in meeting needs (which are included in this report).

Research with key stakeholders

2.9. In addition to research as part of the action research and case studies, interviews and discussions with a range of stakeholders from the Welsh Government, the Welsh Local Government Association (WLGA) and the academic and voluntary sectors have been undertaken. In total 54 professionals and 17 parents and carers were interviewed.

2.10. In September 2014, emerging findings were discussed with the ASD SAP steering group and ASD leads/co-ordinators, in order to help test findings and identify where there were differences at a local level. ASD leads were also surveyed in order to collect additional data on awareness-raising and training.

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[8] This included work as part of a separate study to draw up a position statement for Carmarthenshire.

[9] Development of the tool was led by the National ASD Co-ordinator with the support of the Local Government Data Unit (LGDU).

3. Developing and commissioning services for people with ASD

Introduction

3.1 The ASD SAP stresses the importance of informed commissioning and identifies that: "informed commissioning relies on a full analysis of incidence, of likely needs and mapping of existing services across all agencies to identify strengths and deficits" (p. 21). It further identifies that: "the response of commissioners is a critical matter on which the success and speed of implementation of this strategic action plan will depend" (ibid.).

Examples of initiatives in this area

National leadership and co-ordination

3.2 The National ASD SAP Implementation Manager and the National Strategic Co-ordinator were both praised by stakeholders. They have both played an important role in raising the profile of ASD in Wales, developing resources, encouraging networking and sharing of practice. The National Co-ordinator in particular was praised for her realism and pragmatism and has co-ordinated and supported the local infrastructure (discussed below). However, their formal authority over the local ASD infrastructure and national projects was limited and the Welsh Government's power to review and approve LA ASD plans was initially exercised but appeared not to have been exercised in later phases.

ASD infrastructure

3.3 In the first year of the ASD SAP, each LA was given £60,000 to develop local infrastructure (such as an ASD lead, co-ordinating group and action plan), with a further £40,000 in subsequent years to maintain the infrastructure and develop activities. The establishment of a local infrastructure marked a significant development (WAG, 2010b). Before the ASD SAP, no LA in Wales had a local ASD action plan and by 2010, all 22 had a plan (ibid.). However, the quality of those plans varied considerably; for example, the review of the ASD infrastructure identified that: “about 50 percent of action plans reviewed were incomplete and 50 percent had not been fully evaluated” (Hay, 2013).

3.4 The position of ASD lead/co-ordinator (originally “ASD champion”) is central to the local infrastructure. Envisaged as a senior role for people with experience of directing change and resources, it is a challenging role and skills, capacity[10] and position are all important. ASD co-ordinating groups were intended to be a multi-agency approach to improving services for people with ASD, co-ordinating the work of children and young people’s partnerships, health, social care and wellbeing partnerships and the LHBs. Their composition, structure and effectiveness vary markedly (Hay, 2013). Some are well established with engagement from a range of stakeholders. Others have struggled to engage with, and recruit, people with ASD and their families and/or services such as health, education or social care. Moreover, like ASD leads/co-ordinators, many have an operational rather than a strategic focus (ibid.).

National collaborative projects

3.5 In 2010-2013, approximately £240,000 (each year) of funding was devoted to collaborative ASD projects. LAs and LHBs were invited to bid for projects that included service or geographical collaboration. The projects included support for the post-diagnosis guides (discussed in section four), training in Autism Observation Diagnostic Schedule (ADOS) and 3Di assessment tools in Powys, and the Orange Wallet scheme (discussed in section ten). Although projects led to positive outcomes, most were regional or local in nature and were not always well co-ordinated with other initiatives.

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[10] The amount of time they can dedicate to the role varies, as does as their access to administrative support (Hay, 2013).

Research

3.6 The development of ASD research in Wales is seen as the key achievement of the ASD SAP (WAG, 2010b). It includes the establishment of the Wales Autism Research Centre at Cardiff University; research into children's assessment and diagnosis (WARC, 2010) (discussed in section five); research into older people with ASD (Stuart-Hamilton et al., 2009); research into MH services for people with ASD (Jackson et al., 2011); the ASD database pilot (discussed in section five); and the Adults Task and Finish Group report (WAG, 2010a), which made a series of recommendations and led to the creation of the CMS worker projects (discussed in section ten).

Evaluating the impact of ASD SAP

3.7 As illustrated by figure one, the strategy (in relation to commissioning) focused upon:

- improving data on the incidence and likely needs of people with ASD and data on services in order to improve commissioning; and
- developing an ASD infrastructure to inform and influence commissioning at local, regional and national levels.

3.8 Key elements of the ASD SAP were implemented. As outlined above, ASD co-ordinating groups and champions were established and appointed. The availability of data on children and young people and adults with ASD, in education (school, FE and HE) in particular, improved considerably (through the PLASC and Lifelong Learning Wales Record (LLWR). However, with the exception of the North Wales Regional Database project, less progress was made in developing health or social services data. Service mapping was undertaken in most areas and important studies in areas such as children's assessment and diagnosis and older people with ASD (outlined above), were undertaken.

3.9 To date however, overall the impact of improvements in data upon commissioning of services by LAs and LHBs has been limited (Holtom et al., forthcoming). Nevertheless, as illustrated in the examples above, there were some notable examples of how studies, such as the Adult Task and Finish Group report, have directly informed commissioning of services.

3.10 The local ASD infrastructure became one of the key mechanisms for delivering the ASD SAP. Its establishment enabled and supported the development of a range of local services. However, given the breadth and ambition of the ASD SAP, it was not realistic to expect the local ASD infrastructure to implement the ASD SAP without action by other bodies at national (e.g. the Welsh and Westminster Governments[11]), regional (e.g. LHBs and educational consortia), and local levels (e.g. LAs). Links to nationally funded projects have been weak and the direct influence of the local ASD infrastructure upon commissioning by national, regional and local bodies was generally limited (Holtom et al., forthcoming). Instead, much of the influence of the local ASD infrastructure has been more indirect, exercised through, for example, actions to raise awareness and understanding (discussed in section four) (ibid.).

3.11 The very breadth of the ASD SAP, which is a strength in many ways (as it reflects the range of issues), meant that its potential to guide and inform the decisions of commissioners and the local ASD infrastructure, was limited. It did not identify clear priorities or, in some cases, actions, and as a consequence, much depended upon local priorities and decisions. With the exception of regional collaborative projects (outlined above) and assessment and diagnosis for adults (discussed in section five) there has been little joint or regional commissioning.

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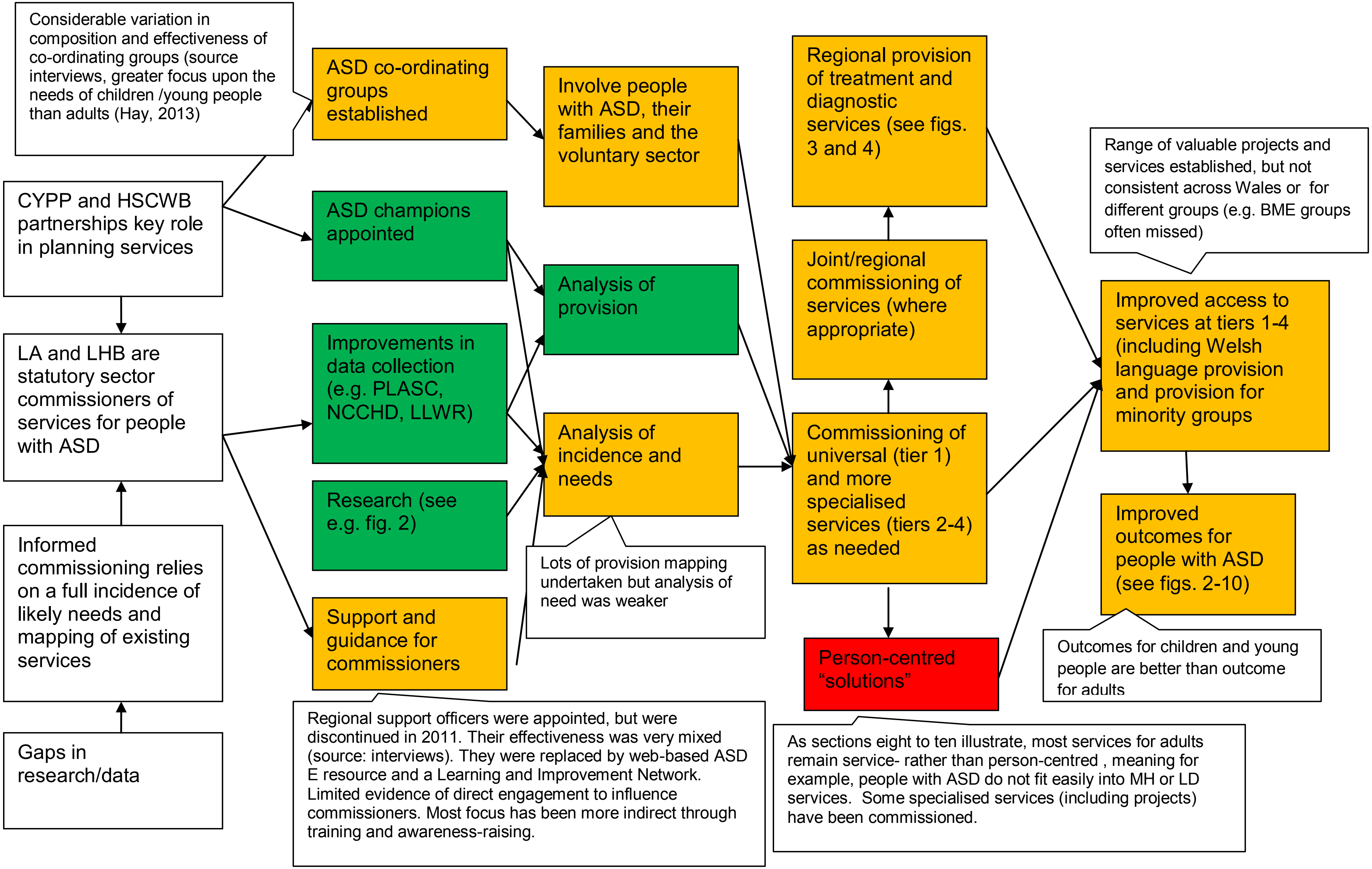
[11] Elements of the ASD SAP depend upon action in “non-devolved” areas, such as aspects of employment support and benefits, which fall under the UK DWP.

Figure 1: Commissioning services for people with ASD and their families



Considerable variation in composition and effectiveness of co-ordinating groups (source interviews, greater focus upon the needs of children /young people than adults (Hay, 2013)

Lots of provision mapping undertaken but analysis of need was weaker

Regional support officers were appointed, but were discontinued in 2011. Their effectiveness was very mixed (source: interviews). They were replaced by web-based ASD E resource and a Learning and Improvement Network. Limited evidence of direct engagement to influence commissioners. Most focus has been more indirect through training and awareness-raising.

Range of valuable projects and services established, but not consistent across Wales or for different groups (e.g. BME groups often missed)

Outcomes for children and young people are better than outcome for adults

As sections eight to ten illustrate, most services for adults remain service- rather than person-centred , meaning for example, people with ASD do not fit easily into MH or LD services. Some specialised services (including projects) have been commissioned.

Developing indicators

3.13 The local ASD infrastructure was tasked with identifying the number of people with ASD in their area and their needs. Interviewees observed that this was an overly ambitious objective. It was noted that people with ASD are spread across multiple databases such as those held by children's and adults' MH services, LD services, social services and education, so it proved very difficult to pull together the data. There are also weaknesses in these databases[12] which could not be easily addressed by the local ASD infrastructure. As a consequence, little progress was made in many areas[13] and, for example, by 2010 only eight LAs had a database for children with autism and seven had a database for adults with autism (WAG, 2010a). Moreover, and more fundamentally, while local ASD leads and groups have used databases, the use of this data by commissioners such as LAs and LHBs has been limited.

3.14 The analysis undertaken for this report indicates that the focus upon creating databases of individuals with ASD in order to inform commissioning was misplaced. Because autism covers a wide spectrum, numbers alone provide little indication of service needs beyond a basic level of incidence, and this can easily be estimated based upon population figures. Moreover, data captured on databases represents a snapshot, recording needs at a point in time, and needs can rapidly change.

3.15 Some people (of all ages) with severe and complex needs require specialist services, and structures such as complex needs panels (in education) have proved effective in commissioning services for the small number of children and young people with ASD who have severe and complex needs.

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[12] For example, the accuracy of the PLASC has been questioned and there are gaps in relation to the recording of data around adults with ASD in the LLWR, Child Health Community Database (CHCD) and social services databases.

[13] For example, Caerphilly operates a database of children and Ceredigion and Cardiff have databases covering adults.

3.16 For less specialist services, the evidence suggests that the planning stage of commissioning can draw upon estimates of the population with ASD and the proportion of those that also have a learning difficulty[14]. This data, coupled with studies such as this evaluation and the published literature on the needs of people with ASD, will generally be sufficient to identify tier one (general awareness) and tier two (specialist awareness) training needs[15] and to plan services for people with ASD with mild to moderate needs.

3.17 In contrast, more and better data is required about the quality and effectiveness of service provision and the experiences of people with ASD and their families (the review stage of the commissioning cycle). Data is available, particularly for people in education (and is used by this evaluation in order to identify or estimate base and end line positions[16]) but this has rarely been effectively used by commissioners. Therefore proposals are made for developing data in relation to the key themes of the ASD SAP in sections four to eleven of this report. As outlined in the introduction, these are informed by "results-based accountability" and focus upon three broad areas:

- effort or quantity (how much was done?);
- quality (how well was it done?); and
- effect or impact (what difference did it make, what changed as a result?).

3.18 To address the gaps in data around adults who are not in education, data collection tools for adult diagnostic services and for CMS support workers have been developed and piloted, with the all-Wales ASD diagnostic and pre/ post counselling network for adults and with the ASD National Co-ordinator, LGDU and CMS services, respectively. These aim to capture more

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[14] For example, prevalence rate of 1.2 percent with 0.4 percent autism and 0.8 percent Asperger/atypical; around half would have a learning disability.

[15] General awareness-raising work (tier one) is for those with occasional contact with people with ASD. Specialist awareness (tier two), is more in-depth information aimed at those with a greater interest in ASD and professionals involved in some support for people with ASD. Advanced knowledge (tier three), is for those with frequent contact with people with ASD, and who have a key role in understanding and meeting their needs.

[16] These are discussed in more detail in the evidence report (Holtom et al., forthcoming).

information about the status and needs of adults with ASD who are known to services. Inevitably, it is harder to gather data about adults with ASD who are not known to services.

4. Improving awareness and understanding of ASD

The ASD strategy: issues and aims

4.1 The ASD SAP reports that: “studies suggest that the lives of children and adults with ASD may only improve if society has a better understanding of their condition. Raising awareness and understanding of ASD is one of the key elements in ensuring that each individual’s needs are fully identified and assessed; that all care packages are appropriate to meet each individual’s needs; and that the core education, health and social services required to undertake assessments and interventions are effectively delivered” (p. 9).

Examples of initiatives in this area

Websites and resources

4.2 A national website, ASD info Wales[17], was launched in 2011 and by 2014 had 37,623 users. The website hosted a range of information including:

- information about the ASD SAP and its implementation;
- a searchable directory of local services;
- a training directory; and
- resources such as the Orange Wallet scheme (discussed in section ten) for people with ASD; Autism: A Guide for Parents and Carers following Diagnosis (discussed in section five), for parents and carers; advice for primary health care professionals; and a national ASD Aware certification scheme[18].

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[17] ASD info Wales is described as: “the national site for Autistic Spectrum Disorders (ASD)”. It includes information about ASD (including autism and Asperger syndrome), service details, training opportunities and updates on the implementation of the ASD Strategic Action Plan for Wales. ((http://www.asdinfowales.co.uk/home.php)

[18] The scheme was established to increase awareness and 5,874 people had completed the scheme by 2014. Take-up of the scheme has varied considerably across LAs, ranging from 925 in one LA to 49 in another.

4.3 Local ASD co-ordinators and groups have also developed:

- online resources and directories. Notable examples include those developed by Carmarthenshire (Haipac[19]) and Rhonda Cynon Taf's[20] and Flintshire's[21] directories of services; and
- resources and training programmes (discussed in sections ten and eleven) such as the Early Bird, to support parents and carers of young children with ASD[22] and the NAS course Socialeyes, to help people with ASD develop social skills[23].

4.4 Monmouthshire has developed and delivered training across three tiers (level one = basic awareness raising; level two = interventions; level three = case studies/stories). The structure aims to get people to work up through the tiers. Between June 2010 and November 2012, 627 people attended training on 44 courses and 90 did the online ASD-aware scheme. A range of groups have been covered. Thirteen of the courses were run within a school; seven were specifically for parents and carers; four were for leisure services; one was for play scheme workers; one for general medical practitioners and staff; and the others were for mixed groups. All volunteers running play schemes in Monmouthshire have had ASD training and managers from adult social services have been on training. A regional project on awareness for leisure managers led to training for all staff in leisure services delivered across nine counties and when the study on the circumstances and support needs of older

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[19] http://www.haipac.org.uk/

[20] http://www.rctcbc.gov.uk/en/relateddocuments/publications/communitycare/carers/autismsdbooklet.pdf

[21] http://www.flintshire.gov.uk/en/PDFFiles/Lifelong-Learning/Schools/Children--Young-People-with-ALN/Autistic-Spectrum-Disorders/Local-Directory-of-Services-for-Children-Young-People--Adults-with-Autistic-Spectrum-Disorders-2013.pdf

[22] The programme: "aims to support parents in the period between diagnosis and school placement, empowering and helping them facilitate their child's social communication and appropriate behaviour in their natural environment" (NAS, n.d.).

[23] Described as: "a new and innovative approach to facilitating social skills and social understanding with people on the autism spectrum". It: "does not ask people on the autism spectrum to change 'inappropriate' social behaviour, or to acquire social skills by copying the 'typical' behaviour of others. Instead, it gives people the option of learning social interaction skills or alternative social strategies." http://www.autism.org.uk/our-services/find-nas-services-in-your-area/local-services/northern-irish-services/belfast-health-and-social-care-trust/socialeyes-groups.aspx

people with autism (Stuart-Hamilton et al., 2009) (discussed in section three) was published, an adults' training package was developed.

Evaluating the impact of the ASD SAP

4.5 As illustrated by figure two, in order to increase knowledge and understanding of services amongst people with ASD and their families, the strategy focused upon:

- developing a range of resources, such as local websites, directories and other resources;
- delivering training and awareness-raising to a range of groups; and
- signposting people with ASD and their families to support and services.

4.6 Implementation of these actions was strong, albeit uneven, across Wales. Awareness-raising and training has been a key part of the work of the local ASD infrastructure, the ASD National Co-ordinator and the CMS service.

4.7 Table one summarises the numbers of LAs reporting work in relation to key services and the total numbers of people participating.

Table 1: Training and awareness-raising work undertaken by local ASD groups

Service area	**# of LAs reporting work in this area**	**Estimated # of participants**
Early years (0-5) (e.g. Flying Start, nursery and including health visitors)	11	890
Education (5-16/19) (e.g. schools, including school nurses)	12	1,460
Post-16 education/training (e.g. FE, HE, work-based learning)	10	885
Other LA services (e.g. children's services, adult services, transition services, youth service, housing, leisure)	12	1,620
Employment support (e.g. Job Centre Plus, Careers Wales) and/or employers	11	585
Health service (e.g. GP, health visitors, speech and language, paediatrics, OT, CAMHS etc., but excluding health visitors included under the early years and ambulance services)	12	590
Emergency services (e.g. police, fire and ambulance services)	8	310
Other (total of all other not included above)	4	140

19 out of 22 LAs provided data. The number of people trained is an estimate[24] *.*
Source: PWU survey

4.8 In addition, national and local websites and resources have been produced and disseminated; for example, as outlined above, a national website, ASD info Wales[25] was established and had over 37,000 users between 2011 and 2014.

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[24] ASD leads were asked to estimate the numbers of participants (if precise figures were not known). They were provided with a series of ranges to record the numbers: 0, 1-10; 11-20; 21-50; 51-100; 101-200; > 200). The number of participants was estimated by multiplying the number of responses by the median value of each range; for example, for 1-10, the median value is 5.5. For values above 200, the number of participants was estimated by multiplying the number of responses by 200.

[25] ASD info Wales is described as: "the national site for Autistic Spectrum Disorders (ASD)." It includes information about Autistic Spectrum Disorders (including autism and Asperger syndrome), service details, training opportunities and updates on the implementation of the ASD SAP for Wales. ((http://www.asdinfowales.co.uk/home.php)

4.9 As table two illustrates, the evidence of the impact of training and awareness across key sectors is mixed. The evidence of a positive impact is strongest in relation to education for school age children and weakest in relation to health services.

Table 2: The impact of training and awareness work with services

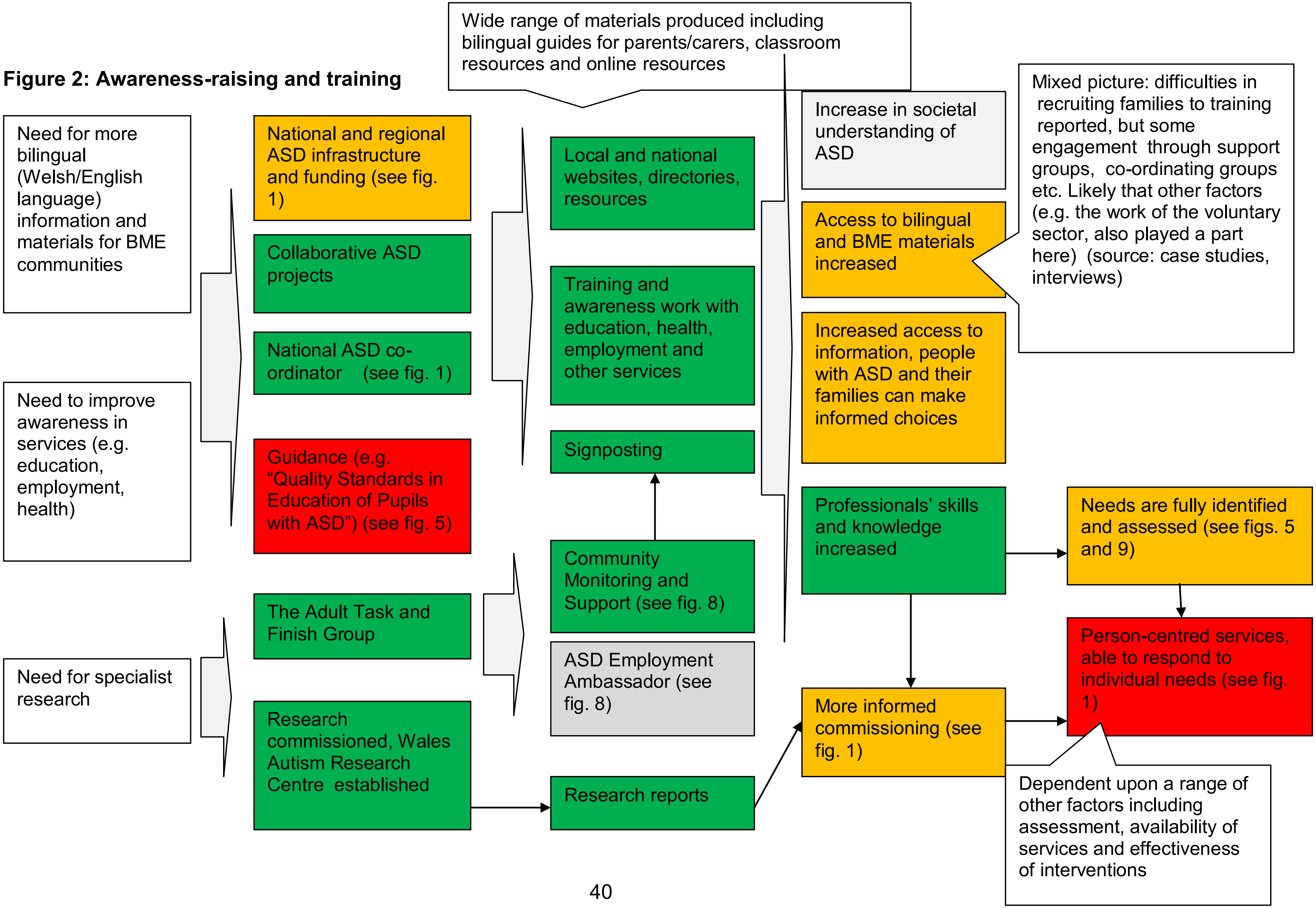
Service	Evidence of impact (in addition to qualitative research)
Education (3-16/19)	Positive (see e.g. SEN workforce development report forthcoming)
Education post 16/19	Positive in relation to HE and, to a lesser degree, FE (see e.g. NAFW, 2010) much weaker in relation to WBL (Townsley et al., 2014)
Health	Limited overall. Some increases in relation to assessment and diagnosis (see section five),significant gaps in skills and knowledge in adult MH services in particular (Jackson, et al, 2011)
Social services	Difficult to assess given limited data, but likely to be mixed. Some services report increased awareness as a result, for example, of NAS training, and inclusion of ASD within training for social workers. However, there are also examples where social services appear to have low levels of awareness and understanding, and expertise within LD services has been questioned (see also Mills and Francis, 2010).
Employment services	Limited overall: there are some small scale projects that have generated very positive feedback, but little in other areas. As a consequence there are pockets of specialist skills and knowledge alongside gaps, particularly in mainstream and pan-disability employment services (Townsley et al., 2014)
Information for adults with ASD and parents/carers	Mixed picture: The local ASD infrastructure and CAMHS workers have undertaken a range of work with families. This includes work to develop directories of services and signposting. However while valuable, adults with ASD, parents and carers still want more information and support. Some groups such as members of black and minority ethnic (BME) groups have been missed.

Source: Holtom et al., forthcoming

4.10 Finally, in considering the impact of the ASD SAP it is important to bear in mind three further factors:

- interviewees indicated that awareness of ASD was increasing in society generally. Therefore some increases in awareness and understanding are likely to have happened even in the absence of the ASD SAP (i.e. they represent “deadweight”);
- the impact of awareness-raising and training depends upon a range of factors, such as the availability of services to meet newly understood needs; and
- ASD represents a complex set of conditions. Developing expertise (e.g. in specialist services) which can then be used to support professionals in more mainstream services when needed, may be more cost-effective than attempting to ensure everyone is an expert in ASD (see e.g. Holtom et al., forthcoming; Townsley et al., 2014).

Figure 2: Awareness-raising and training



Developing indicators to measure progress in relation to awareness-raising and training

4.11 Table three summarises the data requirements identified by the study and the proposed measures and sources.

Table 3: Indicators to measure progress in relation to awareness-raising and training

Data requirements	Measures	Sources
Quantity How many/how much?	The numbers of professionals taking part in training or awareness-raising activities	ASD leads/co-ordinators
	The numbers of parents or carers taking part in training or awareness-raising activities	ASD leads/co-ordinators
Quality How good is awareness raising and training?	The percentage of professionals taking part in training or awareness-raising activities reporting it was good or better	Participant feedback (collected by ASD leads/co-ordinators)
	The percentage of parents or carers taking part in training or awareness-raising activities reporting it was good or better	Participant feedback (collected by ASD leads/co-ordinators)

5. Identification and diagnosis of ASD: children and young people (0-17)

Introduction

5.1 The ASD SAP highlights the importance of early assessment and intervention to maximise opportunities for recognising children's difficulties and needs and for improving their development and health.

Examples of initiatives in this area

Developing children's diagnostic services

5.2 Since 2010, improvements to children's assessment and diagnostic services have been made in a number of areas including Powys (where a multi-disciplinary social communication assessment team (SCAT) operates an assessment and diagnostic pathway for children and young people up to the age of 18 years, in line with National Institute for Health and Care Excellence (NICE, 2012) guidelines[26]; Cardiff and Vale (where a new speech and language communication pathway has been established); and Hywel Dda, with new services and processes established in Carmarthenshire and Pembrokeshire. With the exception of Powys[27], many of these improvements were made only in the last two years and the situation in Pembrokeshire in particular, was described as very poor before changes were made.

Post-diagnosis support pack

5.3 Autism: A Guide for Parents and Carers Following Diagnosis[28] was developed in response to calls from parents and carers for more post-diagnosis information. The wide-ranging guide introduces parents and carers to ASD; provides practical advice and lists services and contacts. Initially developed by Rhondda Cynon Taf's ASD lead and co-ordinating group, in collaboration with parents and carers and the ASD National Strategic Co-ordinator, it has been distributed throughout Wales.

Developing data

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[26] In Powys 3Di and ADOS training was provided to over 40 professionals.

[27] The SCAT was established in 2005.

[28] http://www.asdinfowales.co.uk/home.php?page_id=6006

5.4 The study of children's ASD diagnostic services in Wales (WARC, 2010, p.1): "aimed to contribute to the delivery of the Welsh Assembly Government's ASD Strategic Action Plan by providing information about diagnostic systems and methods of practice and by identifying areas for future improvement in service provision and organisation". The study provides an in-depth view of children's ASD diagnostic services, but appears to have had relatively little impact upon the development of children's diagnostic services by LHBs.

Evaluation of impact of the ASD SAP

5.5 As figure three illustrates, the ASD SAP aimed to increase the extent of early identification of ASD, to strengthen assessment and diagnostic services for children and to ensure that children did not need a diagnosis to have their needs met.

5.6 Implementation of the strategy was mixed. Key inputs, such as awareness-raising in schools (discussed in section four), research into services, and the model pathways were delivered. Moreover, as the examples outlined above illustrate, improvements in services were made in particular areas, such as Powys and, to a lesser degree, Betsi Cadwaladr LHBs. However, little progress was made by other LHBs.

5.7 The evidence of outcomes is positive overall, but uneven across Wales. There is evidence that the extent of identification and diagnosis has increased sharply over the last ten years. Over 1 percent of the pupil population is now recorded as having ASD, indicating most school age children with ASD are getting a diagnosis. However, rates vary considerably from LA to LA and young adults (aged 18-25) are still being diagnosed by adult diagnostic services, not by children's services. (Holtom et al., forthcoming).

5.8 There is also some evidence of earlier identification. This includes a lowering of the average age at diagnosis to around eight years of age in Betsi Cadwaladwr and Powys LHBs. However, there is also evidence of increasing diagnosis across Wales amongst young people aged 11-17 (Holtom et al., forthcoming). This may mean opportunities for early identification are being missed, but it may also indicate increased awareness, meaning that cases which were missed during early childhood are now being identified later.

5.9 Views on whether children and young people with undiagnosed/ unrecognised ASD could have been identified earlier were divided. Some parents and professionals cited examples where they felt ASD should have been identified much earlier. However, examples were also given where ASD was only identified following changes in a child's or young person's circumstances, such as a transition from primary to secondary school, or from school to college. The disruption caused by these changes meant that the child or young person's ASD was more apparent (and easier to identify).

5.10 Opinions about whether ASD should have been diagnosed early were also divided. There may be differences between what parents and carers felt they needed (such as a diagnosis to help them understand their child's behaviour), and what schools felt they needed to meet the child's educational needs; for example, some parents and carers reflected on what one described as the "Jekyll and Hyde" nature of ASD, which meant that children or young people's problems might be hidden in school, but only manifest themselves at home (meaning they could be missed by education staff). Equally, some education staff expressed the view that a diagnosis was not important, provided the child or young person's needs were understood and met. Examples were also given of parents who were reluctant to have a diagnosis and to have their child "labelled".

5.11 There are therefore tensions about when to diagnose, which can contribute to late diagnosis; for example, while a diagnosis may not be needed while a child is young, examples were given of how the failure to get a diagnosis had caused problems for a child later in life (e.g. following a transition, like a change from primary to secondary school). At this stage in the child or young person's life, a diagnosis was often seen by parents/carers as important in ensuring that their needs were fully understood (and they were not for example dismissed as a "naughty" child/young person) and they could access support and services (which in some cases, still require a formal diagnosis). Lengthy waiting lists for assessments which could lead to a diagnosis (discussed below) were seen as a particular problem in this situation.

5.12 Although an important (and positive) outcome, increases in identification rates have increased pressure upon diagnostic services and contributed to lengthy waiting lists in many areas. (Holtom et al., forthcoming). In contrast, in those areas like Powys, where new services and referral pathways have been developed, fewer inappropriate referrals are being made, reducing pressure on waiting lists.

5.13 The limited progress made in strengthening children's diagnostic services and building their capacity, particularly given increasing identification of ASD, was a key weakness of the ASD SAP. Overall, whilst the ASD SAP defined the standard to be reached[29] , it did not provide the resources or the pressure to reallocate the existing resources needed to meet the standard and so progress was overly reliant on the commitment of individuals (Holtom et al., forthcoming). More positively, there is recognition of the need to improve services, and models such as the Powys SCAT have been established and are now informing developments in other LHBs, such as Cardiff and Vale

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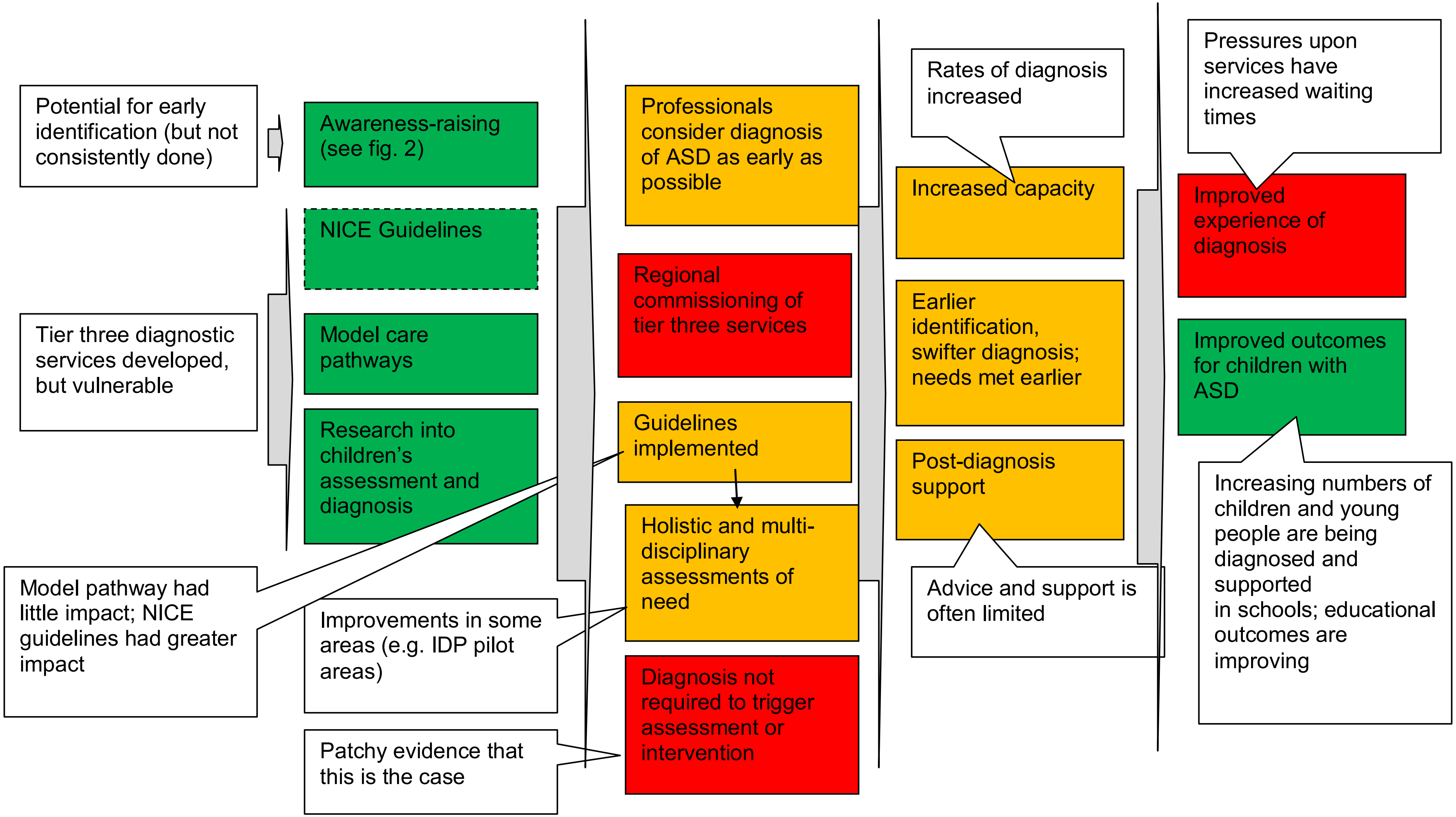
[29] The Royal College of Psychiatrists' Report (2006) and a Model Pathway (in the ASD SAP) are referenced. Both are now effectively superseded by the NICE Guidelines, issued in 2012.

Figure 3: Appraisal of the impact pathways for identification, assessment and diagnosis: children (0-18)



Developing indicators to measure progress in relation to the identification, assessment and diagnosis of children with ASD

5.14 Table four summarises the data requirements identified by the study and the proposed measures and sources.

Table 4: Indicators to measure progress in relation to the identification, assessment and diagnosis of children with ASD

Data requirements	Measures	Sources
Quantity How many/how much?	The numbers of children (aged 0-18) diagnosed	PLASC and the North Wales Regional Database
Quality How good is identification and assessment for children?	The percentage of children (aged 0-18) diagnosed, compared to an standard prevalence rate of 1%	PLASC and the North Wales Regional Database
	The percentage of children (aged 0-18) referred for a diagnosis, who are diagnosed as having ASD	the North Wales Regional Database
	Compliance with NICE Guidelines	Self evaluation by LHBs
	Age at diagnosis	PLASC and the North Wales Regional Database
	The length of time from referral to diagnosis	The North Wales Regional Database; LHBs
Impact Is anyone better off?	Educational outcomes for pupils with ASD (see section six)	National Pupil Database
	Support for the parents/carers of children with ASD (see section ten)	Survey of parents/carers in contact with voluntary sector organisations.

6. Identification and diagnosis of ASD: adults

Introduction

6.1 The ASD SAP identifies that: "there are many adults who have ASD that remain undiagnosed" and that access to diagnostic services is unequal.

Examples of initiatives in this area

6.2 The All-Wales ASD diagnostic and pre/post counselling network for adults was established in 2010. The three primary functions of the network were to: "agree and facilitate a standardised process of assessment and diagnosis, interpreted and described within each Local Health Board, building on existing knowledge and structures; to develop and deliver training to increase the number of clinicians skilled in the field and to prove the quality and consistency of diagnostic practice; [and] to enable the development of local improvements and sharing of best practice by maintaining an expert reference group" (Betsi Cadwaladr, 2011, p.3).

6.3 The network has provided a focus and increased ownership of ASD within health services and developed a model for services for adults. A pre- and post-assessment, diagnosis and counselling service for adults has now been established in areas like Hywel Dda, where previously there was no formal service. Services in other areas, such as Aneurin Bevan, Bro Morgannwg and Powys have been consolidated and extended. In contrast, the impact in some health board areas such as Cwm Taf, where there is currently no clinical lead, and Betsi Cadwaladr, where there has been little increase in capacity and no service in some areas, has been more limited.

Training in diagnosis

6.4 The Diagnostic Interview for Social and Communication Disorders (DISCO) is a clinician-led, semi-structured interview schedule used to help judge an individual's level of development, behaviours, disabilities and needs, and to aid an assessment of whether the international criteria for a diagnosis of ASD are met or not (Carrington and Leekam, 2014).

6.5 The DISCO Abbreviated Tool is an adaptation of the full DISCO tool[30]. It uses a reduced set of questions, to reduce the time needed for assessment. A new training course for the DISCO Abbreviated Tool was designed and developed by the training sub group of the all-Wales ASD diagnostic /post counselling service for adults. In total, 45 clinicians from Wales were trained in 2013-14. Evaluation of the training itself was very positive (ibid.). However, not all clinicians trained have been undertaking diagnosis, and research has identified a range of barriers which have reduced the impact of training on diagnostic capacity in Wales; for example, although more clinicians now have the skills required to diagnose ASD, they do not always have the time needed (Holtom, n.d.).

Evaluation of the impact of the ASD SAP

6.6 As figure 4 illustrates, the ASD SAP aimed to increase the extent of identification and diagnosis of ASD (amongst adults) and to strengthen assessment and diagnostic services for adults.

6.7 Implementation of the strategy was fairly strong. Key inputs, such as awareness-raising with services (discussed in section four) and the model pathways were delivered. Crucially, through the work of the Adult Task and Finish Group the strategy has evolved, and the all-Wales ASD diagnostic and pre/post counselling service for adults (discussed above) was established.

6.8 The evidence of improvements in diagnostic services is positive, but uneven across Wales. Capacity and confidence to assess and diagnose adults has increased and the target set of 125 assessments a year has been achieved. As the examples above illustrate, new services were established in some areas like Hywel Dda LHB, where there was no formal service, and existing services, in areas like Aneurin Bevan and Abertawe Bro Morgannwg LHBs,

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[30] It was developed by developed by the WARC and the Lorna Wing Centre.

were strengthened. Nevertheless in other areas, the increase in diagnostic capacity was more limited.

6.9 The uneven impact reflects, in part, the establishment of the adult network as a "clinical" rather than a "managed" network and also the way that competing priorities within LHBs have limited its influence. The influence of the standards set out in the ASD SAP, the Royal College of Psychiatrists' Report and the model pathways were also limited. In contrast, the subsequent NICE guidelines (NICE, 2012), which came after the ASD SAP was launched, have been more influential.

6.10 The impact of improvements in diagnostic services upon adults' experiences has been mixed. Adults are reported to value having a diagnosis (which we discuss further below) and the establishment of pre- and post-diagnosis counselling has been welcomed. However, weaknesses in referral processes and post-diagnosis support were highlighted by a small qualitative study of users' and family members' experiences of the ASD Assessment Pathways (established by the service) undertaken in the first half of 2014[31]. The study identified frustration amongst some, with the failure to recognise ASD early and with the time needed and, in some cases, the process for getting a referral for assessment. The study also identified mixed experiences of post-diagnosis counselling, with some people experiencing a feeling of "abandonment" after diagnosis, given the absence of support other than signposting to an ASD support group (Barker and Griffith, 2014). Professionals interviewed for this study identified particular gaps in post-diagnosis counselling in Conwy (in Betsi Cadwaladr UHB) and Cwm Taf LHB.

6.11 The impact of improvements in diagnostic services upon adults' access to services has been much more limited. Crucially, as the impact pathway for adults (section ten) illustrates, there are few services targeted at meeting the needs of adults with ASD who do not have a learning disability. Therefore, diagnosis has little impact upon access to services, and opinions about the

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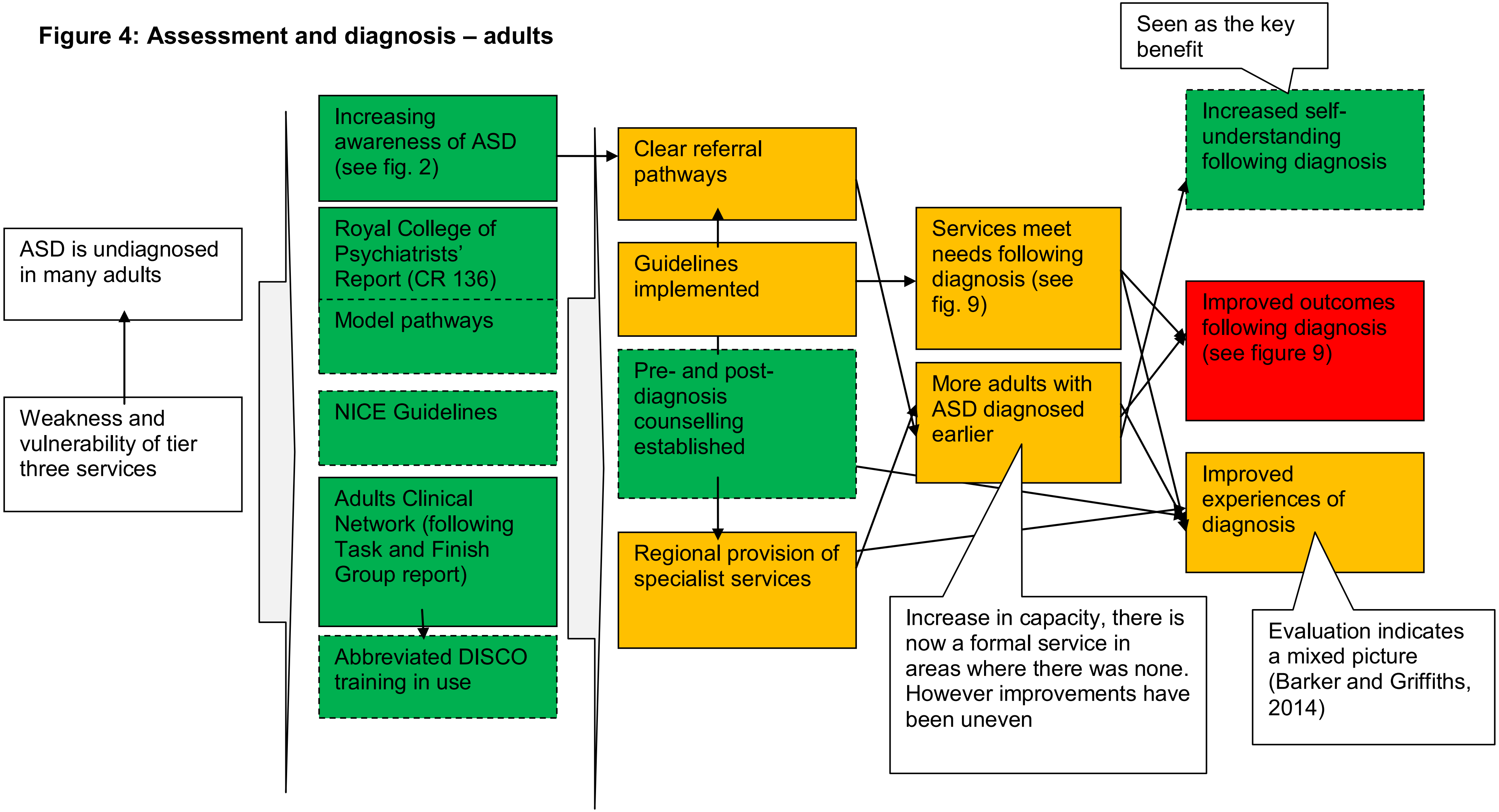
[31] 54 service users and family members were approached. Two service users and seven family members agreed to take part in the study (Barker and Griffith, 2014).

value and ethics of diagnosis for adults amongst those professionals interviewed for this study were divided; for example, as one put it: “I don’t know how helpful it is for people [adults] to be more aware of their diagnosis” and others questioned whether it was ethical to invest in a process that produces a diagnosis when there is no service to meet that need. However, others pointed to the relief that some adults and some families experienced after receiving a diagnosis, as it helped them make sense of their feelings and experiences and enabled them to explain them to others.

6.12 Unlike the strategy for improving children’s diagnostic services, the strategy for improving adults’ diagnostic services not only defined the standard to be met, but also provided funding and a structure to enable it to be met. However, like the children’s diagnostic services, much progress has still been driven by individuals, leading to uneven impacts across Wales, and meaning improvements may be fragile (and vulnerable if, for example, key people move on).

Figure 4: Assessment and diagnosis – adults



Developing indicators to measure progress in relation to the identification, assessment and diagnosis of adults with ASD

6.13 Table five summarises the data requirements identified by the study and the proposed measures and sources.

Table 5: Indicators to measure progress in relation to the identification, assessment and diagnosis of adults with ASD

Data requirements	Measures	Sources
Quantity How many/how much?	The numbers of adults diagnosed	The adults ASD pre and post diagnostic and counselling network (a data collection tool is being piloted)
Quality How good is identification and assessment for adults?	Compliance with NICE Guidelines	The adults ASD pre and post diagnostic and counselling network performance reporting framework.
	The numbers of adults accessing adult MH services and LD services being diagnosed	The adults ASD pre and post diagnostic and counselling network (a data collection tool is being piloted)
	The length of time from referral to diagnosis	The adults ASD pre and post diagnostic and counselling network (a data collection tool is being piloted)
	Adults' satisfaction with the assessment and diagnosis process	The adults ASD pre and post diagnostic and counselling network (a data collection tool is being piloted)
Impact Is anyone better off?	The percentage of adults diagnosed with ASD able to access a service/services that meets their needs	The adults ASD pre and post diagnostic and counselling network (a data collection tool is being piloted)

7. Education (for children and young people aged 3-16/19)

Introduction

7.1 The ASD SAP outlines how special educational needs such as ASD should be assessed and provided for within schools. The ASD SAP also highlights how 14-19 Learning Pathways aim: "to ensure that all young people... receive learning provision that is flexibly tailored to meet their individual needs and aspirations" and that they can access: "personal and learning coach support" (p. 34).

Examples of initiatives in this area

The Additional Learning Needs Pilot projects

7.2 The Welsh Government is committed to reforming the statutory framework for children and young people with special educational needs[32]. The current system has been described as:

> "complex, bewildering and adversarial. .. Needs are sometimes identified late and interventions are not planned or implemented in a timely or effective way. Families tell us that they feel they have to battle at each stage of the system to get the right support for their child" (WG, 2014, p.2).

7.3 In 2009, in response to these weaknesses, four pilot projects were set up as part of a programme of action research designed to inform and enable reform of the statutory framework for children and young people with SEN. Progress was slower than anticipated and the white paper outlining legislative proposals for ALN was not published until 2014 (WG, 2014).

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[32] Section 312 of the Education Act 1996 provides the legal definition of SEN. In 2006, the statutory guidance Inclusion and Pupil Support' (NAfW, 2006b) introduced the concept of additional learning needs and provides the current policy framework for children and young people with ALN. This guidance identifies children and young people as having ALN when their learning needs are greater than the majority of their peers (ibid.).

7.4 Because legislative reforms have not taken place, the impact of the reform process has been limited to the eight pilot areas (Bridgend, Cardiff, Carmarthenshire, Caerphilly, Flintshire, Newport, Pembrokeshire and Torfaen) which have been developing and trialling aspects of the proposed reforms. In these areas improvements have been identified in the quality of information about a child and a better understanding of their needs, principally due to the introduction of person-centred planning (PCP) and in action planning (principally due to the piloting of individual development plans (IDPs). (Holtom and Lloyd-Jones, 2014).

The Caerphilly Autism Spectrum Service

7.5 The Caerphilly Autism Spectrum Service (CASS) works with children, young people and their families and aims to provide home and communication support. The support for parents includes one-to-one support, Early Bird and Early Bird Plus (discussed in section ten) and schools are also provided with training and support. The project has also developed a database to monitor and evaluate effectiveness. Parents and carers interviewed for this study valued the support offered, although some wanted a more responsive service. Much of the support is structured, but this can mean that parents have to wait until a place on a course is available, when what they wanted was someone with whom to talk through their immediate problems and concerns.

Training and awareness-raising work with schools

7.6 As outlined in section four, a wide range of training and awareness-raising work has been undertaken with schools. Information packs have also been developed for schools in areas like Cardiff and Vale. Across Wales, awareness and understanding of ASD within schools has increased (Holtom et al., forthcoming).

Evaluation of impact

7.7 As figure 5 illustrates, the ASD SAP aimed to ensure school age children's and young people's needs were met, and educational outcomes were improved through:

- the existing SEN Code of Practice (COP) and reform of the statutory framework for SEN and new guidance on educational provision for pupils with ASD;
- awareness-raising and training; and
- support from specialist SEN services, such as speech and language therapists, when needed.

7.8 Implementation of the strategy was mixed. The large increases in identification and rates of diagnosis (discussed in section four), mean many more children's and young people's needs are now being identified. Awareness and understanding of ASD within schools has also increased (Holtom et al., forthcoming). However, new standards and guidance were not developed or implemented[33], reform of the statutory framework for SEN has been delayed and specialist SEN services are under pressure (Bowen and Holtom, forthcoming).

7.9 Although reform of the statutory framework of SEN has been delayed, the ALN pilots (discussed above) were established in eight LAs. The introduction of PCP and IDPs led to changes (and improvements) in assessment processes in these areas. Nevertheless, as outlined in section five, a formal diagnosis is often still required to ensure a child's or young person's needs are understood and they can therefore get the support they need in school; for example as one professional put it:

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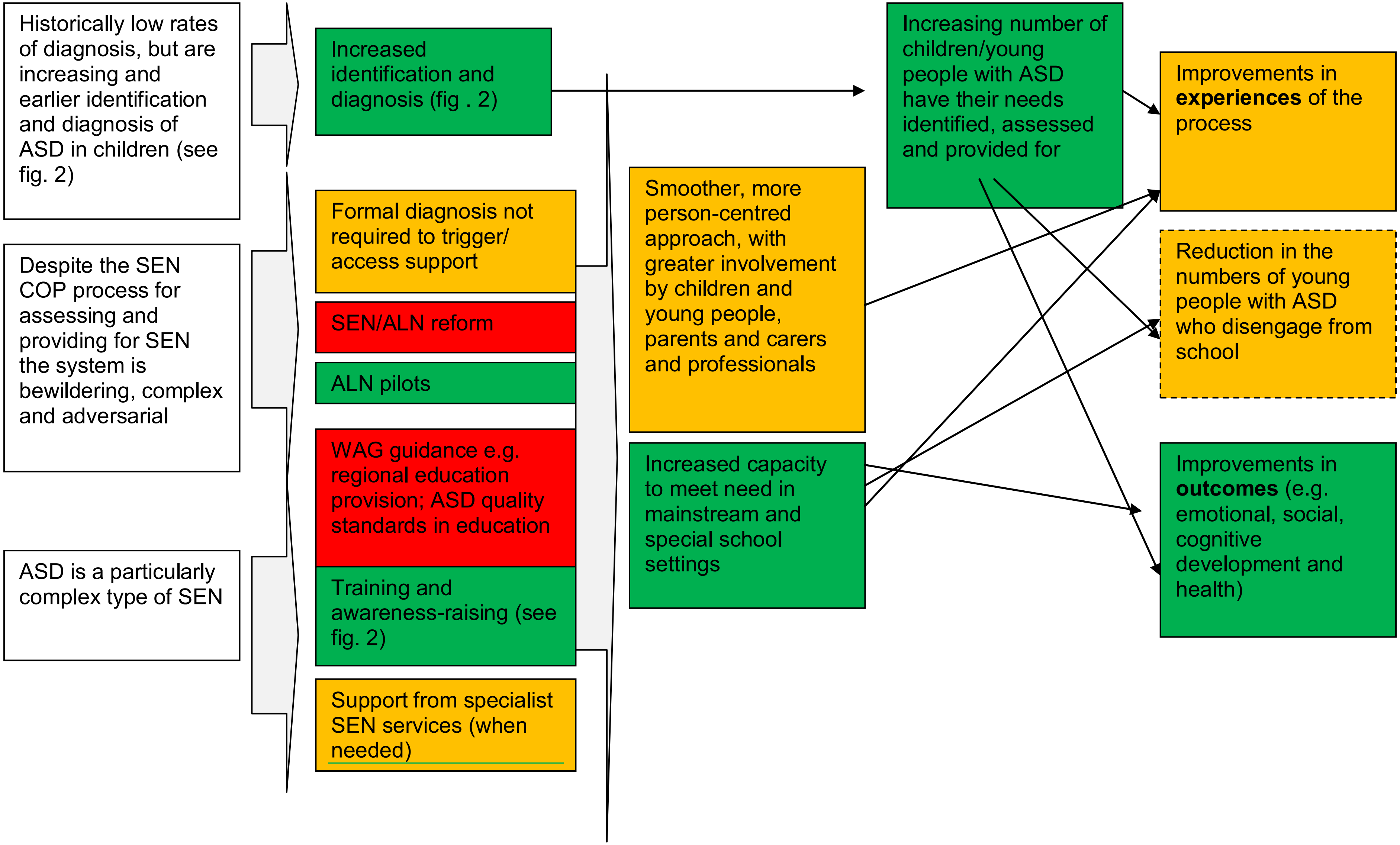
[33] During the early stages of the ASD strategy it was thought that quality standards in education for children with ASD could improve consistency. However, it was decided that a more inclusive approach was needed which would avoid having separate strategies and standards for every type of SEN.

> “A diagnosis is absolutely crucial so that the school, services, family and child can understand what is happening and needs to happen. It is lovely to think that needs would always be met without a diagnosis but it does not happen”.

7.10 The evidence of improved outcomes is more positive – although not uniformly so. There is evidence that overall, education of children and young people with ASD has become more inclusive and educational provision for pupils with ALN has improved (Holtom et al., forthcoming). However, educational provision remains weaker in mainstream schools where increasing numbers of children and young people with ASD are educated. Moreover, a disproportionate number of parents of children with ASD are dissatisfied with their children’s education and there is evidence that a disproportionate number of young people who are not in employment, education or training (NEET) have ASD (ibid.). Educational outcomes for children and young people with ASD have improved. However, it is unclear whether these changes are because more children and young people with ASD and less severe and complex needs are being identified (ibid.).

Figure 5: Education for school age children and young people (4-16/19)



Developing indicators to measure progress in relation to the education of children and young people with ASD

7.11 Table 6 summarises the data requirements identified by the study and the proposed measures and sources.

Table 6: Indicators to measure progress in relation to the education of children and young people with ASD

Data requirements	Measures	Sources
Quantity How many/how much?	How many pupils have ASD recorded as their primary or secondary SEN?	The PLASC
Quality How good is educational provision?	The percentage of settings (primary, secondary and special schools) whose provision is good or better	Estyn
	The percentage of LAs whose support for ALN and educational inclusion is good or better	Estyn
Impact Is anyone better off?	The percentage of pupils with ASD recorded as their primary or secondary SEN achieving the expected level at the end of each key stage	The National Pupil Database

8. Young people's transitions

The aim in the ASD SAP

8.1. The ASD SAP aims to ensure that adults with ASD "are supported to reach their full potential in all aspects of their life" (WAG, 2008). In relation to transition, the SAP highlights policies to ensure advance planning and co-operation between schools, Careers Wales, post-school education and training providers, employers and carers, such as the SEN COP for Wales and the National Service Framework (NSF) for Children, Young People and Maternity Services.

Examples of initiatives in this area

8.2. In June 2008, LAs were invited to apply to the Welsh Government for funding to become transition key working (TKW) pilot sites. Five pilots were set up. In total the pilots worked with 234 young people over three years. A report on the costs and benefits of five pilot TKW projects in Wales (Holtom et al., 2012) showed that young people with learning difficulties or disabilities (LDD) and their families generally felt that their experience of transition was improved through the key worker role. They had better information and appreciated the emotional and practical support offered. There was less evidence of an impact on the outcomes of transition from the key working pilots, in part because few of the young people involved in the pilot had left education or training.

8.3. Welsh Government funding for the pilots ran from September 2008 until March 2011. In some areas, European Social Fund (ESF) funding kept the work going longer but despite their positive impact, in the face of competing priorities and budgetary pressures, LAs have struggled to sustain the model.

The Real Opportunities Project

8.4. The Real Opportunities Project[34] worked with young people aged 14 to 19 and with a learning disability, severe and complex needs or an ASD, to help them become as independent as possible in their adult lives. The project covered nine local authorities: Caerphilly, Bridgend, Carmarthenshire, Rhondda Cynon Taf, Neath Port Talbot, Swansea, Merthyr, Pembrokeshire and Torfaen.

8.5. Professionals interviewed for this study were consistently very positive about the Real Opportunities Project; for example, one professional described how if they could refer a young person to the project it was like: "giving them a warm cup of tea and a blanket" as the project was so supportive for both young people and their parents and carers. The independent evaluation of the project was also positive. It identified that the project demonstrated that a supported employment model, with individually designed placements and job coach support, was effective in building young people's skills. However, it also identified that "family reactions to employment remained ambiguous" and that although many young people supported by the project made a successful transition to college, there was a lack of support to enable them to progress from college to employment (which is consistent with the findings of this study)[35] (Beyer et al., 2014).

Evaluation of impact

8.6. As figure 6 illustrates, the ASD SAP aimed to improve transition planning for young people, supporting them to access FE and HE and employment opportunities. The strategy focused upon:

- existing and proposed new guidance and standards;

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[34] The project's formal title is the Regional SEN Transition to Employment Initiative.

[35] The project focused upon young people aged 14-19, so did not cover the transition from college. Although not an aim of the project, a small number of young people secured paid employment (Beyer et al., 2014).

- the role of existing services such as Careers Wales and Job Centre Plus (JCP), disability employment advisors (DEAs) and strategies such as Learning Pathways 14-19; and
- new projects, such as the TKW pilot projects (discussed above) to develop new approaches and build capacity.

8.7. With the exception of new guidance, which was either not developed or not published, implementation of the strategy was fairly strong. In part this was because many elements of the strategy were already in place. Nevertheless, increases in awareness-raising contributed to increases in diagnosis and therefore access to support (discussed in sections four and five) and a number of new ESF-funded projects (discussed above) were established.

8.8. The evidence of the impact of the guidance, services and projects upon young people's transition from school to FE and HE is mixed and uneven across Wales. There have been improvements in compliance with the NSF standards related to transition (LGDU, 2011). Increasing numbers of young people with ASD are entering FE and HE (Holtom et al., forthcoming) and (as outlined above) evaluations of projects such as Real Opportunities and the TKW pilot projects have been positive. They indicate a positive impact upon young people's and their families' experiences of transition, but also indicate that the projects have struggled to change the outcomes of transition (discussed further below). As regional projects they only covered some young people and their families, and parents and carers from across Wales report mixed experiences of transition planning. The strength of partnership working, particularly around specialist placements, remains mixed (ibid.).

8.9. Proposals for reform have been put forward in the white paper on Additional Learning Needs Reform (WG, 2014) to address weaknesses in partnership working and, in particular, the split in responsibility for pre- and post-16 provision for learners with LDD (which would include learners with ASD) [36],

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[36] Currently, responsibility for the assessment of post-16 learners with learning difficulties and/or disabilities who have left or are about to leave school rests with the Welsh Ministers and there is separate legislation relating to FE and provision for post-16 learners with LDD. LA responsibility ends

but have not been implemented yet. The Welsh Government also commissioned research into effective practice at transition for people with SEN or LDD in 2014 (Holtom and Lloyd-Jones, forthcoming).

8.10. The evidence of the impact of the guidance, services and projects upon young people's transition from post-16 education and training to employment is much more limited. Professionals and parents and carers interviewed reported that transition planning for young people with ASD was often focused upon the transition from school to FE but that transition planning beyond this was often very weak.

8.11. Qualitative evidence from CMS services and those involved in assessment and diagnosis indicates that many young people struggle to make a transition to independent living and to find employment. They can become increasingly withdrawn, isolated and dependent upon their parents. In some cases this may increase the young people's level of disability and constrain the lives of their parents or carers.

8.12. The lack of services for adults with ASD but no learning disability (discussed in section nine) is also a key constraint on transition planning, as there may not be a service to which young people with ASD can be referred. It contributes to the anxiety and frustration many families experience during transition. Some interviewees also questioned the extent to which LD services could meet the needs of young adults; for example as one observed: "it is assumed that learning disability services pick up those with a learning disability, but it's not sufficient, they just end up in day centres". Others reported that LD services may not recognise their autism and just see them as having challenging behaviour.

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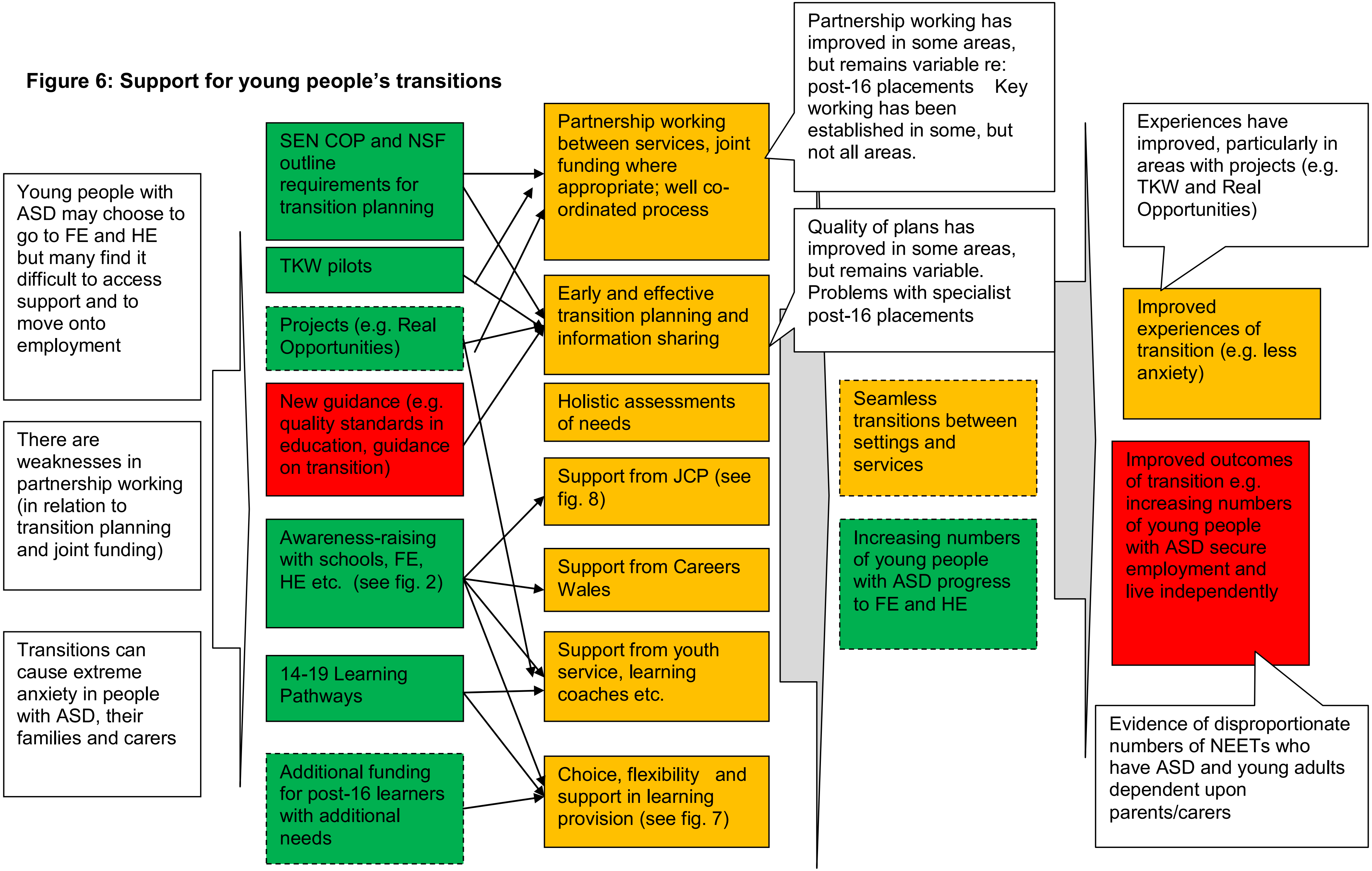
at the completion of compulsory schooling, even where a young person has had a statement of special needs. The white paper on Additional Learning Needs Reform (WG, 2014) identifies that this situation (in effect a hand-over of responsibility) can lead to delays in assessing needs and securing non-mainstream placements and creates a disincentive for LAs to plan for post-16 provision or collaborate with FE colleges. It can also mean that post-16 education and training providers can find it hard to access adequate information about the needs of young people with learning difficulties and/or disabilities (ibid.).

Figure 6: Support for young people’s transitions



Young people with ASD may choose to go to FE and HE but many find it difficult to access support and to move onto employment

There are weaknesses in partnership working (in relation to transition planning and joint funding)

Transitions can cause extreme anxiety in people with ASD, their families and carers

SEN COP and NSF outline requirements for transition planning

TKW pilots

Projects (e.g. Real Opportunities)

New guidance (e.g. quality standards in education, guidance on transition)

Awareness-raising with schools, FE, HE etc. (see fig. 2)

14-19 Learning Pathways

Additional funding for post-16 learners with additional needs

Partnership working between services, joint funding where appropriate; well co-ordinated process

Early and effective transition planning and information sharing

Holistic assessments of needs

Support from JCP (see fig. 8)

Support from Careers Wales

Support from youth service, learning coaches etc.

Choice, flexibility and support in learning provision (see fig. 7)

Partnership working has improved in some areas, but remains variable re: post-16 placements Key working has been established in some, but not all areas.

Quality of plans has improved in some areas, but remains variable. Problems with specialist post-16 placements

Seamless transitions between settings and services

Increasing numbers of young people with ASD progress to FE and HE

Experiences have improved, particularly in areas with projects (e.g. TKW and Real Opportunities)

Improved experiences of transition (e.g. less anxiety)

Improved outcomes of transition e.g. increasing numbers of young people with ASD secure employment and live independently

Evidence of disproportionate numbers of NEETs who have ASD and young adults dependent upon parents/carers

Developing indicators to measure progress in relation to young people's transitions

8.13 Table 7 summarises the data requirements identified by the study and the proposed measures and sources.

Table 7: Indicators to measure progress in relation to young people's transitions

Data requirements	Measures	Sources
Quantity How many young people are supported?	The number of young people aged 16, 17 and 18 with ASD supported by Careers Wales	Careers Wales
	The number of young people aged 14-25 with ASD supported by transition services	LA Transition Services
	The number of young people aged 14-25 with ASD supported by any future ESF projects (e.g. a successor to Real Opportunities)	ESF funded projects
Quality How good is support for young people (with ASD) making transitions?	The extent to which NSF (WAG, 2006) actions relating to transitions for disabled young people have been fully implemented	LGDU Wales
	The percentage of students with ASD reporting the information they were given when choosing their course was "good" or "very good"	Post-16 education and learning statistics (drawing upon the Learner Voice Wales survey)

9. Post -16/19 education, training and employment

Introduction

9.1 The ASD SAP identifies: “that individuals with disabilities, particularly social and communication difficulties, often find it difficult to access appropriate support and training and consequently move into employment” (p.35). In response, the SAP highlights policies such as Learning Pathways 14-19 and pan-disability services such as that offered by JCP, intended to ensure people with ASD are supported to access education, training and employment.

Examples of initiatives in this area

Support in Higher Education

9.2 Cardiff University’s Discovery Project supports 14-19 year olds that have an ASD to develop confidence, aspirations and prepare for university life. Accessed via special education needs co-ordinators (SENCos) in schools, the project involves existing students as mentors and offers support with homework and revision and with making university applications. Special visit days are organised for young people with ASD and their teachers and parents or carers, and a summer school gives young people the opportunity to stay a night in a hall of residence and be supported to experience aspects of student life such as attending a social event, cooking a meal and finding their way around campus.

9.3 Support services for people with ASD in other universities include two dedicated ASD support officers at the University of Wales Swansea, student MH services at Bangor University, who have been supported and trained to support students with ASD by members of the Bangor University School of Psychology, and the Mind group at Aberystwyth University.

Wales Autism Employment Ambassador

9.4 The role of the Wales Autism Employment Ambassador developed from a recommendation of the Adult Task and Finish Group (WAG, 2010a). The role is to promote the value of employing people with autism to employers in Wales, to use media outlets to raise awareness of ASD in the workplace, to support the ASD SAP's employment strands and to promote collaborative working between ASD support bodies and statutory bodies like JCP and Careers Wales.

Community Monitoring and Support

9.5 CMS workers were established in response to recommendations from the Adult Task and Finish Group report (discussed in section three). Their primary role is intended to be "signposting"; directing adults with low level needs to services that can help them, such as MH, employment or housing services. In practice, some CMS workers have taken a more interventionist role, in response to the lack of services to signpost people to. This can include talking to relatives to explain why someone is behaving as they do; helping people who struggle with the requirement to use the telephone to apply for help; or helping people to start using public transport. CMS workers also provide training and support to staff in services, such as Job Centres, on working with people with ASD.

9.6 By getting to know adults in the course of their support, CMS workers can also become involved in identifying problems; for example, it was described as common in one area for young adults with ASD to become regular cannabis users as a mechanism for coping with their difficulties. CMS workers can identify this and refer them to a drug rehabilitation service. Their work has identified a need for low level, responsive support that can help someone with ASD function in a family, in work and in using mainstream services. There are also examples of where a relatively small intervention, sometimes as simple as explaining something (such as a form or a service), can make a big difference to people’s lives. However, their work has also illustrated gaps in services that they are not trained or resourced to fill.

The Cardiff and Vale employment project

9.7 The Cardiff and Vale employment project developed out of the CMS project, in response to the large number of enquiries to the service for employment support (a common feature across all the CMS projects). Given the range of existing employment support services in South East Wales, the focus of the project has been on developing materials to support adults with ASD in finding and preparing for work (e.g. by matching their skill to jobs), and working with existing services, such as JCP, to improve their awareness and understanding of ASD. The project also offers more specialist advice to services, when it is needed. Feedback on the project from both people with ASD and services has been very positive and the materials have been shared across Wales.

The impact of the ASD SAP

9.8 As figure 7 illustrates, the ASD SAP aimed to ensure that adults with ASD can access appropriate support and training and move into employment. The strategy highlights:

- existing support services, such as JCP;
- existing policies such as Learning Pathways 14-19, intended to ensure learners have choice and support; and
- the importance of awareness-raising and training, including greater collaboration between learning providers, to increase the capacity of learning providers and support services.

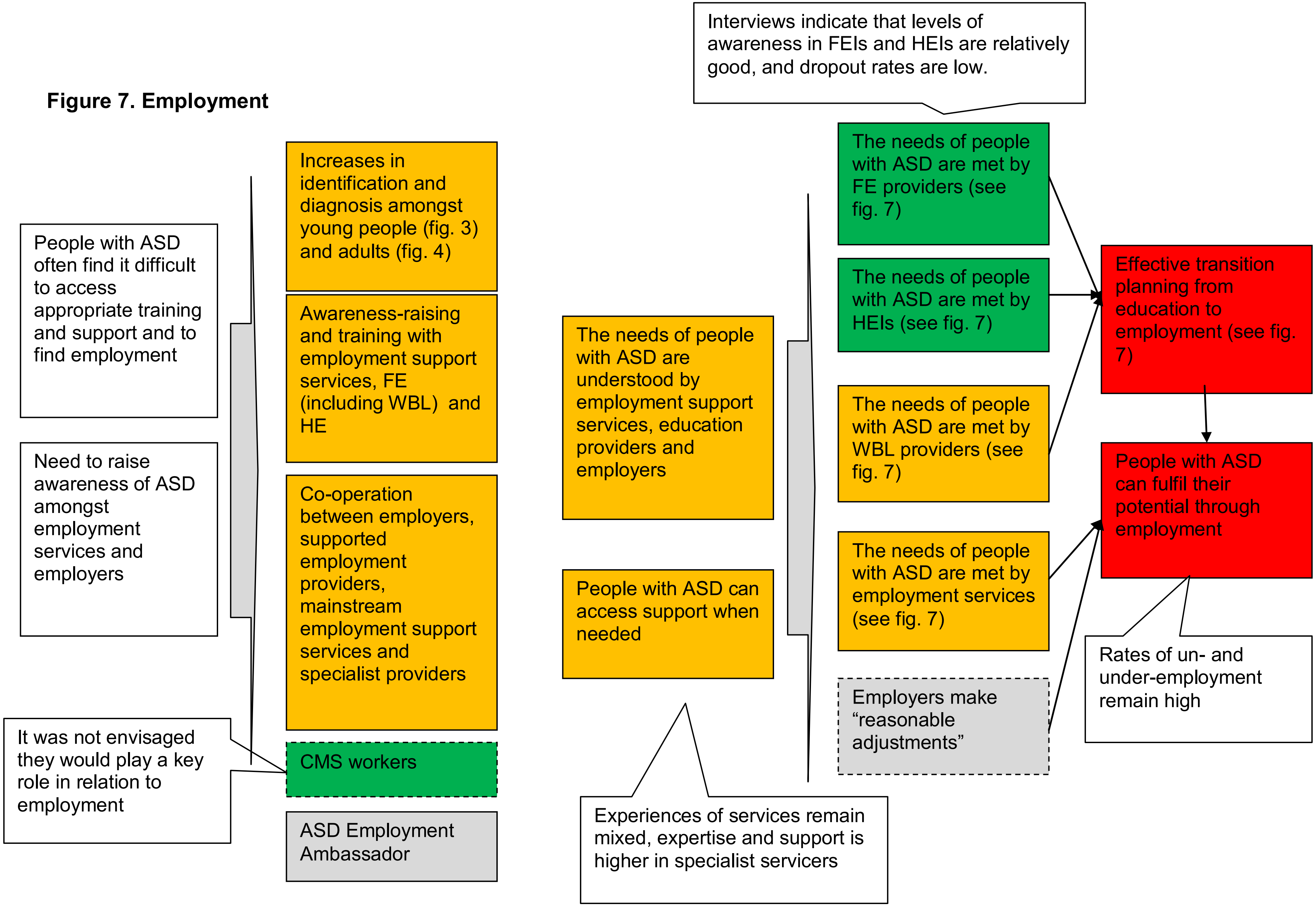
9.9 Implementation of the strategy in relation to post-16 education and training was fairly strong. In part this was because many elements of the strategy were already in place.

9.10 Outcomes for young people and adults have improved in relation to post-16 education and training. As outlined in sections four and five, awareness-raising has contributed to increases in diagnoses amongst young adults in particular (rates of diagnosis amongst older adults remain low) and helped increase their access to support in education and training. The numbers of young people and adults with an ASD in FE and HE has also increased. Nevertheless, in part, increases in the numbers of learners identified as having ASD may reflect increasing rates of diagnosis, rather than an increase in the total number of learners with ASD, whether diagnosed or not.

9.11 In contrast, implementation of the strategy in relation to employment support was more mixed. Existing services (such as JCPs and DEAs) continued; a number of new projects (discussed above) were established and, together with increases in diagnoses, improved support for young adults in particular. However, there is only patchy evidence of increased co-operation between mainstream and specialist providers. This is a key weakness, given the strategy's dependence upon this and recommendations to address this have been made to the Welsh Government (Townsley et al., 2014). The number of young people with ASD in work-based learning (WBL) also remain very low and levels of expertise and confidence in meeting the needs of learners with ASD and support for learners with ASD is lower amongst WBL providers, compared to ASD specific and pan-disability providers (ibid.).

9.12 Outcomes for young people and adults in relation to employment remain poor. Unemployment rates are high (Holtom et al., forthcoming) and there is qualitative evidence of under-employment (where for example, people with ASD work below their qualification level). Despite increasing participation in FE and HE (discussed above), learners struggle to make the transition into employment and the study of employment outcomes for young people with ASD identifies that: "there is evidence of high, unmet demand from people with ASD for effective employment support" (Townsley et al., 2014, p.36). This is consistent with data from CMS workers and other studies (e.g. NAS, 2011). (Holtom et al., forthcoming).

Figure 7. Employment



9.13 Table 8 summarises the data requirements identified by the study and the proposed measures and sources.

Table 8: Indicators to measure progress in relation to employment

Data requirements	Measures	Sources
Quantity How many/how much?	The number of students with ASD in FE or WBL	Post- 16 Education and Learning Statistics (drawing upon the LLWR)
	The number of students with ASD in HE	HESA
	The number of young people aged 16, 17 and 18 with ASD supported by Careers Wales	Careers Wales
	The numbers of adults with PDD on the work programme	DWP
	The numbers of adults with PDD claiming employment and support allowance (ESA) in the work-related activity group [37]	DWP
Quality How good is post-16 education, training and employment support provision?	The quality of provision for learners with ALN in FE institutions	Estyn inspections
	The quality of provision for learners with ALN in WBL providers	Estyn inspections
	The percentage of learners with ASD reporting provision is “good” or “very good”	Post-16 education and learning statistics (drawing upon the Learner Voice Wales survey)

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[37] ESA claimants are placed in two groups: the work-related activity group, where claimants have regular interviews with an adviser, and the support group, for those whose disability or illness severely limits what they can do and where claimants do not have interviews.

Table 8: Indicators to measure progress in relation to employment (cont)

Data requirements	Measures	Sources
Impact Is anyone better off?	The percentage of learners with ASD leaving FE and achieving positive outcomes (e.g. progressing to further study or employment)	Post-16 education and learning statistics (drawing upon the LLWR)
	The percentage of learners with ASD leaving WBL and achieving positive outcomes (e.g. progressing to further study or employment)	Post-16 education and learning statistics (drawing upon the LLWR)
	The percentage of learners with ASD leaving HE and achieving positive outcomes (e.g. progressing to further study or employment)	HESA destinations survey

10. Support for adults

Introduction

10.1 The ASD SAP identifies that: “services for adults are patchy across Wales “…many adults may not be accessing the care assessment system or their care assessment may not identify any specific needs arising from their autistic spectrum disorders” (p. 36).

Examples of initiatives in this area

The Adult Task and Finish Group

10.2 The Adult Task and Finish Group (WG, 2010a) was established in 2000 to: “identify the issues that adults with ASD face and take forward work to tackle them” (p. 5). Reporting in 2010, it identified that: “adults with ASD do not fit easily into LD or MH services” (ibid., p. 4) and that: “services to adults with ASD in Wales are currently patchy” (ibid., p. 5). In 2010, in response to the Adult Task and Finish Group Report, Gwenda Thomas announced that: they would work to: “provide additional support for adults with Asperger syndrome on a regional basis…and to provide a website information site for adults with ASD and their carers”[38].

Ceredigion Autism Service

10.3 Work in Ceredigion to support people leaving school with ASD who had complex needs began in 2003 and a multi-agency strategic vision for the county was developed in 2005. This resulted in an autism-specific post, working across the whole spectrum but with a specific focus on those who do not meet the criteria for support from other services. The role focuses on providing information for adults with ASD and family members, raising awareness of ASD and skilling up existing teams and services that work with people with ASD, and helping to support people to get a diagnosis. In addition, the role involves collecting and collating data about known adults

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[38] Written statement to the WAG:the implementation of the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales, by Gwenda Thomas, Deputy Minister for Social Services.

with ASD in the county including who has a diagnosis, where they are, their circumstance and what services they have accessed.

10.4 The aim of data collection is to identify and set up extra services to meet need and this led, in 2010, to the appointment of a specialist social worker to support adults with ASD who do not have a learning difficulty or a mental health problem, but do have a need for support. The caseload started with 12 and had reached 36 by 2014. The strategy enables a responsive approach with people able to self-refer, or referrals coming from GPs, transition services, MH teams, families or diagnostic services, and the social worker is able to refer people to specialist provision such as community speech and language therapy (SALT) services. In addition there are two ASD project workers who work with all people with ASD who are able to provide personal support.

The Orange Wallet scheme

10.5 The Orange Wallet scheme was developed from work done in Devon and Pembrokeshire and is a tool to help people with communication difficulties, and especially ASD, use public transport. Bus and train company staff have been given information and training so that they recognise the orange wallet and there are templates downloadable from the ASD info Wales website which can be put into the wallet and used to request tickets or information.

Evaluating the impact of the ASD SAP

10.6 As figure 9 illustrates, the ASD SAP aimed to ensure that the needs of adults with ASD are properly assessed and that they can access services when needed. The strategy highlights:

- the importance of awareness-raising and training to ensure professionals have a good understanding of ASD and the impact it can have upon adults;

- how the Unified Assessment Process (UAP) should identify a person's needs and how they constrain or support their capacity to live a full and independent life; and
- the need to identify adults with ASD already known to services.

10.7 The strategy was developed in response to the Adult Task and Finish Group report (discussed above) which recommended that guidance be produced for LAs to help them deliver the UAP more effectively to people with autism and that regional and local support services should be developed for people with high functioning autism or Asperger syndrome[39] .

10.8 Implementation of the strategy was mixed. As outlined in section four, awareness-raising and training has increased understanding of ASD in many services for adults. Nevertheless, the impact of awareness-raising and training has been uneven, and significant gaps remain in areas like MH services. As outlined above, CMS workers have been established in many areas. However, the pilot project to develop new guidance around the UAP was abandoned and the regional autism support teams[40] were never established.

10.9 Outcomes for adults with ASD remain very mixed. Levels of unemployment and under-employment are high (see section eight) as are levels of low self-esteem, depression and anxiety (NAS, 2011). Overall, there has been little change in the general situation where most adults with ASD and a learning disability can access a statutory service, while those without a learning disability cannot (Holtom et al., forthcoming). As outlined in relation to

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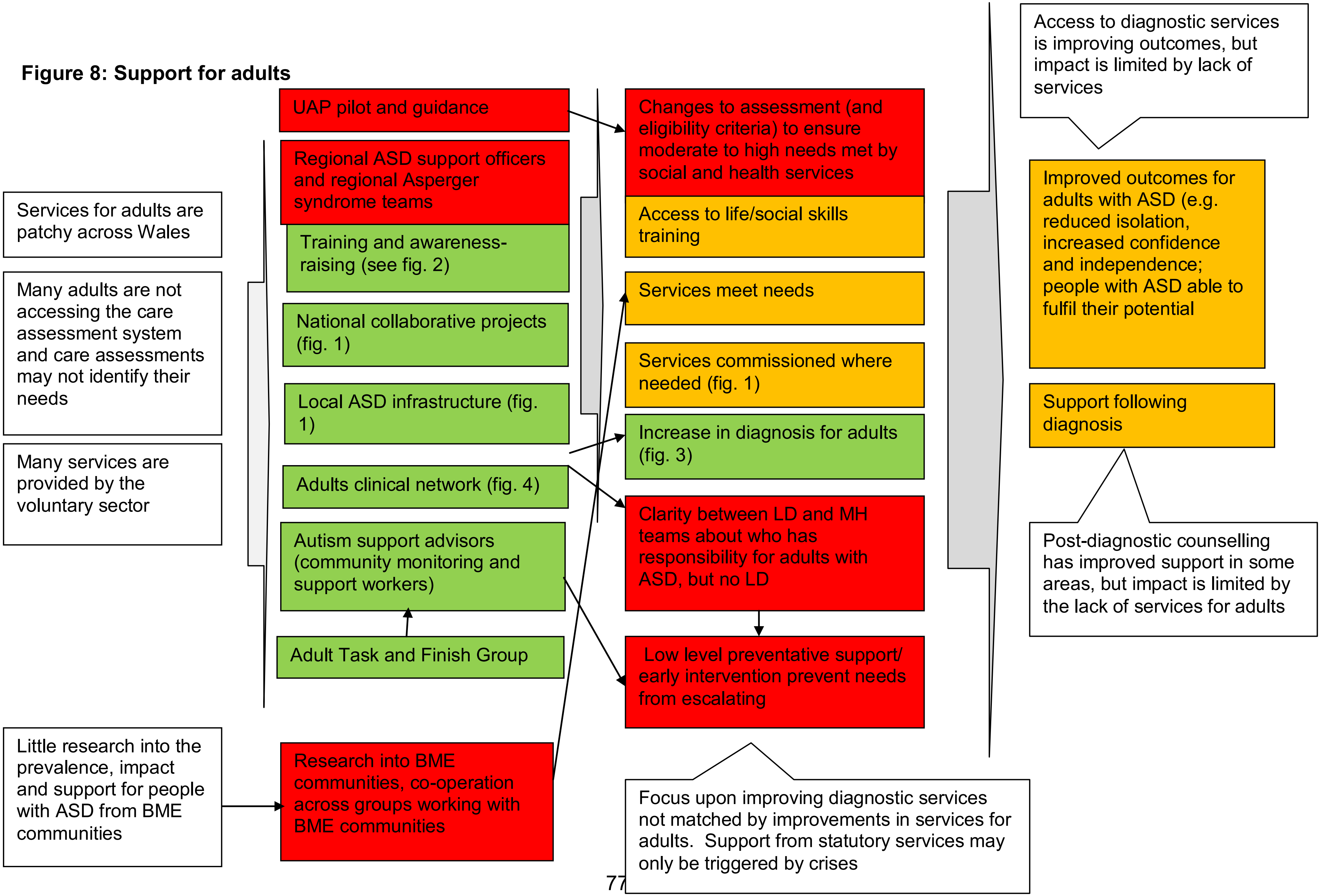
[39] In relation to adults with a lower level of need (who were not eligible for statutory services) the Task and Finish Group called for provision of both "low level" support and monitoring of people's stress and anxiety levels: "to broker swift and appropriate support when required". In order to provide this, the group recommended the appointment of autism support advisors who would provide "a point of contact and support" and "would provide individual support and advice, equipping adults to find and sustain their way through services (both mainstream and more specialist as appropriate) and maintain their lives" (p. 24).

[40] This would complement the planned regional ASD support officers based with the Social Services Improvement Agency (SSIA), who were to: " be the catalyst between local areas by collecting information from the existing local action planning and drawing together regional themes which can be translated into regional service planning and delivery" (p. 5). The group also proposed the development of: "regional Asperger syndrome teams" to: "provide a specialist service for adults with Asperger syndrome" (WAG, 2010a, p.27).

transition services (in section eight) the extent to which LD services could meet the needs of adults with ASD has been questioned. A small number of examples where adults with learning disability and ASD did not or might not meet eligibility thresholds were also identified. These issues are important because the assumption that there is a service for adults with ASD and a learning disability has meant less attention has been paid to developing services for this group.

10.10 Pressure upon public services, as a result of increasing demand (through demographic changes and increasing expectations) coupled with cuts in resources as a result of austerity (Williams, 2014) have made it difficult to develop new services for adults and pushed thresholds for eligibility for services up in some areas. The lack of services for adults means that the impact of both increases in diagnosis amongst adults (discussed in section six) and the establishment of CMS services (discussed above) have been blunted.

Figure 8: Support for adults



Developing indicators to measure progress in relation to adult services

10.11 Table 9 summarises the data requirements identified by the study and the proposed measures and sources.

Table 9: Indicators to measure progress in relation to adult services

Data requirements	Measures	Sources
Quantity How many adults with ASD are supported?	The number of people with ASD supported by adult social services.	Social Services databases*
	The number of people with ASD supported by community monitoring and support workers.	LGDU [41]
	The number of people diagnosed by the Wales ASD Diagnosis and pre- and post- Counselling Network who are supported by health services	The ASD diagnosis and pre/post counselling network for adults[42]
Quality How good is provision for adults with ASD?	Performance of adult services	CSSIW inspections of adult services
	Are interventions compliant with NICE guidelines?	Self evaluation by the ASD diagnosis and pre/post counselling network for adults
Impact Is anyone better off?	The percentage of people with ASD supported by CMS workers whose primary need is fully or partially met	LGDU [43]
	The percentage of people diagnosed by the ASD diagnosis and pre/post counselling network for adults who are can access a service that meets their needs	The ASD diagnosis and pre/post counselling network for adults [44]

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[41] A data collection tool, administered by the LGDU, has been developed to collect this type of data.

[42] A data collection tool is currently being piloted to collect this type of data.

[43] A data collection tool, administered by the LGDU, has been developed to collect this type of data.

[44] A data collection tool is currently being piloted to collect this type of data.

11. Family and carer support services

Introduction

11.1 The ASD SAP highlights the range of support roles that family members can take and the stress and strains this can place upon them: “enormous stress can be placed upon families simply fighting to find out what services may, or equally important, may not, be appropriate to their son’s or daughter’s needs” (p. 42).

Examples of initiatives

11.2 Service mapping has been a key activity in many areas and has improved information about the availability of services; for example, Rhondda Cynon Taf’s Directory of Services[45] has been identified as an example of good practice and has been adopted by a number of other LAs. However, professionals interviewed for this study highlighted the challenges of keeping directories up to date. Directories are also constrained by the range of services available, which, as outlined in the preceding sections, is often limited. Parents and carers interviewed for this study and those surveyed by NAS Cymru (2011) both identified a desire for more information.

Advocacy services

11.3 There is a range of advocacy services available for people with ASD and the parents and carers of people with ASD. These include national and regional organisations supporting children and young people, such as the NAS Advocacy for Education Service, SNAP Cymru, Tros Gynaal and organisations supporting people with learning disabilities[46] such as People First and Learning Disability Wales (Advocacy Matters Wales). There is also a

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[45] http://www.rctcbc.gov.uk/en/relateddocuments/publications/communitycare/carers/autismsdbooklet.pdf

[46] In 2004 the Welsh Government introduced a scheme to provide grant assistance to further develop the availability of advocacy services for adults with a learning disability in Wales. The scheme was introduced as a “pump priming” grant designed to build on existing investment in such advocacy services and address service gaps. In 2010 Welsh Ministers decided that the Advocacy Grant Scheme should continue for a further three-year period but that it should end in March 2014. http://gov.wales/about/cabinet/decisions/dr2013/aprjun/addysg/7414954/?lang=en

range of local groups offering advocacy services. However, with the partial exception of SNAP Cymru, advocacy services were rarely identified by interviewees in the course of the study.

Training for parents and carers

11.4 In several areas such as Bridgend, Caerphilly, Carmarthenshire, Monmouthshire, Flintshire and Wrexham, training for parents and carers, including courses such as Early Bird[47] and Early Bird Plus, has been provided. Feedback from professionals indicates that parents and carers find the training valuable but there is still demand for further support as and when they encounter problems. Moreover, because Early Bird is focused upon parents or carers of pre-school children and Early Bird Plus is focused upon the parents or carers of children aged 4-8 years, there is a gap for parents and carers of older children (e.g. following a late diagnosis or a development or change in symptoms).

Access to parent groups and local and voluntary sector organisations

11.5 Interviewees reported that support groups, including both traditional meeting-based groups and newer, virtual groups, such as Facebook groups, could provide valuable support and help people put their problems into perspective. The voluntary sector, including organisations such as NAS Cymru and Mencap, provides support groups in a numbers of areas, including Rhondda Cynon Taf and Flintshire, and have supported the development of new support groups for parents and carers. However, access to groups varies across Wales and some interviewees reported that they did not feel comfortable or feel they fitted into existing groups.

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[47] The programme: “aims to support parents in the period between diagnosis and school placement, empowering and helping them facilitate their child's social communication and appropriate behaviour in their natural environment” (NAS, n.d.).

Evaluating the impact of the ASD SAP

11.6 As figure 11 illustrates, the ASD SAP aimed to ensure that the needs of families and carers, including siblings of those with ASD, are properly assessed and that they can access information, support (including that provided by parent groups and the voluntary sector) and services when needed. The strategy highlights:

- the importance of access to information so that people know what services are available and so can make informed decisions;
- the role carers' assessments and advocacy services should play in ensuring carer's needs are assessed and provided for;
- the need for access to support, including that provided by parent groups and the voluntary sector where appropriate, short break arrangements and self-help groups and resources; and
- the role that training can play in helping family members provide therapeutic input for people in their care.

11.7 Implementation of the strategy was fairly good. Access to information and resources was strengthened through the work of the national and local ASD infrastructure. This included provision mapping (discussed in section three); the production of resources, awareness-raising and training (discussed in section four); the signposting role that CMS workers have played and, in some cases, support for local groups (such as parent and carer groups). There is some evidence that indicates that services for carers are being improved and expanded but are also being increasingly focused on those in greatest need. Practice also remains very variable across Wales (Holtom et al., forthcoming).

11.8 The evidence of outcomes is more mixed. Although, as outlined above, access to information and, to a lesser degree, support, has increased, parents and carers interviewed for this study and those surveyed by NAS Cymru (2011) both identified a desire for more information and for more support. The difficulties carers experience in accessing support were frequently identified by interviewees for this study and also by the study of service users' and carers' experiences of the ASD diagnostic pathway (Barker and Griffith, 2014; NAS Cymru, 2011).

11.9 Parents and carers described the systems and processes for accessing care and support for children and adults with ASD as complex and difficult to understand. They often expressed frustration at the lack of information - of not being told what was going on - and what they saw as the unreliability of professionals, which meant they had to keep chasing up people to ensure they did what they said they would - or what parents and carers had understood that they would do. Behaviour that might seem appropriate to a professional, such as not ringing back until some progress had been made, or until the information sought had been identified, was experienced by parents and carers as dismissive and rude; for example, as one said: "it doesn't take much just to pick up the phone and say I can't get that information for you at the moment, but I will ring back when I do". Another said: "two weeks might seem nothing when you are in work, but when you are jumping every time the phone rings, it feels like a lifetime".

11.10 The reasons why people cannot access services and experience such high levels of stress are complex. In part they reflect informational barriers, where carers do not know what services are available, or do not realise they would be entitled to support. However, they also reflect institutional barriers, including the absence of appropriate services, thresholds for eligibility to interventions (rationing access to services), cultural divides between professionals and users and carers, which can lead to misunderstanding and even conflict[48] and a lack of awareness or understanding of ASD (discussed in section three).

11.11 Interviews with parents and carers (whose sons or daughters had ASD) also highlighted the impact of a lack of support and the lack of services for adults with ASD. It meant that families often felt alone and had taken on much of the

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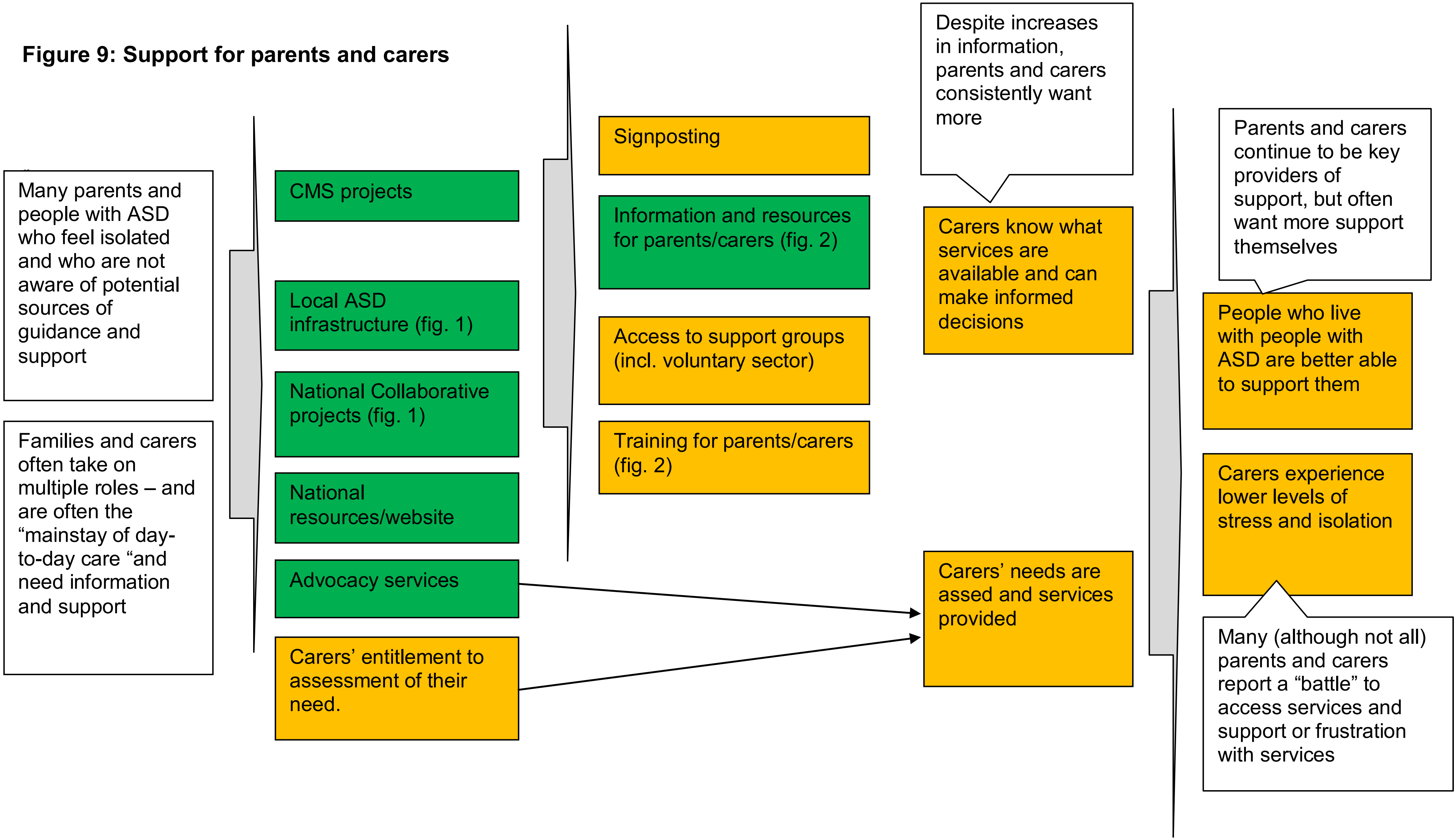
[48] As a consequence of differences in assumptions, values, attitudes and behaviours, professionals can see families as the problem, as dysfunctional or unable to understand what they are being told, whilst families see professionals as uncaring, cold or uncommunicative (Levine and Muury, 2004:6).

burden and responsibility for providing support. In many cases, while they were coping, they were coping by accommodating and adapting their lives to fit around the needs and behaviour of their son or daughter. This limited and constrained parents' and carers' lives and those of siblings, whose lives were described as sometimes very difficult.

11.12 Because parents and carers took on so much responsibility, fears about what would happen if, and when, they are no longer able to provide support (e.g. due to ill health or aging) were highlighted by professionals and parents and carers interviewed for this study and by other research with adults (Barker and Griffith, 2014; NAS, 2011).

11.13 Professionals interviewed for this study also identified that parents and carers from BME groups may be particularly isolated and vulnerable to stigmatisation and language and cultural barriers. There are only isolated examples of work in this field (e.g. by Cardiff and Vale and ABCD Cymru).

Figure 9: Support for parents and carers



Many parents and people with ASD who feel isolated and who are not aware of potential sources of guidance and support

Families and carers often take on multiple roles – and are often the “mainstay of day-to-day care “and need information and support

CMS projects

Local ASD infrastructure (fig. 1)

National Collaborative projects (fig. 1)

National resources/website

Advocacy services

Carers’ entitlement to assessment of their need.

Signposting

Information and resources for parents/carers (fig. 2)

Access to support groups (incl. voluntary sector)

Training for parents/carers (fig. 2)

Despite increases in information, parents and carers consistently want more

Carers know what services are available and can make informed decisions

Carers’ needs are assed and services provided

Parents and carers continue to be key providers of support, but often want more support themselves

People who live with people with ASD are better able to support them

Carers experience lower levels of stress and isolation

Many (although not all) parents and carers report a “battle” to access services and support or frustration with services

Developing indicators to measure progress in relation to support for parents and carers

11.14 Table 10 summarises the data requirements identified by the study and the proposed measures and sources.

Table 10: Indicators to measure progress in relation to support for parents and carers

Data requirements	Measures	Sources
Quantity How many/how much?	Numbers of people accessing parents/carer groups	NAS Cymru
	Numbers of parents/carers on Early Bird and Early Bird Plus courses	ASD leads/co-ordinators
Quality How good is support for parents and carers?	the percentage of carers who were offered an assessment or review of their needs in their own right	CSSIW
	The percentage of parents /carers on Early Bird and Early Bird Plus courses reporting they found it useful	ASD leads/co-ordinators (using self-evaluation)
	The percentage of parents and carers who are members of support groups (for parents and carers of people with ASD) reporting they know what services are available for them and their son or daughter.	Survey of members[49]
Impact Is anyone better off?	The percentage of parents and carers who are members of support groups (for parents and carers of people with ASD) reporting they have adequate (or better) support.	Survey of members[50]

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[49] The principle of surveying members has been discussed with NAS Cymru, but has not been agreed or piloted.

[50] The principle of surveying members has been discussed with NAS Cymru, but has not been agreed or piloted.

12. Conclusions

Has the ASD SAP achieved its aims?

12.1 Stakeholders interviewed from across the government, voluntary and academic sectors welcomed the ASD SAP. It was consistently felt to be an important development that put Wales at the forefront of international developments. It was widely felt to have directly contributed to raising the profile and awareness of ASD, particularly in relation to policy makers. It also provided resources and enabled the development of a local infrastructure (including a national co-ordinator, ASD leads/co-ordinators, ASD co-ordinating groups and action plans) and national infrastructure (including a national co-ordinator and all-Wales clinical network) that provided a basis and focus for action.

12.2 However, the breadth and ambition of the SAP, which was welcomed by stakeholders, proved to be a double-edged sword. As we outline below, its aims and the means for achievement - its "strategy" - was not always explicitly articulated; the additional funding was important and sizeable, but was not sufficient to meet the scale of need; priorities were not identified; accountability structures were weak (making it difficult to direct developments) and in some cases there was a lack of detail on what was needed (illustrated by the impact pathways discussed in this report); all of which limited the SAP's value as a guide to action planning and contributed to considerable variation in actions at a local level (and therefore, led to inconsistencies in service developments across Wales).

Improving commissioning for service for people with ASD

12.3 The SAP's aim in relation to commissioning focuses upon developing a local ASD infrastructure; improving the availability and use of data and improving partnership working (including joint funding and regional working). As outlined in section three, a local and national infrastructure has been established and has helped raise the policy profile of ASD and provided a focus for developments. It has generally had a greater impact upon services it has commissioned itself, rather than services commissioned by LAs or LHBs. Progress was made in improving data, particularly around people of all ages with ASD in education, but remains weak in areas like health and employment. The use of this data has often been limited. Regional projects such as the CMS posts have been established, but little progress has been made in developing regional working in relation to education or health. Overall, the aim of improving commissioning has been only partially achieved.

12.4 Developing person-centred, rather than service-centred, services remains a significant challenge. As the NAS observe:

> Most local authorities provide services via learning disability or mental health teams. Autism is a developmental disorder, not a learning disability or a mental health issue, so people with autism do not fall easily under either of these teams. (NAS, 2011, p.21).

This criticism about LA services could also be applied to many secondary adult health services[51].

12.5 As this report outlines, there are examples of integration, and the creation of more person-centred services, that better meet the needs of people with ASD. However, much of this integration has been driven by individuals. This has created islands of effective practice, but has not created systematic change (Ham et al., 2013) and means that experiences of services vary across Wales. Initiatives such as CMS workers can help improve signposting and increase the chances that people with ASD are referred to the right people (reducing the risk of people with ASD being “bounced” between services/teams), but they do not create new services.

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[51] In theory GPs can offer a “person-centred” service and it could be argued that paediatrics is a ‘wrap-around’ discipline that can offer a child-centred service.

12.6 The sustainability of the services that have developed is also uncertain. This reflects the dependence, in many cases, upon individual initiative and short-term funding, and the prediction of increasing demands upon services alongside cuts in resources (Williams, 2014). Given these considerations, proposals for developing more integrated services across Wales, particularly for adults with ASD, are likely to be important here.

Improving understanding of ASD: awareness-raising and training

12.7 The SAP's aim in relation to awareness-raising and training was very ambitious: "ensuring that each individual's needs are fully identified and assessed; that all care packages are appropriate to meet each individual's needs; and that the core education, health and social services required to undertake assessments and interventions are effectively delivered". As outlined in section three, a wide range of awareness-raising and training activities have been delivered and are reported to have had a positive impact. Nevertheless, more awareness-raising and training is still needed; for example, as outlined in sections seven to ten, gaps in awareness and understanding of ASD still contribute to weaknesses in assessment and provision for both children and adults. Therefore, while important progress has been made, the aim proved to be overly ambitious.

Identification, assessment and diagnosis for children and adults

12.8 The SAP's aim in relation to assessment and diagnosis of children includes early identification and intervention, post-diagnosis counselling and support and a strengthening of diagnostic services, but this was not clearly articulated. As outlined in section four, there is evidence of earlier identification (linked to increases in awareness) and increasing identification of ASD, but practice remains inconsistent. Diagnostic services have been improved in many parts of Wales, but much of this improvement is recent and post-diagnosis support and counselling remains patchy. Therefore, while progress toward realising this aim has been made, further work is needed.

12.9 The SAP's aim in relation to assessment and diagnosis for adults is similar to that for children. It includes increased recognition and diagnosis, post-diagnosis counselling and support and a strengthening of diagnostic services. As outlined in section five, the SAP has contributed to increases in the numbers diagnosed, improvements in post-diagnosis counselling and support and improvements in services. However, improvements have been uneven across Wales and services remain fragile. Moreover, gaps and weaknesses in services for adults with ASD, outlined in section nine, mean the impact of improvements in diagnosis and pre/post counselling and support upon outcomes for adults, has been constrained. Therefore, the aim was only partially achieved.

Education, training and employment

12.10 The ASD SAP aimed to ensure that special educational needs, such as ASD, are identified and assessed early, that additional support and interventions are put in place to meet needs and that the education of pupils with a SEN is "inclusive". As section five outlines, increasing recognition of ASD means that a child or young person with ASD has a much better chance that their needs will be identified and addressed and that additional support will be put in place. Education provision and outcomes have both also improved. Nevertheless, as section seven outlines, key parts of the SAP's strategy, such as reform of the statutory framework for SEN, were not implemented. As a consequence, assessments of SEN can be lengthy and complex. Therefore, while progress toward realising this aim has been made, further work is needed.

Young people's transitions

12.11 The ASD SAP aimed to ensure that adults could fulfil their potential in all areas of their lives, including for example, post-16 education and training, employment (discussed below) and independent living (where wanted). The strategy in the SAP focuses upon improving planning and multi-agency working, and developing TKW. Transition planning and multi-agency working has improved and projects, like Real Opportunities, have improved outcomes in some areas. However, key elements of the strategy, such as new standards and guidance, were either not developed or not published. Moreover, young people with ASD are not always eligible for support from transition services and the lack of services for adults, discussed in section ten, means the support available for them as adults may be limited, constraining the effectiveness of transition planning. Planning and support for the transition from school to college or university is generally much stronger than planning and support for the transition from post-16 education. Qualitative evidence indicates many young people struggle to make a transition to independent living and/or to find employment. They can become increasing withdrawn, isolated and dependent upon their parents. In some cases this may increase their level of disability. Overall, the aim has been partially achieved and more work is required.

12.12 The ASD SAP aimed to ensure that adult's could fulfil their potential in areas like employment. The strategy focuses upon assessing and supporting the needs of people with ASD in education, training or employment. As section seven outlines, the numbers of learners with ASD in FE and HE is increasing, and dropout rates are low (indicating that support is effective). However, outcomes in terms of employment remain poor. Support from specialist employment services is good, but support from non-specialist services is more variable. Overall, the aim has been partially achieved and further work is required.

Improving services for adults

12.13 The SAP aimed to ensure that the needs of adults with ASD were assessed and provided for. The Adult Task and Finish Group identified the need for changes to the UAP and additional support and information for people with Asperger syndrome, in particular. As section ten outlines, although CMS workers were established, other key elements of the strategy proposed by the Adult Task and Finish Group, such as the development of regional support teams and changes to the UAP, were not implemented. Therefore, as section ten identifies, with some notable exceptions such as the development of adult services in Ceredigion, there has been little change to the situation, in which adults with ASD and learning disability can generally access a (statutory) service but those without a learning disability, cannot.

12.14 Although ASD is a lifelong condition, people's level of disability is not fixed. The weakness in services for adults means that in some cases adults start to lose the skills and independence developed through their education, and becoming increasing disabled. In some cases they become dependent upon family members for care and support, constraining the lives of family members, and creating the risk of crises in the future when family members pass way. Given the weakness in services for adults, the vision (in the ASD SAP) of adults with ASD fulfilling their potential in all aspects of their lives, has not been achieved.

Improving information and support for parents and carers

12.15 The SAP's aim in relation to parents and carers focuses upon improving information and support. As section ten outlines, access to information has improved. Nevertheless, parents and carers consistently report that it remains difficult to identify support and services and they often experience high levels of stress and anxiety as a consequence. There are a number of reasons for this; no single service has responsibility for ASD and there is often no single point of contact which can help, access to services is sometimes limited (e.g. by eligibility criteria) and there can be a cultural divide between professionals and families. Overall, the aim of improving information and support has been only partially achieved.

Advancements in ASD infrastructure, services and projects across Wales

12.16 The establishment of an ASD infrastructure is seen as a key achievement of the ASD SAP (WAG, 2010a) although its impact has been mixed and difficult to quantify (Hay, 2013). Moreover, elements such as a regional Asperger service (proposed by the Adult Task and Finish Group) were not established, leaving gaps in services.

12.17 As sections four to eleven outline, improvements have been made to a number of services including health (through improvements to assessment and diagnosis); education (through increased awareness of ASD); employment (through the development of specialist provision) and transition services for young people (through increased capacity). However, there remain substantial regional variations and there is less evidence of improvements in adult services or services for parents and carers.

12.18 Projects supported by the ASD SAP have delivered important improvements in services in some areas, but have not covered all of Wales or all groups of people with ASD. Notable projects include the CMS service project, the Caerphilly Autism Spectrum Service, the Cardiff and Vale Employment project and the Ceredigion ASD Team (for adults). Each has been effective, but each has focused only upon adults or children and, with the partial exception of the CMS service project (which covered most of Wales), each is a local rather than a national project. Given the assumption that adults with ASD and a learning disability could access services, few projects have sought to improve outcomes or experiences for this group.

The impact of the strategy

12.19 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, were not solely caused by the strategy, although the strategy contributed to them.

12.20 It is not possible to isolate the impact of having a strategic action plan. In part this is due to the challenges associated with impact attribution (see e.g. HM Treasury, 2011). In part it is because the strategy itself includes a number of elements which pre-dated the strategy (such as programmes like Learning Pathways 14-19) or which are likely to have happened even if the strategy had not been developed (such as the TKW pilots). The focus of this report is therefore primarily upon whether the ASD SAP achieved its aims or not – i.e. whether the intended outcomes were achieved - rather than trying to isolate the contribution of the ASD SAP to these outcomes (the impact of the ASD SAP).

12.21 Although it is not possible to definitively isolate the impact of the strategy, the logic models developed for this study highlight some key strengths and weaknesses, which cast light on the difference it made, 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 has often been focused upon services or projects it has commissioned itself, rather than those commissioned by LAs and LHBs;
- new national standards and guidance were intended to drive improvements in areas like education and young people’s transitions. The failure, in a number of areas, 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. There is, however, the potential to look at approaches to meeting the standards that have been developed locally or regionally in fields such as awareness-raising, children's assessments and diagnosis and education and support for adults, and to explore how they can be scaled up across Wales in the strategy's next phase.

The impact of the SAP upon the experiences of individuals with ASD, their families and carers and professionals

12.22 The ASD SAP has improved the experiences of both individuals with ASD and their families, but has not done so consistently across Wales or across services. As a consequence, experiences of some services may be positive and experiences of others may be very negative. Parents and carers interviewed for this study were generally more positive about services for children than they were for adults. Parents and carers sometimes expressed frustration at delays in having their child's needs identified and assessed. However, crucially, once needs were identified, and particularly following a formal diagnosis, they generally felt that education offered their child a structure and a focus upon progression and development, that was often lost when they left education. Parents talked of young people's skills "going backwards" and hard won confidence being lost.

12.23 Parents and carers felt particularly vulnerable if their child had a crisis or a particular change in behaviour or problems, because they did not know who to turn to for support. Parents and carers most frequently wanted access to a named person with expertise, who could be easily accessed and who could provide advice, link them into relevant services and talk them through how to manage the day-to-day problems they faced.

12.24 The impact of the ASD SAP upon the experiences of professionals has been mixed. Some, such as education and employment staff, have benefited from (and value) increased awareness and understanding of ASD. However, others have not benefited and lack the confidence or expertise to work with people with ASD. This lack of knowledge can be disempowering and can lead professionals to close their doors to people with ASD. More broadly, while staff working with people with ASD report it is rewarding, the gaps and weakness in services and, in some cases, a lack of support from service leaders, means they can also find it very frustrating.

Developing data and indicators

12.25 As outlined in section three, in many ways the focus upon creating databases of individuals with ASD was misplaced. Data on the numbers of people with ASD may be valuable in identifying the extent to which ASD is being recognised and diagnosed but, with the exception of very specialised services (for the small numbers of people with severe and/ or complex needs), for most purposes estimates of prevalence, together with existing research into the needs of people with ASD, will usually be sufficient to commission services. In contrast, much better data about the effectiveness of services in meeting needs is required and recommendations are made in the report to assess the quantity, quality and the impact of services.

Implications of the refreshed SAP

12.26 The first ASD SAP marked an important first step, but there is a clear need for the strategy to continue and to be refreshed. This study illustrates that the needs of people with ASD of all ages and their families are complex, so there is no single solution. Given the pressures facing public services as a result of increasing demand and cuts in resources, there are no easy solutions or choices. In refreshing the SAP, the study highlights the need for systems thinking in, for example, considering in depth how and why expected changes – or outcomes - are expected to be realised. The study also highlights the need for better monitoring and evaluation to enable progress and the strengths and weakness of any refreshed SAP to be to be assessed.

12.27 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 LD or MH services); and
- 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).

12.28 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[52], which are better able to meet the complex needs of people with ASD who do not easily fit 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 all-Wales 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 in ensuring that it is shared.

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 assessment, diagnostic and pre/post counselling network, and 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).

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

Improving the education of children and young people with ASD

R6. The Welsh Government continue work to reform the system for identifying, assessing and supporting children and young people with 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 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 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 JCP and work programme providers, from the 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[53] 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[54].

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, Ceredigion ASD Team and CMS workers.

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[53] Eligibility criteria will be detailed in forthcoming regulations.

[54] LAs will be under an enhanced duty to provide people in need, and their carers, with information about the care and support that is available in their area.

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. though 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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