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Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan Interim Report

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Evaluation of the Integrated Autism Service and ASD Strategic Action Plan: Interim Report

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Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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Table of Contents

Acknowledgements	1
List of figures	3
Glossary.....	4
Summary	5
1. Introduction.....	8
2. Approach and methodology.....	12
3. Context for the establishment of the Integrated Autism Service (including baseline position).....	14
4. The theory of change for the Integrated Autism Service.....	21
5. Responses of key stakeholders.....	22
6. Outcomes (implementation to date).....	27
7. Conclusions	30
8. Recommendations.....	38
9. Bibliography.....	40
Annex A. The ASD SAP's theory of change for adults	43
Annex B The theory of change for children and families	47
Annex C. List of stakeholders interviewed for the study.....	50
Annex D. Semi structured interview schedule for IAS staff	51

List of figures

Figure 1. Establishing an Integrated Autism Service	45
Figure 2. The theory of change – the impact of the IAS and the ASD SAP upon Adults	46
Figure 3. Strengthening children’s assessment and diagnosis and post-diagnostic support	48
Figure 4. The impact of Together for Children and Young People, IAS and ASD SAP: children.....	49

Glossary

Acronym/Key word	Definition
ASD SAP	Autistic Spectrum Disorder Strategic Action Plan
IAS	Integrated Autism Service
ICF	Integrated Care Fund
LA	Local Authority
LHB	Local Health Board
NAS	National Autistic Society
NHS	National Health Service
NICE	National Institute of Care Excellence
PHW	Public Health Wales
PNA	Population Need Assessment
RPB	Regional Partnership Board
T4CYP	Together for Children and Young People
ToC	Theory of Change
WLGA	Welsh Local Government Association

Summary

The aim of this work is to evaluate the refreshed Autistic Spectrum Disorder Strategic Action Plan (ASD SAP) and accompanying Delivery Plan, with specific focus on the implementation and impact of the Integrated Autism Service (IAS). This interim report focuses upon the research conducted in 2017 and findings in relation to the initial development of the IAS in the first four regions where it is being rolled out - Cardiff and Vale, Cwm Taf, Gwent and Powys. The final report scheduled for January 2019 will explore how the IAS continues to develop and how the recommendations have been taken forward.

This interim report draws upon a desk-based review of key documents and in-depth interviews and discussions with 16 stakeholders from the Welsh Government, Welsh Local Government Association (WLGA), Local Health Boards (LHBs), Local Authorities (LAs) and National Autistic Society (NAS) Cymru and Autism Spectrum Connections Cymru from the voluntary sector.

Key findings

- Weaknesses and inconsistencies in both assessment and diagnostic services for adults with autism and in support services for adults and children with autism provide a strong case for national action to drive up standards and ensure good practice is adopted across Wales. All stakeholders interviewed support this view.
- Establishing a new integrated service like the IAS is challenging. The inherent challenges, such as difficulties associated with integrating different systems and recruiting senior staff, have been compounded by differing visions for the IAS and the need to fit the model into a 'patchwork' of existing services (which differ from region to region), if the aspiration to enhance, rather than replace or duplicate existing services was to be realised.
- This tension was not easily resolved and the desire for a standardised national model limited the scope for flexibility when difficulties were encountered. Prolonged negotiations between key stakeholders contributed to

longer development periods for establishing the service in Cwm Taf, Cardiff and Vale and Gwent in particular.

- Important progress has been made in establishing an IAS in Cardiff and Vale, Cwm Taf, Gwent and Powys and this represents a considerable achievement. Stakeholders expect the service to make important improvements to the quality and timeliness of assessment, diagnosis and support.
- To be effective, the IAS needs to be – and also to be understood by stakeholders as an integral part of a broader approach to working with autism including, but not limited to, developments in learning disability and mental health services, housing and employment support. Communicating this to stakeholders is likely to be a key challenge.

Recommendations

R1. For the Welsh Government, WLGA and Public Health Wales (PHW)¹: consider the case for establishing a Programme Board to support the National ASD Lead and national team. This could include, for example, supporting communication and engagement with key stakeholders and providing challenge and approval in relation to key decisions, such as the appropriate balance to strike between national direction and local autonomy.

R2. For the Welsh Government, WLGA and PHW, Regional Partnership Boards (RPBs) and the Cardiff and Vale, Cwm Taf, Gwent and Powys IASs: establish a communication strategy with key stakeholders, to help clarify the roles and responsibilities of the IAS and of other services supporting people with autism.

R3. For the Welsh Government, WLGA and PHW and the West Wales Care Partnership, Western Bay and North Wales RPBs²: consider the case for employing a project manager to establish the IAS.

¹ The WLGA and PHW host the national ASD team.

² These three regions are still in the process of developing proposals for their IAS.

R4. For the West Wales Care Partnership, Western Bay and North Wales RPBs: ensure an early start is made on preparations for establishing an IAS (given the time taken by the first four regions); for example, this could include consulting stakeholders across mental health and learning disability services and planning for recruitment and the challenges this is likely to pose in rural areas.

R5. For the Welsh Government, WLGA and PHW and RPBs: monitor demand for the IAS and pressure upon other services (that may impact upon demand for the IAS), to ensure that the service has sufficient capacity to fulfil all its functions (including assessment and diagnosis, support for individuals and families and support for other services).

R6. For RPBs: as the IASs get established, ensure that the focus and attention of regional strategy groups includes the full range of services that support people with autism and their families.

R7. For the Welsh Government: to consider whether the Integrated Care Fund (ICF) is an appropriate vehicle to fund national models (as it has traditionally given considerable autonomy to regions in how ICF monies are used, which can lead to variation in practice across Wales).

1. Introduction

- 1.1. Autism is a lifelong developmental condition that affects: “how a person communicates with and relates to other people, and how they experience the world around them”³.

Assessment and diagnosis

- 1.2. Timely access to assessment and diagnostic services can help ensure that an individual’s needs are understood and appropriate services are put in place to support them to lead fulfilling lives. It can also help people with autism and their families and friends better understand their lives and experiences (WG, 2016a). Although autism can (and should) be identified and diagnosed at a young age, some people do not receive a diagnosis until adulthood – either because opportunities for diagnosis were not available when they were young or because the impact of their autism increased as they became adult.

Meeting support needs

- 1.3. Individuals with autism, and their families, have a range of needs. This reflects both differences in the impact of autism (which is a “spectrum” condition) (Baron-Cohen, 2008) and in their circumstances (for example, differences in the capacity of families and support services) which shape their needs⁴. While autism is a lifelong condition, levels of disability are not fixed and if needs are not met, individuals with autism and their families can struggle to live fulfilling lives.

³ [Http://www.autism.org.uk/about/what-is.aspx](http://www.autism.org.uk/about/what-is.aspx)

⁴ This means needs are dynamic, and as a person’s circumstances change, and they, for example, make a transition from school to further education or employment, their needs can also change.

Wales's Autism Strategy

1.4. In order to improve outcomes for people with autism and their families, in 2008 the ASD SAP for Wales was published (WAG, 2008). Consultation with stakeholders and evaluation of the strategy identified that, although the ground-breaking strategy achieved a great deal, there was a need for greater focus. In 2016, a refreshed ASD SAP and Delivery Plan, which included proposals for a national integrated autism service, were published (WG, 2016a, 2016b).

The Integrated Autism Service

1.5. The IAS is being introduced on a three year rolling basis. The first four regions (Cwm Taf, Cardiff and Vale, Gwent and Powys) aimed to commence roll out by April 2017. Abertawe Bro Morgannwg and Hywel Dda and Betsi Cadwaladr will start implementation during 2017-18. The IAS is intended to offer:

- advice and training for families and carers of children, young people and adults;
- advice, support and interventions for people with autism to help them with their daily lives;
- training and support for professionals to help them understand the needs of people with autism when they are delivering services, care and support;
- integrated provision of services and support across health and local authorities;
- teams of professionals providing support in the local community, including psychology, occupational therapy, speech and language therapy, nursing and support workers from across health and social care; and
- diagnostic services and post-diagnostic support for adults⁵ (WG, 2016a, p.18).

⁵ Diagnosis and assessment for children is provided through the Together for Children and Young People (T4CYP) programme.

1.6. Although described as “a national service to provide lifetime support to children and adults with autism, and their families”⁶ the IAS is not intended to replace existing services, but to address gaps in service provision; for example, as the revised guidance makes clear:

“the service has been developed to meet the needs of autistic individuals (and their family and carers) who do not meet the eligibility criteria for statutory services due to absence of a moderate to severe mental health need or moderate to severe learning disability. Those who do meet eligibility criteria for statutory services should be supported by the service that addresses the most significant need and not the Integrated Autism Service.” (WLGA, n.d. b, p.5)

1.7. Alongside the IAS:

- assessment and diagnosis of children will continue to be undertaken by neuro-development services, with the support of the Together for Children and Young People programme (discussed in section three)⁷;
- specialist post-diagnostic support for children will be provided by existing services (e.g. SEN specialist services such as educational psychologists and children’s disability teams); and
- assessment and diagnosis and post-diagnostic support for adults with moderate to severe mental health or learning disabilities will be through existing mental health and learning disability services.

⁶ <http://gov.wales/newsroom/health-and-social-services/2017/170327autism/?lang=en>

⁷ The revised Guidance (WLGA, n.d. b) makes it clear that: “The service will provide diagnostic assessment for those aged 18 and over who are not accessing appropriate support from LD or MH services due to eligibility exclusion. Local flexibility between the IAS and ND service in relation to those bordering the age cut off for services will be employed, with the focus on the most appropriate approach for the young person.” and “The service provides advice and supportive interventions for individuals of all ages. The decision about how this is delivered will be based on the individual’s developmental age. For children, this will likely be via parents/carers and adults directly. Older children/young people may need a combination of approaches. Age should not be the only factor used to make decisions about the way an individual is supported.” *ibid*, p.5).

Aim and objectives of the evaluation

- 1.8. The aim of the evaluation is to evaluate the refreshed ASD SAP and accompanying Delivery Plan, with specific focus on the implementation and impact of the IAS. The evaluation has two main objectives. The primary objective is to undertake an assessment of the delivery and impact of the national Integrated Autism Service; this includes evaluating:
- progress in delivering the integrated service model across each RPB area;
 - assessing the impact of the IAS across health, social care and education and the third sector;
 - assessing compliance with the agreed national service standards for the IAS and, where required, suggesting improvements to the standards;
 - assessing progress towards achieving the key success; and
 - assessing the interface of the IAS with other relevant services.
- 1.9. The evaluation is also required to take into account the experience of individuals, families and professionals in accessing the IAS and their views on the impact of the services delivered, and, as a secondary objective, to undertake an assessment of how the refreshed ASD SAP is meeting its aims.

This Report

- 1.10. This interim report focuses upon the research conducted in 2017 and findings in relation to the initial development of the IAS in the first four regions where it is being rolled out - Cardiff and Vale, Cwm Taf, Gwent and Powys. The final report scheduled for January 2019 will explore how the IAS continues to develop and how the recommendations have been taken forward.

2. Approach and methodology

- 2.1. The evaluation integrates a process evaluation, focused upon delivery of the key actions in the refreshed strategy and delivery plan, and a theory-based impact evaluation, focused upon identifying the extent to which the aims of the ASD SAP are achieved – or are likely to be achieved.
- 2.2. A realistic evaluation approach was used to identify how and why observed processes and outcomes occurred (Pawson and Tilly, 1997; Westthorp, 2014). This approach is based upon the premise that interventions, like the strategy, work by influencing the thinking and behaviour of stakeholders, and that context has an important influence upon how stakeholders respond to such a programme. Realistic evaluation therefore focuses upon exploring how and why stakeholders' behaviour changes, and involves:
- elucidating the programme's Theory of Change (ToC), outlining how and why stakeholders' behaviour changes and, ultimately, how outcomes are expected to be generated⁸; and
 - collecting qualitative and quantitative data on the IAS in order to explore the relationships between the programme context, the programme intervention (such as the "levers" used to establish the IAS), the responses of key stakeholders, and outcomes (what changes).
- 2.3. In order to enable the evaluation to include staff involved in developing the IAS from the National Health Service (NHS), applications for permission to undertake a service evaluation were made to LHB research and development departments. Although permission was swiftly granted by Powys's research and development department, there were unexpected delays in securing permission from the other three LHBs (Aneurin Bevan, Cwm Taf, Cardiff and Vale). This delayed the start of fieldwork in these areas by several

⁸ i.e. the "resources, opportunities or constraints" the programme is expected to produce, and the consequent changes in stakeholders' reasoning and the behaviour that this is expected to generate (Westthorp, 2014).

months⁹. Once permission had been granted, semi-structured interviews with the lead in Cwm Taf, Cardiff and Vale, Gwent and Powys's IAS were undertaken. In addition, in the case of Cardiff and Vale and Gwent, four other members of the IAS teams were also interviewed. Further interviews with regional ASD leads, IAS staff and individuals, families and professionals accessing the IAS are planned in the next phase of the evaluation, which will focus upon the impact of the IAS in Aneurin Bevan, Cwm Taf, Cardiff and Vale and Powys, and the roll out of the IAS in the other three regions (Betsi Cadwaladr, Hywel Dda and Western Bay).

- 2.4. Semi-structured interviews with the lead for each IAS, and in the case of Cardiff and Vale and Gwent, other key members of the IAS¹⁰, were complemented by interviews and discussions with the Welsh Government's Adult Social Services Lead (who leads on autism policy in the Welsh Government), the National ASD Lead, the WLGA's three Regional Autism Development Officers, and representatives from the NAS Cymru and Autistic Spectrum Connections Cymru (key voluntary sector organisations).
- 2.5. A desk-based review of key Welsh Government and WLGA¹¹ policy documents was carried out, such as the ASD SAP and national guidance for the IAS.
- 2.6. This qualitative approach enabled an in-depth exploration of how different stakeholders shaped and responded to the IAS model, and how the context influenced this. The approach was dependent upon the openness of stakeholders to share, for example, the challenges they encountered, and the acuity of their analyses of how and why they and others acted in the ways they did. Stakeholders' responses were triangulated, to ensure that as complete a picture as possible of what happened and why, could be generated.

⁹ In response, in June 2016, it was agreed with the Welsh Government that the Interim Report would be delayed and that, in the intervening period, a case study focused upon Powys would be developed.

¹⁰ A copy of the interview schedule is included in annex 4.

¹¹ The WLGA and PHW host the National ASD lead and team of Regional Autism Development officers.

3. Context for the establishment of the Integrated Autism Service (including baseline position)

Health and care services

- 3.1. Health and social care services face a very challenging context, with rising demand as a result of demographic changes and increasing expectations, alongside cuts or freezes in their budgets. Consequently, many services are under pressure and access can be rationed through waiting lists and/or increasingly strict eligibility criteria. There are also concerns that pressures may lead to “cost shunting” where cuts or restrictions in access to one service increases demand upon other services (NHS Providers, 2016).
- 3.2. A focus upon co-production, prevention and integration of services is seen as a key part of the response to this challenge (see e.g. the [Wellbeing of Future Generations](#) and [Social Services and Wellbeing Acts](#)). RPBs¹² and the ICF¹³ are key vehicles for advancing this agenda. RPBs are responsible for undertaking Population Needs Assessments (PNAs), which include the needs of people with autism, and which should inform regional planning and priorities.
- 3.3. The focus upon co-production and prevention is expected to help improve effectiveness and reduce demand (e.g. by preventing escalation of needs) and integration is expected to help maximise synergies and create more seamless services for users/citizens ([Parliamentary Review 2017](#)); Williams, 2014). However, evidence of the impact and efficiencies generated by integration remains weak (Cameron et al., 2012).

¹² RPBs were established in response to the Social Services and Wellbeing (Wales) Act 2014. They bring together health, social services, the third sector and other partners to take forward the effective delivery of integrated services in Wales¹². RPBs administer the ICF, which supports delivery of the Social Services and Well-Being Act (2014).

¹³ Established in 2014 as the “Intermediate Care Fund” to: “support initiatives which prevent unnecessary hospital admission, inappropriate admission to residential care, and delayed discharges from hospital”, in April 2017 it was rebranded as the Integrated Care Fund to better reflect an expanded scope (WG, 2017).

The Together for Children and Young People Programme

- 3.4. The Together for Children and Young People Programme (T4CYP) was launched in February 2015 to reshape and refocus emotional and mental health services for children and young people. One of the programme's priorities was improving neuro-developmental services for young people and the workstream to support this included plans for developing care pathways for children and young people with autism (NHS, 2015).
- 3.5. Some stakeholders interviewed for this study reported that the experience of the T4CYP s programme's implementation informed thinking about the IAS and the approach taken. Specifically, because (as part of the T4CYP Programme) different LHBs were given funding and the freedom to develop their own proposals before the national programme was fully established, different models and approaches have emerged. Some stakeholders reported concerns that if a similar approach was taken in relation to the IAS, it would contribute to the continuing fragmentation of existing autism services and consequent post-code lotteries.

NICE Guidelines

- 3.6. In 2012 the National Institute of Care Excellence (NICE) published clinical guidelines on: "autism spectrum disorder in adults: diagnosis and management" (NICE, 2012), outlining best practice advice on the care of adults with autism. The guideline recommendations included establishing a local autism multi-agency strategy group and a specialist community-based multi-disciplinary team for adults with autism (the specialist autism team)¹⁴ (ibid., p.14). The guidelines suggest that this team: "should have a key role in the delivery and coordination of:

¹⁴The membership should include: clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists, support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

- specialist diagnostic and assessment services;
- specialist care and interventions;
- advice and training to other health and social care professionals on the diagnosis;
- assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team);
- support in accessing, and maintaining contact with, housing, educational and employment services;
- support to families, partners and carers where appropriate;
- care and interventions for adults with autism living in specialist residential accommodation; and
- training, support and consultation for staff who care for adults with autism in residential and community settings” (ibid, p.15).

3.7. However, the guidance also identifies that:

“... there is little evidence to guide the establishment and development of these teams. There is uncertainty about the precise nature of the population to be served (all people with autism or only those who have an IQ of 70 or above), the composition of the team, the extent of the team's role (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), the interventions provided by the team, and the team's role and relationship with regard to non-statutory care providers. Therefore, it is likely that in the near future a number of different models will be developed, which are likely to have varying degrees of success in meeting the needs of people with autism” (ibid., p.40).

Autism policy and practice

3.8. As outlined in section one, in 2008, Wales’s first autism strategy was published (WAG, 2008). A new ASD infrastructure was established, based around local ASD leads in each local authority (LA), to help drive improvements and deliver the strategy. In 2010, in order to address continuing weaknesses in assessment and diagnosis for adults, and to address the NICE guidelines, an All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults was launched¹⁵. Community monitoring and

¹⁵The 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).

support projects were also established¹⁶ in order to address the continuing gap between mental health and learning disability services. In 2012 a commitment was given to refresh the ASD SAP, stakeholder consultation events were held and an ASD Stakeholder Advisory Group was established.

- 3.9. The All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults contributed to important improvements. However, in the absence of strategic leadership, whilst “islands” of practice and expertise developed, in some areas services struggled to develop, or collapsed after key people left¹⁷. As a consequence, in some parts of Wales, adults struggled to access assessment and diagnostic services, creating inequalities in access and provision, and contributing to long waiting lists ([WG 2016](#)).
- 3.10. Given the problems, in 2015 the ASD Diagnosis Task and Finish Group was established to review assessment, diagnosis and support services. It identified the need for:
- improvements in assessment and diagnosis (including reductions in waiting times);
 - clearer pathways and more information, advice and support at the point of diagnosis; and
 - more effective post-diagnostic support around areas such as emotional and behavioural issues; ASD specific issues; social skills and life skills; information and advice; access to services, and support in relation to employment ([WG, 2016d](#)).

¹⁶ The Community Monitoring and Support Worker 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. In practice, some CMS workers have taken a more interventionist role, in response to the lack of services to which to signpost people (WG, 2016c).

¹⁷ As the Task and Finish Group identified: “improvements were only being driven by clinicians engaged with the network, as there has been an absence of strategic direction for autism services across health boards.”

- 3.11. In April 2015 an Interim [Autism Strategy] Delivery Plan was published¹⁸ and included proposals for scoping an Integrated Autism Service (WG, 2015). To support this work, the ASD National Development Lead undertook a consultation with parents, carers and individuals with an ASD through surveys and workshops. This consultation identified similar issues to those highlighted by the Task and Finish Group (outlined above). Subsequently, in parallel to the work of the Task and Finish Group, the ASD National Development Lead undertook a scoping study to consider options for establishing an Integrated Autism Service. This was presented to the Welsh Government in September 2015.
- 3.12. In March 2016, the Minister for Health and Social Services announced a £6 million investment in the development of an Integrated Autism Service for Wales. A twelve-week consultation on the proposals was undertaken and confirmed strong support for the proposals for an IAS, albeit with questions about detail (which were not outlined in the consultation document) ([WG, 2016d](#)).
- 3.13. Following the Minister’s announcement, in March 2016, ICF funding for 2016/17 was announced. £188,000 was allocated to Powys, £204,000 to Cardiff and Vale, £204,000 to Cwm Taf and £249,000 to Gwent, to support the development of an IAS. The ICF Guidance for 2016/17 (published in April 2016) included the objective to:
- “develop an integrated autism service, focusing on a multidisciplinary team to support autism in adults and enhancing existing children’s neuro-developmental services” ([WG, 2016e](#), p.4).
- 3.14. In March 2017 it was announced that initial funding of £6m for three years would be increased to £13m over five years. This helped address concerns about the sustainability of the service over the medium term. Funding for RPBs in 2017/18 totalled £2,674,400, with a further £80,000 for the WLGA with £245,600 retained by the Welsh Government ([WG, 2017](#)).

¹⁸ An “interim”, rather than full strategy was published: “to enable further policy development and to provide some time to ensure that future priorities took into account new legislation which included the Social Services and Wellbeing Wales Act 2014 and the Wellbeing of Future Generations (Wales) Act 2015. (IASD SAP WG, 2015).

3.15. Proposals are required from RPBs on the use of ICF, to demonstrate how they meet (i) the objectives of the grant (such as developing an integrated autism service) and (ii) the criteria for funding¹⁹, because “needs vary within regions”, and it is up to:

“each region, with their partners, to develop proposals and determine the most appropriate model of delivery to best meet the specific needs within their area” ([WG, 2016e, p.10](#)).

3.16. In July 2017 the initial guidance for the IAS (WLGA, n.d. a) was revised, to provide additional detail on the national model and approach (WLGA n.d. b).

Provision in Cardiff and Vale, Cwm Taf, Gwent and Powys before the IAS was established

3.17. Interviews with stakeholders in the summer of 2017 (before a national pathway for adult diagnosis was implemented) confirmed the varied picture for the provision of adult assessment and diagnostic services outlined above (and the consequent need for action to address inequalities in access and provision across Wales):

- in Cardiff and Vale services, which had been reliant upon a specialist nurse, things were improving, with an experienced clinician undertaking assessments, clearer pathways being established and some post-diagnostic counselling and support being provided;
- in Cwm Taf, assessment and diagnosis were reliant upon a single clinician and referral pathways were unclear and unpublished;
- in Gwent, assessment and diagnosis was reliant upon a single, albeit very experienced, clinician with support from a specialist nurse (rather than multi-disciplinary team); and
- in Powys, an adult diagnostic pathway, including pre- and post-diagnostic support was in place and primary healthcare staff, such as GPs and health visitors had received training to support the pathway. There was a clinical lead

¹⁹ i.e. proposals should encourage integrated working, be “strategic” and “transformational”, “new/additional”, “deliver benefits” and be “fair” and “equitable” (WG, 2017, pp 9-10).

for adult autism, and a directory of services for families and people with autism was being developed.

- 3.18. Interviewees confirmed that adult and family experiences after diagnosis also remained very mixed. As earlier studies had identified, there was a lack of information and post-diagnostic support in some areas. Many adults fell into a gap between mental health and learning disability services, and consequently unmet needs could escalate in severity leading to crises, and “emotional / mental health problems for both the individual with autism and those who support them” (WLGA, n.d. a.; WG, 2016c).

The Autism Bill

- 3.19. Despite the progress made since 2008, concerns about inconsistency in provision across Wales and the sustainability of services have driven calls by individuals and groups, such as the National Autistic Society, for an Autism Bill. In June 2017, a private members’ bill to establish specific autism legislation²⁰ was introduced by Paul Davies AM, and passed by the National Assembly for Wales. In response, the Welsh Government pointed to the refreshed ASD SAP, including the commitment to establish the IAS and the Social Services and Wellbeing Act, and announced plans to introduce statutory guidance on autism under the Social Services and Wellbeing Act to underpin delivery of the ASD SAP. Paul Davies has said that, if the “milestones” changes are made, and if they significantly improve the lives of autistic people in Wales, he will reconsider the need for his Autism Bill. This has created additional pressure to get the IAS established in Wales.

²⁰ If enacted, the Bill could include: a duty on every local area in Wales to have a pathway to diagnosis of autism; duties on local authorities and health boards about the way they organise local services and support for autistic people and their families in Wales; a requirement on key staff working with autistic people to receive autism training; duties around ensuring that local authorities and health boards publish information on the services they provide for autistic people in their areas; and a duty on Welsh Government to regularly review progress.

4. The Theory of Change for the Integrated Autism Service

- 4.1. The ToC for the ASD SAP was developed through a workshop²¹ with the Welsh Government's Adult Social Services Lead and the National ASD Lead and is included in Annexes A and B. The ToC focuses upon both the establishment of the IAS – which is the focus of this paper – and the expected impact of the IAS on children and young people and adults.
- 4.2. Previous initiatives in this area, such as the All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults and the Community Monitoring and Support projects, relied upon a mix of “extrinsic levers”²², most notably additional funding and targets, and “intrinsic levers”²³ such as the development of networks of practice. As outlined in section three, these contributed to important improvements, but also to unjustified inconsistencies in practice across Wales²⁴.
- 4.3. In response, a different approach has been taken to establishing the IAS. The ToC describes how primarily extrinsic levers would encourage and enable each RPB to establish an IAS, most notably:
- additional resources, allocated through the ICF;
 - national standards (WLGA, n.d. a, b) based upon the NICE Guidelines (NICE, 2012); and
 - support and challenge from the WLGA's ASD national team.

It was intended that:

“the national approach will ensure consistency, enabling people with autism to access comparable services across Wales, whilst taking into account differing regional or local circumstances” (ibid.).

²¹ This workshop is described in the “Theory of Change” paper produced as part of the evaluation.

²² These “...tend to ‘direct’ health and social care organisations to do specific things that can create added focus and momentum for delivery. Regulation, targets, national performance management, national contracts and nationally designed financial incentives are examples. (Parliamentary Review 2017, p.54)

²³ These: “rely on supporting key individuals to do the right thing. This includes developing leaders to manage staff better to instil more effective cultures and behaviours within an organisation and providing professionals with information and analysis to allow them to review their performance and that of their peers” (ibid.).

²⁴ While some differences in provision: “reflect different challenges, contexts and priorities”, too many people: “receive markedly worse service simply because of where they live” (Williams, 2014, p. 66).

5. Responses of key stakeholders

5.1. In response to the Minister's announcement on the IAS and allocation of ICF funding, four regions began developing proposals for establishing an IAS. Interviews with those responsible for establishing for the IAS in each region and members of the WLGA's ASD team and the Welsh Government's policy lead, were used to explore how key stakeholders responded to the announcement.

Powys

5.2. Powys made the swiftest progress and, in many ways, is a special case. This reflects a number of factors including, in particular:

- its co-terminus LA/LHB, with a history of collaborative working²⁵, making it easier to establish an integrated service;
- continuity, as the existing ASD County Lead had already been engaged in developing an assessment and diagnosis pathway for children and young people using a similar model to that proposed for adults, and could provide a project management role in developing the new IAS and liaise with the National ASD Lead; and
- crucially, there was consensus around a regional vision, based upon the NICE guidelines, which were seen as achievable and important in ensuring consistency with the national IAS model. This meant that, unlike other areas discussed below, there was no disagreement between the region and Welsh Government on their proposals.

5.3. Consequently, the region was able to move swiftly in establishing its IAS. In July 2016 all service heads met and it was agreed to commit to the IAS as a sustainable all age service for an initial period of five years²⁶. The dedicated

²⁵For example, there were existing multi-agency models operational in the county. Powys already had an established integrated learning disabilities service (IDS) 0-25 years and at a senior management level there have been significant moves in recent years towards integrating services. The Chief Executive of the Powys Teaching Health Board (PTHB), for example, is also now the interim Director of Social Services. The fact that the county has just one health board and one local authority has helped in developing a shared IT system across services

²⁶ All jobs created for the IAS in Powys have been advertised as permanent.

Project Manager worked closely with the National Support Team, whose support was described as “invaluable”, and the model has been developed in line with the national guidance. There is some frustration, nevertheless, that national systems – such as a national database, agreed evaluation and monitoring criteria and tested adult diagnostic tools – were not able to be trialled and in place before the service was launched.

Cwm Taf, Cardiff and Vale and Gwent

- 5.4. In contrast to Powys, initial communication was more fractured in Cwm Taf, Cardiff and Vale and Gwent, contributing to misunderstandings. The shift in focus from an ASD infrastructure, structured within LAs themselves, to RPBs introduced a range of new stakeholders, and left some stakeholders feeling side-lined. The National ASD Lead, who at that point had not yet recruited Regional Autism Development Officers (limiting her capacity), initially struggled to get RPBs to engage, and the Welsh Government and WLGA had to intervene with senior officials in RPBs.
- 5.5. In addition to the difficulties the National Lead experienced in engaging with key stakeholders, there was also a short delay before the national guidance, setting out in detail the Welsh Government’s vision, was issued (following the announcement of ICF funding, outlined in section three). This delay contributed to misunderstandings²⁷. The “Background and Guidance Information” (WLGA, n.d. a) to support and guide the development of the new service was formally issued in June 2016 and made it clear that:

“It is essential that the service is developed as a national approach to ensure there is consistency of practice across Wales. A repeated criticism of autism services is that because of local and regional differences in how services are configured there is a perception of a post-code lottery as services can be very different in often neighbouring areas. To support consistent delivery of a national approach and to share good practice across areas, a time limited implementation team [²⁸] will be established. This team will be managed by the ASD National Lead who will have national oversight of the programme delivery” (ibid., p.7).

²⁷ Guidance was issued by the National lead in May (pers. Comm. Jo Manikiza).

²⁸ Comprising the National ASD Lead and three Regional Autism Development Officers.

- 5.6. The national ASD lead worked hard with the four regions to set out the rationale for the service, but the delay in issuing written guidance, problems with engagement and communication with RPBs contributed to the way in which the initial proposals from the three regions differed in important ways from the national model; for example, some favoured a greater emphasis upon medical specialists and interventions, rather than the focus upon support for day to day life skills/needs, suggested by the national scoping work.
- 5.7. These different visions for the IAS were influenced by RPBs' prior experiences of ICF funding, which (as noted) usually gave flexibility to develop the: "most appropriate model of delivery to best meet the specific needs within their area" ([WG, 2016e](#)), and were rooted in past practice, assessments of existing provision and regional needs and, arguably, institutional inertia.

Given the disagreements, the timetable for submission of the first proposals was extended from the end of May to the end of July 2016 and there was a period of negotiation with the Welsh Government and the WLGA and each region. Whilst supporting the national model approach, the Welsh Government acknowledged that there needed to be some flexibility. As an example, proposals to include dieticians and project managers funded by the IAS (neither of which were in the original model) have been agreed. This period of negotiation contributed to delays in the roll-out of the service in these regions

- 5.8. Although valuing some of the support and guidance²⁹, neither Cardiff and Vale nor Cwm Taf have sought much support from their Regional Autism Development Officer. In Cardiff and Vale, having a dedicated manager means they feel they do not need the help, and in Cwm Taf, there is a feeling that the support offered is not what they need. There is also a view amongst stakeholders in these areas in particular, that having agreed the model they should now be given the freedom to develop it themselves. Equally there are concerns from stakeholders within the Welsh Government and WLGA that,

²⁹ Some of the guidance was useful – e.g. the requirement for a speech and language therapist where "some clinicians might have asked why we needed one?"

without on-going intervention and support from the regional team, there could be divergence from a national model, creating inconsistency and inefficiencies, as opportunities to develop material and approaches “once for Wales” will be lost.

- 5.9. In contrast, in Aneurin Bevan, where a new Service Manager was recruited, there has been strong engagement with the Regional Autism Development Officer. Whilst there have been some disagreements they reported very much valuing the support from the National ASD team.

Responses of other stakeholders

- 5.10. The responses of other services, most notably adult services and mental health services, are seen as critical. There are concerns across all four regions that mental health and learning disabilities services in particular, may not fully understand the purpose of the service – which is intended to complement and strengthen, but not replace, existing services for people with autism. As one interviewee put it: “they [learning disability and mental health services] are thinking they’ll all go there [to the IAS]; people think it’s “*the* autism service”. Given the pressures these services face (outlined in section three) and, in some cases, a lack of confidence and/or expertise in working with people with autism, there are concerns that they may make “inappropriate” referrals to the IAS³⁰, meaning the IAS will be “swamped” as one interviewee put it. The study will explore whether these fears crystallise in the next phase of the evaluation.
- 5.11. At a strategic level, the voluntary organisations interviewed expressed some frustration, saying that they felt excluded from the process. There is a more mixed picture at a regional level; for example, in Powys engagement with the voluntary sector is reported to be going well. The service is working with Mind Powys and values the involvement of Powys Association of Voluntary Organisations (PAVO). The Powys IAS has focused on housing and

³⁰ Instead the model envisages that these services will seek advice and training from the IAS, to help them meet people’s needs themselves.

employment – in line with key priorities³¹ - and they are working with a range of partners in these two priority areas. In contrast, in Cardiff and Vale, Cwm Taf and Gwent, concerns have been voiced by both interviewees from the voluntary sector and the IASs, that the services that some voluntary sector organisations offer, such as post-diagnostic support, have not been linked to the IAS. Equally, other interviewees from the Welsh Government, WLGA and one of the IASs have questioned how effectively some voluntary sector organisations have sought to engage with the IAS.

³¹ The plan is that the project board becomes a strategy group and housing and employment will sit on the group long term.

6. Implementation of the IAS by November 2017

6.1. As outlined in section five, Powys began work on developing its IAS in 2016 and in the remaining areas, progress picked up speed in early 2017.

Nevertheless, the rate of progress has been constrained by:

- structural or organisational barriers to integration, such as difficulties reconciling differing IT and human resource systems, establishing where the service “fits” in LHB and LA structures³², and governance arrangements and the dependencies created by the need for different partners to collaborate, and in some cases, to cede power, change practice, and trust others; and
- difficulties, particularly in rural areas, in recruiting senior staff for the new service, with the recruitment of senior psychologists and therapists emerging as key challenges. This was seen to be a feature of the small size of the available workforce and there was some evidence of services competing for staff.

Powys

6.2. Powys took ten months to recruit their full team and experienced problems recruiting speech and language and occupational therapists and the appropriate level clinical psychologist. The service was launched in July 2017 and in the first quarter supported 20 adults. The number is expected to be much higher in the second quarter.

6.3. People are able to self-refer, or are referred by other services and the model of support that the IAS offers is a short task and finish model that will help someone access employment, find suitable housing or develop their independence. It is seen as important that the way that the IAS is described makes it clear that it is not an on-going service but a targeted intervention that moves forward people who are ‘stuck’. People can come back to the service if

³² For example, as an all age service, it cuts across Children’s and Adults’ services and Mental Health and Learning Disability Services.

a new problem arises but they cannot expect or access on-going care delivered by the IAS.

Cardiff and Vale

- 6.4. Cardiff and Vale experienced fewer difficulties recruiting than the other three regions. Their team includes an 8b psychologist, who previously worked for the Adult Autism Service within the Bristol Autism Spectrum Service (BASS) – one of the models that informed the IAS; a speech and language therapist who previously worked for the Sheffield Autism Service– another model that informed the IAS; a specialist autism practitioner from Kent’s Autism Service; a dietician; an administrator and support workers. However, by September 2017, they had not yet recruited a team leader. As a consequence, although they had a very experienced team, and were keen to develop the service, the working practices of the team had not yet been fully worked out. The service was formally launched in September 2017 (despite not at that stage having a full team). By November 2017, the full team was in place.

Cwm Taf

- 6.5. The recruitment process in Cwm Taf was delayed by disagreements over the service model and hosting for some posts. It was also complicated by differences in LA and LHB systems. By September 2017, Cwm Taf had recruited an occupational therapist and a speech and language therapist, a dietician, a specialist nurse and an administrator but was still in the process of recruiting a psychologist, team leader (expected to be a specialist social worker) and support workers. The team attended training delivered by the National ASD Lead and continued to work with partners to build links and understanding of the service. By January 2018, they had recruited nine of the eleven posts, with the remaining posts expected to be recruited by early February 2018. The team expects to begin accepting referrals in early 2018.

Gwent

- 6.6. The recruitment process in Gwent was also delayed by negotiations over the service model. It was originally envisaged that an 8b psychologist would lead the service. However, problems recruiting a psychologist led to change, and an operational manager with a social services background was recruited. Attempts to recruit a psychologist at band 7 proved difficult, and alternative hours and grades were considered, before a psychologist was recruited in September 2017
- 6.7. Recruiting for other roles was more straightforward, including a specialist practitioner who was already performing a similar role in the LHB, an occupational therapist and support workers. The team has attended training delivered by the National ASD Lead and the Gwent service became operational in September 2017).

7. Conclusions

The case for the National IAS

- 7.1. Given the baseline position (outlined in section three), there was a strong case for action to improve assessment and diagnosis for adults and post-diagnostic support for adults and families. The need for action was unanimously supported by stakeholders interviewed for this study.
- 7.2. There is also a strong case for creating an integrated service, which was also unanimously supported by stakeholders interviewed for this study. Poorly co-ordinated care is associated with poorer outcomes, delays, multiple assessments and transfers, and lower levels of patient satisfaction (Parliamentary Review 2017; Williams, 2014).

The case for a nationally led programme

- 7.3. As outlined in section three, earlier initiatives such as the All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network for Adults led to important improvements, creating islands of good practice, but failed to drive systemic change, leaving a “post code lottery” (WG, 2016c). There were also concerns that the T4CYP programme (which had given regions considerable autonomy) had struggled to create a national neuro-developmental model for children and young people. Given the evidence of “what works” (NICE, 2012) there was a clear case for national action to drive up standards and ensure good practice was adopted across Wales (Parliamentary Review 2017³³; OECD, 2016; Williams, 2014)³⁴. Stakeholders interviewed for this study also supported the vision of a national service offering consistency across Wales.

³³The [Parliamentary Review of Health and Social Care in Wales](#) identified the need for: “stronger national direction and a better balance across the continuum of national direction and local autonomy in generating change.” (ibid. 2017, p.7)

³⁴ For example, as the Williams review identified: “a co-ordinated and nationally-led programme of service change can lead to major improvements. ... Where there is clear evidence that adopting good practice would demonstrably and consistently lead to better outcomes, it is incumbent on service providers to adopt that practice, and on the Welsh Government to ensure that they do so. Where reasons are there why a particular service-provider cannot adopt a specific good practice approach, that needs to be fully justified. That is particularly important in areas where there are wide disparities in performance now; and especially if that persists, the Welsh Government needs to consider compelling the adoption of good practice” (Williams, 2014).

7.4. Nevertheless, the experiences of, for example, the Wales Diagnostic and Counselling Network, and reviews of practice (such as the those undertaken by the OECD (2016) and the Commission on Public Service Governance and Delivery (Williams, 2014) do not advocate micro-management³⁵; for example, as the [Parliamentary Review of Health and Social Care in Wales](#) (Parliamentary Review, 2017, p.59) identifies:

“A national set of standards appeared to our interviewees as essential, but this should not be confused with standardisation of approaches. Stakeholders considered this would stifle local innovation and initiatives. While a small number of ‘Once for Wales’ decisions are important, in general decisions made at the regional and local level according to local population needs, informed by good practice elsewhere, and with agreed outcomes, can aid progress towards a more effective and efficient system more compellingly than mandating nationally. Local implementation can flourish when the expected outcomes are clear; indeed, clarity of intended outcomes is the golden thread that links action at all levels.”

7.5. This point about allowing for local responses was echoed by many interviewees developing the IAS. The challenge therefore, is striking the right balance between ensuring a consistent national model, based upon best practice, without stifling local innovation and flexibility to best meet local needs and circumstances and “ownership”.

The challenge of establishing a new integrated service

7.6. Establishing a new service (like the IAS) is challenging. It requires new systems, approaches and recruitment, and it takes time, skill and money. Whilst funding was available, the capacity of RPBs and those charged with developing IASs in each region was often limited, particularly in the early stages. The delays caused by differing visions for the IAS added to the time pressures, and “people problems”, such as resistance to change and differing visions, caused further complications.

7.7. Moreover, although as outlined above, there is a compelling case for integration of services like health and social care, it is not easily achieved (see e.g. Cameron et al., 2012), compounding the challenges associated with establishing a new service. In this case, the national IAS model had to be

³⁵ For example, the review goes on to add this caveat: “we do not expect the Welsh Government to prescribe in detail how each service is managed” (Williams, 2014).

'fitted' into a 'patchwork' of existing services, if the aspiration to enhance, rather than replace or duplicate existing services was to be realised; and this patchwork of services differs from region to region. The desire for a standardised national model also limited the scope for compromise when difficulties were encountered, and meant one side, usually the region, had to compromise. As a consequence, as interviewees from the Welsh Government, WLGA and IASs all observed, setting the IASs up has been very "hard work" and has taken longer than anticipated. Equally, there is considerable pride at what has now been achieved.

Autism services

7.8. To be effective, the IAS needs to be an integral part of a broader approach to supporting people with autism including, but not limited to, learning disability and mental health services. It is also crucial that this is communicated to, and understood by, professionals, adults with autism and the parents and carers of children with autism (e.g. to ensure referrals are appropriate and IAS do not become "swamped"). As outlined in section one, the service is not intended to work with everyone with autism; for example:

- children will continue to be diagnosed and supported by neuro-developmental services; and
- adults with co-existing moderate to severe mental health or learning disabilities will continue to be diagnosed and supported by mental health or learning disability services.

7.9. The challenge in communicating this to adults with autism and the parents and carers of children with autism, may be considerable. It is too early to tell how integrated the IAS is with other services that support people with autism/their families, and whether, for example, psychiatrists (in mental health services) will join IAS multi-disciplinary team meetings to discuss individual cases. This will also depend upon the IAS's effectiveness at building capacity in these services, ensuring, for example, that they are less reliant upon individuals with an interest and expertise in autism (as many at present are). The test of the IAS will be not only how many adults and families it helps

directly, but also how much capacity it can help build in other services that also support people with autism/their families.

Lessons learned

- 7.10. Successful transformation requires effective leadership, with leaders having the “capacity and skills to plan, drive, and deliver change.” (Parliamentary Review, 2017). The National ASD Lead has played a central role in defining the vision for the IAS and the establishment of the first IAS is an important achievement. However, the reliance upon one person to drive the IAS development has created some problems. The process through which the IAS was developed was seen by many interviewees to lack transparency³⁶. It failed, initially, to bring some people along and some interviewees felt actively excluded from the process. It also placed considerable strain upon one person – as one interviewee put it: “a lot rests upon the shoulders of one person”³⁷ – and, with the benefit of hindsight, the experience suggests that a programme board should have been established, to aid engagement, offer greater authority and reduce the dependence upon the National ASD Lead.
- 7.11. At a regional level, RPBs and local leads have often been constrained by limited capacity, and competing demands upon their time and attention (with the IAS representing only one of many regional priorities). In response, project managers, a role not included in the original IAS model, have played a key role in establishing the service in Powys, Cardiff and Vale and Gwent. There are, nevertheless, concerns that the managers of IAS services in Cwm Taf and Gwent were not in post in time to recruit their own teams. As the IASs get established, leadership from other services (e.g. mental health and learning disabilities) will become increasingly important in ensuring that all the key services collaborate effectively.

³⁶ For example, concerns were raised that other options were not openly considered and that learning from projects like the community monitoring and support projects was not adequately used; that there was insufficient attention paid to workforce planning and to the governance of the national team.

³⁷ Although now supported by Regional Officers, as outlined in section four, the capacity to support IASs has been limited by the reluctance of some IASs to engage and there has been, therefore, more of a focus upon promoting resources.

- 7.12. Success requires a co-productive approach involving staff, service users and carers in the design, implementation and evaluation of the IAS. There are concerns that the “top down” approach, driven by extrinsic levers such as funding, the pressure to be seen to move quickly felt by some, and difficulties consulting with services/stakeholders³⁸ following the initial national consultation which informed the IAS, has stifled this.
- 7.13. In particular, whilst performance management and accountability is vital to: “support continuous improvement through effective organisational action and strong external challenge” (Williams, 2014), there are concerns that the reliance upon extrinsic levers to drive improvement has soured relationships between those who are “policing” the system [i.e. the national ASD team] and those delivering services in some areas. This may undermine learning and improvement – key intrinsic levers (cf. Parliamentary Review, 2017, p.60).
- 7.14. The limited capacity of key stakeholders, and difficulties in engaging some key stakeholders, contributed to, and was exacerbated by, weaknesses in communication - a cornerstone for effective change management. Success required “clarity of purpose” with everyone clear from the very beginning what the service would be and what it would offer (cf. Williams, 2014). However, the decision to announce the IAS before the detail of how it would work and what it would offer, and to fund it through the ICF, caused problems in all four regions. As outlined in sections five and six, in Powys, the problems have been relatively minor and related to the development of common tools and structures. However, in Cardiff and Vale, Cwm Taf and Gwent, much time and energy was expended trying to agree the approach, rather than developing the service. While these problems have now been largely overcome (meaning they delayed the establishment of, but did not weaken, the IAS), there are fears that misunderstandings about the role and remit of the IAS will cause problems, such as inappropriate referrals, once services are operational.

³⁸ The time pressure to establish the IAS meant that the time allocated to consultation may have been truncated.

7.15. Finally, the chosen model is an efficient one, maximising additionality by purposefully neither duplicating nor replicating existing provision; a point emphasised and supported by interviewees from the Welsh Government, WLGA and IAS. It is also felt to be a necessary one, as the IAS alone does not have the capacity to diagnosis and support all people with autism (it is neither expected nor funded to do so). However, it has created a complex model, and given the way it has been presented at times, it is a model that may be misunderstood by stakeholders. Crucially, as noted in section one, the service will not work with everyone with autism³⁹, and as outlined above, it is not *the* autism service, but part of a wider approach to supporting people with autism.⁴⁰ As a consequence, much time has been spent by the National ASD Team and IASs, working out who should be and who should not be supported directly by the IAS. This complexity risks creating confusion and thwarted expectations on the part of adults with autism, families and professionals, who may look to the IAS for support, when another existing service, such as a learning disability or mental health service, is better placed to support them.

Expectations, concerns and risks

7.16. Stakeholders expect important improvements in assessment and diagnosis and post-diagnostic support for adults and families as a result of the establishment of the national IAS. It should, for example, offer a service that is compliant with NICE guidelines, improving quality and offering much greater capacity and consistency than existing services, which are fragmented and often fragile.

7.17. Improving the experience and the timeliness of diagnosis and post -diagnostic support should improve the quality of people's lives. It can help build greater understanding and acceptance of their autism, including adaptive strategies to improve daily life and cope with a lifelong condition, and help provide better

³⁹ The separation of neuro-developmental services for children was a particular cause for concern for some stakeholders in the health service in particular.

⁴⁰ For example as an interviewee put it, "it's part of the local offering; it's not the local offer" for people with autism.

access to, and support from, services like employment and housing⁴¹ and, where applicable, more specialist services such as learning disability and mental health⁴².

7.18. However, this interim report has illustrated some of the key challenges around the IAS, including concerns that:

- if the IAS is not able to build the capacity of other services working with people with autism, most notably learning disability and mental health services, it could create a two - or three - tier system, in which the quality and speed of assessments, diagnosis and post-diagnostic support is better for those seen by the IAS than for those directly accessing mental health or learning disability services;
- demand for the service may outstrip the capacity, particularly if there are misunderstandings about the service's offer⁴³ and/or cuts in other services which increases pressures upon the IAS ("cost-shunting");
- there is a tension between a standardised national model, which may be too inflexible to meet local conditions and needs, and locally informed models that can lead to what began as a national approach becoming increasingly regionalised over time;
- the decision to not fully integrate the IAS with other neuro-developmental services for adults and children risks creating a service driven, rather than person centred, model;
- the long-term sustainability of the model has been driven to date by external rather than intrinsic levers, and that it will need senior buy-in to survive, which is not yet in place in all regions; and

⁴¹ For example, in Powys, work has been done with housing services to get housing officers to better understand issues around autism and encourage them to access funding to adapt housing (e.g. noise reduction processes).

⁴² In Powys the vision is that, for example, people with a co-diagnosis with, say schizophrenia, will have better support if their workers understand autism i.e. the core model is not about a service to everyone, but about a service that focuses on autism and supports others who are working with it, and plugs gaps where no-one is working with people with autism i.e. where people do not have complex needs.

⁴³ Powys's experience is that this has happened but the expectation is that it will diminish as people come to understand the IAS. The recent training provided by the National ASD Lead, which included 60 case studies to help IASs think about who would and would not access the service, illustrates the complexities.

- the focus on establishing the IAS, and the challenges it has posed, is felt by some interviewees to have drawn time and attention away from developing other important aspects of the ASD SAP at both a national and regional level.

7.19. The model also raises questions; for example:

- about the configuration of the team and whether the roles and skills of the team match the needs of the population - this will not be clear until services are fully operational. Given the uncertainties⁴⁴, some interviewees suggested that it might have been prudent to have piloted the model before rolling it out nationally⁴⁵;
- about the types of support offered and the balance between one to one and group work, and the IAS's role in relation to children. Whilst the service is not expected to work directly with children, some have suggested that it could have a role working with older children (young people) aged 14 and over, where children's services may have less expertise than adult services⁴⁶.
- about the balance struck by IAS between diagnosis, support and capacity building, and which is prioritised if the service struggles to meet demand?
- how best to evaluate outcomes? While a quality of life measure developed by the World Health Organisation (WHO) is being developed, some services are not yet confident that it will meet their needs. There have also been delays establishing a common database.

⁴⁴ As outlined in section three, the NICE guidelines, which informed the model, note the uncertainties about the most appropriate team.

⁴⁵ For example, the review of health and social care suggests that: "to translate the vision into concrete action, in the first instance a limited set of new models of care should be developed, trialled, evaluated, and scaled up rapidly. These should be developed and tested against clear standards, tailored to local circumstances and needs, and supported by a national learning programme and robust independent evaluation" (Parliamentary Review, 2017).

⁴⁶ For example, it was noted that at this age, children (young people) often became increasingly independent and less willing to work with their parents.

8. Recommendations

8.1. The role of the evaluation at this stage is, in part, to help inform the roll-out of the IAS development in the other three regions. In many ways the work of these three regions will not face the same problems as those faced by the first four regions as there is now clarity about what the model will look like, and there is a guidance document and available examples to demonstrate its functions. There may be similar difficulties in recruiting a team, however, and similar tensions between developing a national model without stifling local innovation or undermining local ownership and in communicating the IAS's offer to key stakeholders.

R1. For the Welsh Government, WLGA and PHW: considering the case for establish a Programme Board to support the National ASD Lead and their team. This could include, for example, supporting communication and engagement with key stakeholders and providing challenge and approval in relation to key decisions, such as the appropriate balance to strike between national direction and local autonomy.

R2. For the Welsh Government, WLGA and PHW, RPBs and the Cardiff and Vale, Cwm Taf, Gwent and Powys IASs: establish a communication strategy with key stakeholders including adults, families and professionals, to help clarify the roles and responsibilities of the IAS and of other services supporting people with autism.

R3. For the Welsh Government, WLGA and PHW and the West Wales Care Partnership, Western Bay and North Wales RPBs: consider the case for employing a project manager to establish the IAS.

R4. For the West Wales Care Partnership, Western Bay and North Wales RPBs: ensure an early start is made on preparations for establishing an IAS (given the time taken by the first four regions); for example, this could include consulting stakeholders across mental health and learning disability services and planning for recruitment and the challenges this is likely to pose in rural areas.

R5. For the Welsh Government, WLGA and PHW and RPBs, monitor demand for the IAS and pressure upon others services (that may impact upon demand for the IAS), to ensure that the service has sufficient capacity to fulfil all its functions (including e.g. assessment and diagnosis, support for individuals and families and support for other services).

R6. For RPBs, as the IASs get established, ensure that the focus and attention of regional strategy groups includes the full range of services that support people with autism and their families.

R7. For the Welsh Government to consider whether the Integrated Care Fund (ICF) is an appropriate vehicle to fund national models (as it has traditionally given considerable autonomy to regions in how ICF is used, which can lead to variation in practice across Wales)

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Annex A. The ASD SAP's theory of change for adults

Context

Assessment and diagnosis

- 1.1. Timely access to assessment and diagnosis services can help ensure that an individual's needs are understood and appropriate services are put in place to support them to lead fulfilling lives. It can also help adults and their families to better understand their lives and experiences (WG, 2016a).
- 1.2. Many adults in Wales have undiagnosed ASD (Stuart-Hamilton et al., 2009) and in 2010, the All-Wales ASD Diagnostic and Pre/post Counselling Network for Adults was established to improve access to, and the consistency of, diagnostic services. The evaluation of the first ASD SAP identified that important improvements in assessment and diagnosis for adults had been made, but that practice differed across Wales (WG, 2016c). In the absence of strategic leadership, 'islands' of practice and expertise developed, but in some areas services struggled to develop, or collapsed after key people left. As a consequence, in some areas adults struggled to access assessment and diagnosis services.

Post diagnosis support and integration of services

- 1.3. The evaluation of the first ASD SAP also identified that adults' experiences after diagnosis remained very mixed, with a lack of information and post diagnostic support, with many adults falling into a gap between mental health and learning disability services. (WG, 2016c). As a consequence, unmet needs can escalate, leading to crises, and "emotional / mental health problems for both the individual with autism and those who support them" (WLGA, n.d. a, b).
- 1.4. Many people with autism need support from health and social services and evidence from a scoping review indicated that integrated services are effective in meeting the needs of people with autism (WG, 2016a). Integration of health and social services is currently patchy across Wales.

- 1.5. RPBs were established in response to the Social Services and Wellbeing (Wales) Act 2014 and have developed in different ways. Some have built upon existing structures such as the Western Bay Health and Social Care Programme and the Mid and West Wales Health and Social Care Collaborative, whereas others lack these foundations. The number of organisations involved also differs, ranging from Powys, with coterminous LA and LHB footprints, to areas such as Gwent covering five LAs.
- 1.6. RPBs bring together health, social services, the third sector and other partners to take forward the effective delivery of integrated services in Wales⁴⁷. RPBs administer the ICF, which supports delivery of the Social Services and Well-Being Act (2014)⁴⁸ and autism has been identified as one of the key priority areas for integration (WG, 2017; 2016a).

Awareness raising and training for services

- 1.7. There are limits on the extent and type of support an integrated autism service can provide (given for example their capacity) and the needs of adults with autism will only be met if existing services are adapted to enable adults with autism to access them. The understanding of autism and the lack of skills and confidence of many staff within existing services has been identified as a key barrier to services adapting to meet the needs of adults with autism (WG, 2016a; WLGA, 2015)

⁴⁷ The RPB is a new statutory responsibility for LAs and LHBs in 2016. Intended as an advisory body that does not take away the existing responsibilities of the individual statutory bodies, it is expected to take oversight of, and provide direction to, any areas of integrated working across health and social care.

⁴⁸ Established in 2014 as the “Intermediate Care Fund” to: “support initiatives which prevent unnecessary hospital admission, inappropriate admission to residential care, and delayed discharges from hospital” in April 2017 it was rebranded as the Integrated Care Fund (ICF) to better reflect an expanded scope (WG, 2017)

Figure 1. Establishing an integrated autism service

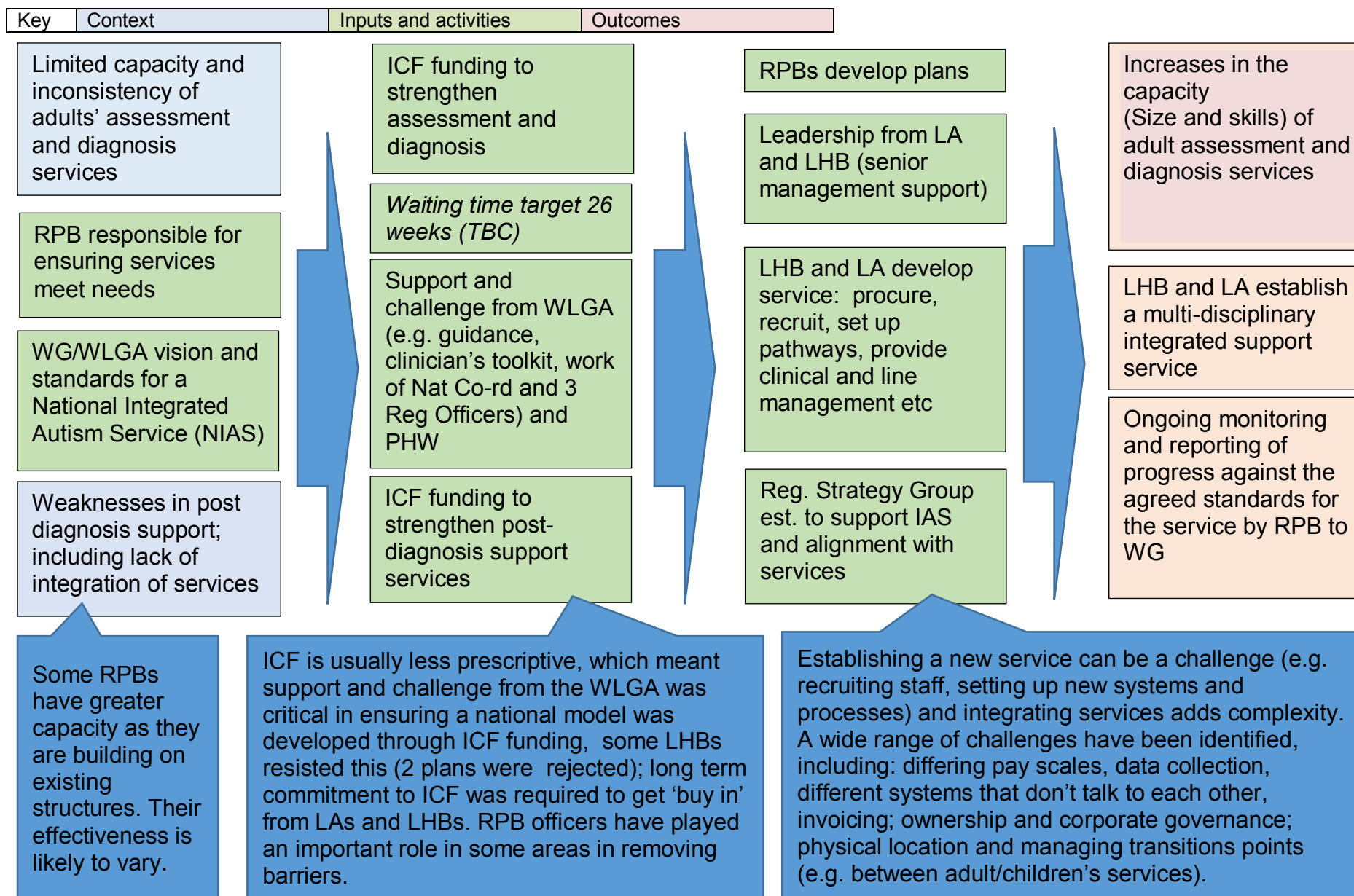
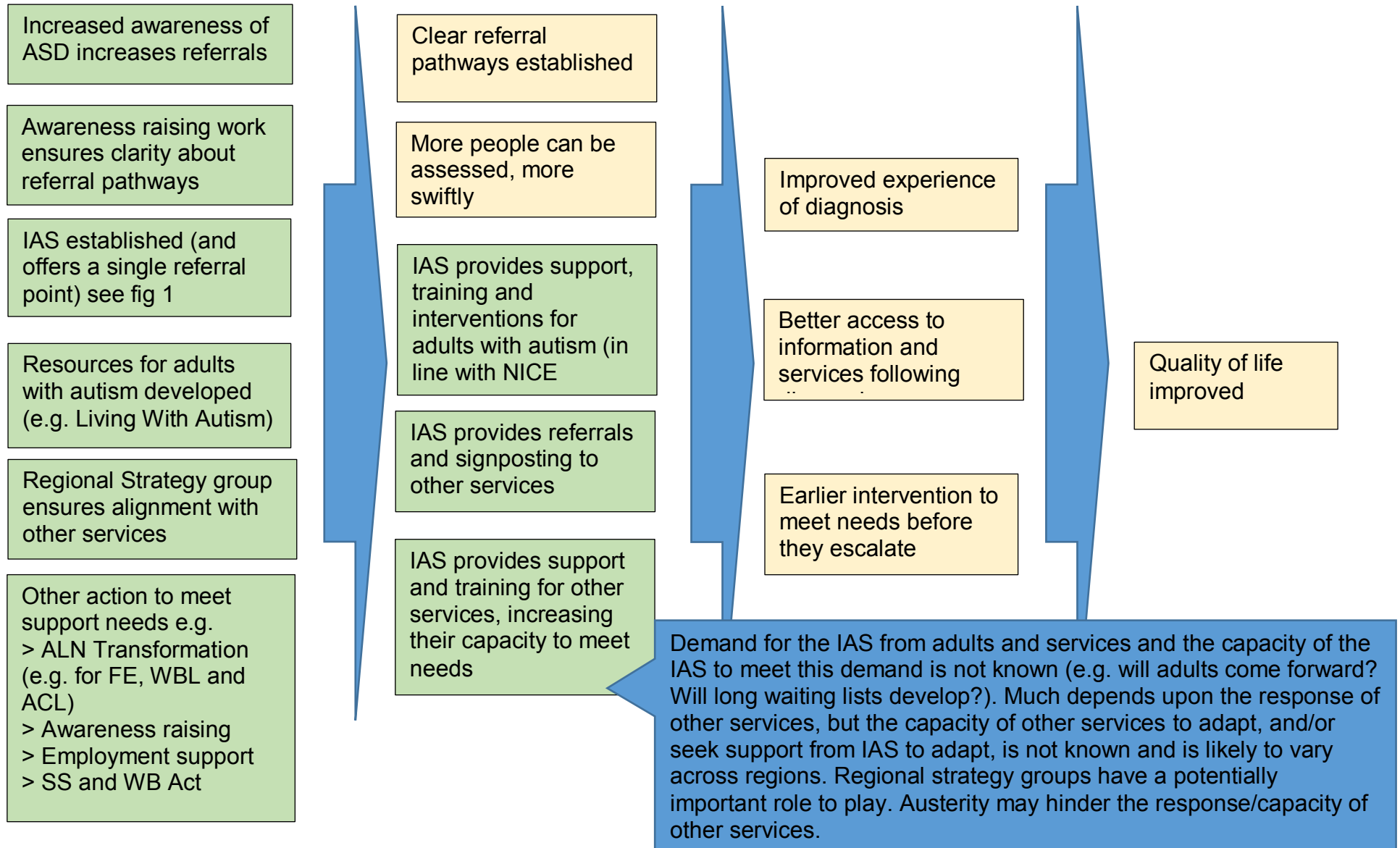


Figure 2. The theory of change – the impact of the IAS and the ASD SAP upon adults



Annex B. The theory of change for children and families

Context

Assessment and diagnosis

- 2.1. Timely access to assessment and diagnostic services can help ensure that an individual's needs are understood and appropriate services are put in place to support them to lead fulfilling lives. The evaluation of the first ASD SAP identified that increasing awareness of ASD had increased recognition and diagnosis of ASD, but also contributed to very long waiting lists in some areas (WG, 2016c). Families have also reported that it can be a "battle" to get a diagnosis and that there is a lack of information about the process.

Support following diagnosis

- 2.2. Following diagnosis, families have reported a lack of post-diagnostic support in many areas, with parents and carers unable to access timely support for emotional or behavioural issues and/or information and support about ASD and life skills; and difficulties accessing local leisure opportunities and respite care. This has contributed to "high levels of stress amongst parents and carers" (WLGA, n.d. a).

Awareness raising and training for services

- 2.3. Like provision for adults, a lack of understanding of autism and limited skills and confidence of many staff within existing services has been identified as a key barrier to services adapting to meet the needs of children with autism and their families (WG, 2016a; WLGA, 2015)

Figure 3. Strengthening children’s assessment and diagnosis and post-diagnostic support

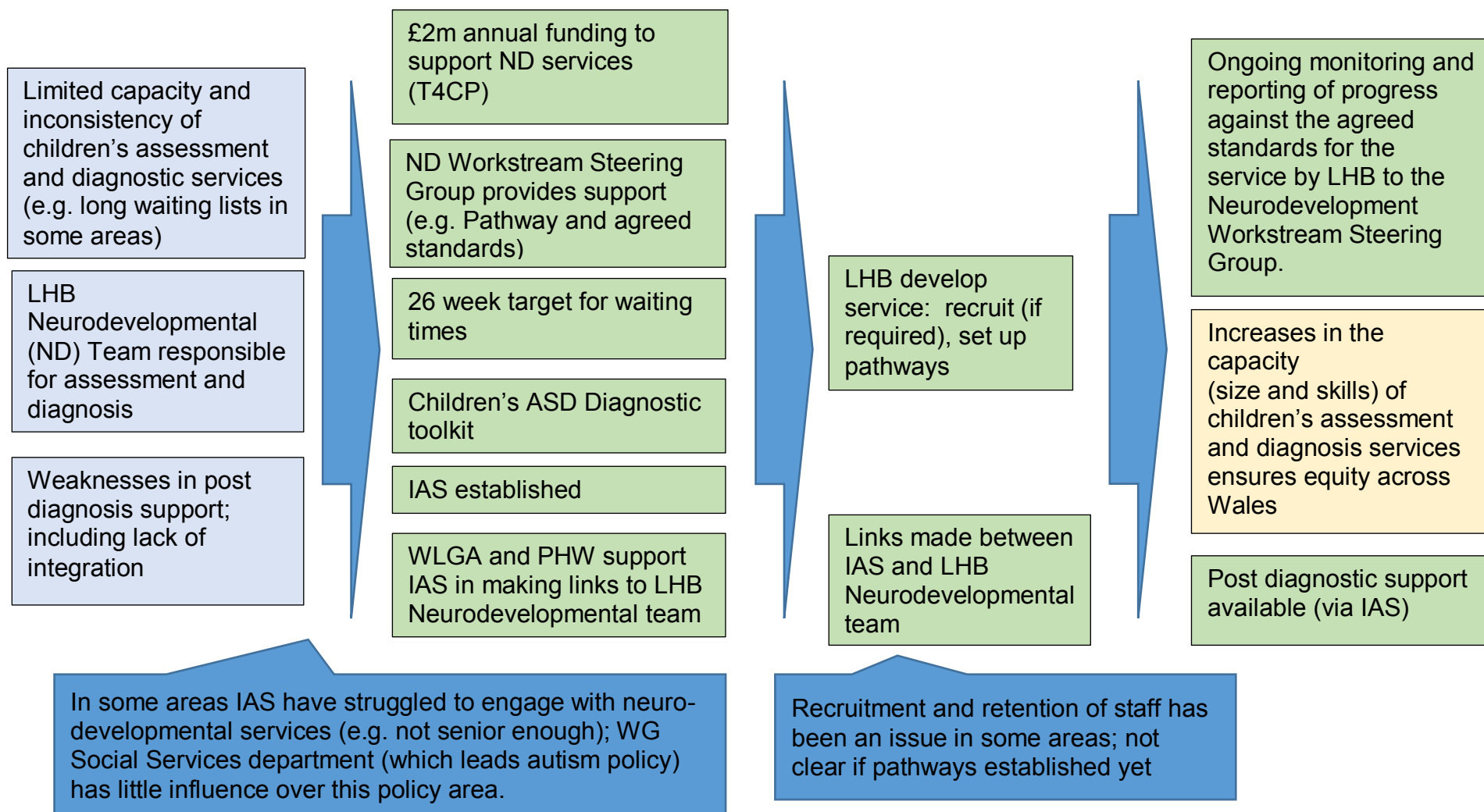
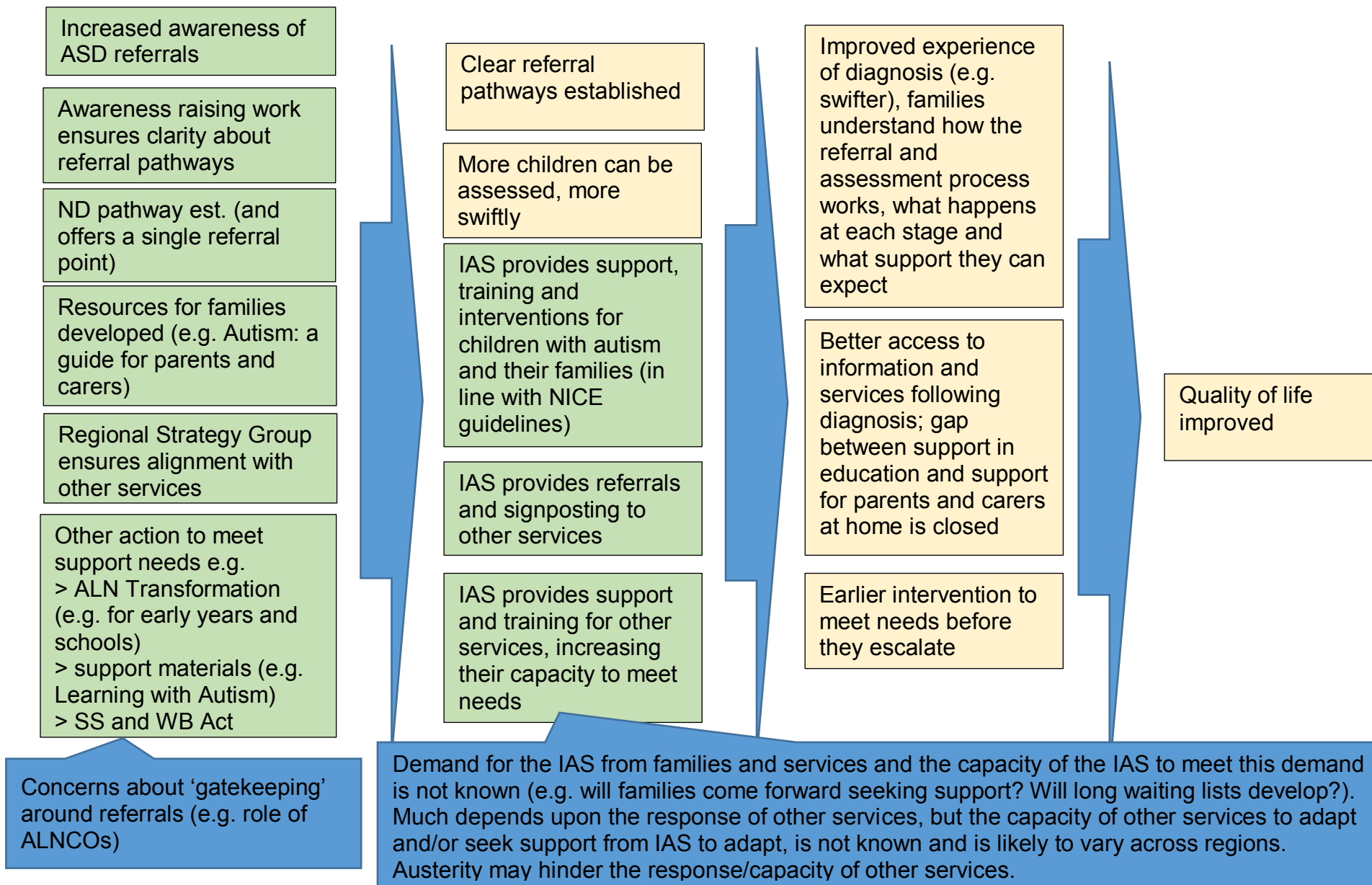


Figure 4. The impact of Together for Children and Young People, IAS and ASD SAP: children



Annex C. List of stakeholders interviewed for the study

Clinical Lead, Cardiff and Vale IAS

Adult Social Services Lead, Welsh Government

ASD Strategy Lead, Cwm Taf IAS

Specialist Practitioner, Gwent IAS

ASD Strategy Lead, Cardiff and Vale IAS

Regional Autism Development Officer, WLGA

ASD Team Manager, Gwent IAS

National ASD Lead, WLGA

Projects Manager, Autism Spectrum Connections Cymru

Regional Autism Development Officer, WLGA

Psychiatrist, Gwent IAS

External Affairs Manager, NAS Cymru

External Affairs Officer, NAS Cymru

Regional Autism Development Officer, WLGA

Occupational Therapist, Cardiff and Vale IAS

Operational Change Manager, Cardiff and Vale IAS

Project Manager for Powys IAS

Annex D. Semi structured interview schedule for IAS Staff

Note for interviewers: this is a semi structured interview. Please use your best judgment about which questions to ask, given for example the interviewee's background and interests and the time available.

Questions

- 1. Can you please tell me what was the baseline position/ the position before the IAS was established in [insert health board name] in relation to assessment and diagnosis for adults and support for children and adults following diagnosis? What arrangements, teams etc were in place before the IAS was established? How long did assessment and diagnosis for adults take? What was known about the experiences of people with ASD and their families following diagnosis?**
- 2. Can you please tell me how the IAS was developed and established in [insert health board name]? How long did it take? Who was involved? What resource has been invested in it? Is this all via the ICF (Intermediate Care Fund)? Are any other external sources of funding available (e.g. Invest to Save) and used? What was the role of the Regional Partnership Board? How well established was the Regional Partnership Board in [insert name of region]. Did you form a regional strategy Group? If so, who was involved? What about staff from the LHB and LA? Were there any other partners? What about the third sector? How was senior management 'buy in' secured? How much of the new service is built on existing provision and how much is new? How does it complement existing provision (including e.g. that funded through the RSG for autism⁴⁹)? What helped you set up the IAS (enablers)? Were there any barriers or problems in setting the IAS up? – if yes, what?**
- 3. What are the governance arrangements for the IAS? How will the service performance be monitored? Do you think the Standard Reporting Template the WLGA have issued captures all the important information? How will the experience of**

⁴⁹ LAs are still provided with £40k each year in the Revenue Support Grant – though not ring fenced it is allocated for autism, so would be interesting to know if this funding is still be used for autism.

stakeholders be assessed? How will progress against the key success factors (see boxed text) be evaluated? Do you think the national standards are useful? Achievable?

Key success factors for the IAS

- The service must provide the same model of support, supported by NICE guidelines, across Wales;
- there should be consistent diagnostic pathways for children and adults, and routes to these should be communicated;
- all partners must be involved in the service – senior management buy-in must be secured;
- there should be a robust infrastructure with clear governance arrangements;
- the service must include / link to existing autism provision where available;
- there will need to be planned roll out and national implementation oversight and support;
- the service must be supported with the resources required to support, enable and train others – to be delivered by the refreshed ASD SAP;
- a sustainability plan must be developed as part of the implementation process to ensure the service is continued after year three;
- there should be continued awareness raising and training for other non-specialist services and community provision.

Adapted from WG, n.d.

4. **Can you please describe the external support and help you/your colleague developing the IAS received?** *What input did you have from the WLGA [Jo Manikiza and her team]? What about Public Health Wales? How supported did you feel by the WLGA and PHW? Did you use the materials the WLGA [Jo Manikiza and her team] developed, such as 'ASD Action Planning: A Guide for Regional Strategy Groups? The National Autism Service: Background and Guidance Information? The model pathways? [Consider showing examples to help jog people's memory]. Did you find them useful? Which ones in particular? What use was made of the NICE guidelines?*

5. **How is the IAS staffed in [insert region name]?⁵⁰ Which professionals are involved?** *How were the skills required by the service identified? How smoothly did the recruitment process go? Were there any posts you struggled to fill? What were the training needs of the staff recruited, how were they identified and addressed? how much of their time is devoted to the IAS? What difference do you think an integrated team will make?*

6. **How integrated is the service?** *Is it well integrated with children's assessment and diagnosis services (e.g. how does the IAS work with children's diagnostic services in terms of two way referrals)? Is it well integrated with other support services? What impact has the IAS had upon these services? What impact have these services had upon the IAS? What impact have cultural differences between services had? Did integration pose particular problems?*

7. **Are all the key partners involved in the service now?** *If not, which partners are not and why not? Is there involvement at senior management level as well as practitioner? How well does the service include / link to existing autism provision where available?*

8. **How will people access the service?** *What are the referral pathways for diagnosis? and how does this compare with the national model for the IAS? How are they publicised? How do professionals hear about and access the service? how much demand for the service - for assessment and diagnosis, post diagnostics support, and/or advice and support for other services are you expecting? Do you expect to be able to meet demand?*

9. **What support, advice, training and interventions will be offered by the IAS?** *How is this decided? How will needs be assessed? Has anyone taken up support, advice, training and interventions yet?*

10. **How will other services seeking information, advice or training access the Integrated Autism Service?** *How will this 'offer' be publicised? What can you offer? What demand do you expect?*

⁵⁰ The idea is that this is standardised and based on the WG/ WLGA/ NICE model – so there should not be much variation in the core team – except where they have not been able to appoint.

11. **Are you confident that the services you refer people on to will have the capacity to meet people's needs?** *For example, do you think staff have the knowledge and understanding of autism and services have the flexibility and resources to adapt – to make 'reasonable adjustments'? Do you think they will seek support from the IAS where appropriate?*

12. **What do you think are the key advantages and disadvantages of establishing an integrated autism service?** *What are the benefits of integration? Do you think the additional costs and complexity associated with integrating health and social care services outweigh the benefits for users? Do you think ICF was an appropriate funding stream to support the IAS? Do you think having separate programmes to improve assessment and diagnosis for children (Together for Children and Young People) and for adults (ICF/the IAS) will cause problems?*

13. **Has any work been done around developing a sustainability plan to ensure the service is continued after 2021?** *What assessments of future need/demand have been undertaken? What workforce planning has been undertaken in response to this? What would be required to sustain the service from 2021 onwards?*

14. **What do you think are the key lessons for other areas looking to set up their IAS?** *With the benefit of hindsight what would you have done differently? What could the Welsh Government, WLGA and PHW do differently? What benefits are you seeing?*

15. **Is there anything else that we've not talked about that you think is important?**

Do you have any questions?

Thank you very much