

Dadansoddi ar gyfer Polisi



Analysis for Policy



Llywodraeth Cymru
Welsh Government

SOCIAL RESEARCH NUMBER:

10/2019

PUBLICATION DATE:

28/02/2019

Evaluation of the National Integrated Autism Service: preliminary findings

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

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Evaluation of the National Integrated Autism Service:
preliminary findings paper

Author(s): Prosser, Nina

Full Research Report: Prosser, N., (2019). *Evaluation of the National Integrated Autism Service: preliminary findings paper*. Cardiff: Welsh Government, GSR report number 10/2019.

Available at: <https://gov.wales/statistics-and-research/evaluation-integrated-autism-service-autistic-spectrum-disorder-strategic-action-plan/?lang=en>

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For further information please contact:

Nina Prosser

Knowledge and Analytical Services

Welsh Government

Cathays Park

Cardiff

CF10 3NQ

Tel: 0300 025 5866

Email: nina.prosser@gov.wales

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1. Introduction / Background

1.1 This independent study sought to evaluate the Welsh Government Refreshed Autism Spectrum Disorder (ASD) Strategic Action Plan (SAP) and accompanying Delivery Plan, with specific focus on the implementation and impact of the Integrated Autism Service (IAS). People & Work were commissioned to undertake the study in April 2017. The objectives of the evaluation were to:

- assess progress in implementing the integrated service model across each Regional Partnership Board (RPB) area;
- ascertain the impact of the IAS across health, social care and education services and the third sector;
- assess compliance with the agreed national service standards for the IAS, and where required, suggest improvements to the standards;
- evaluate progress towards achieving the key success factors [identified by Welsh Government];
- explore the experience of individuals, families and professionals in accessing the IAS and their views on the impact of the services delivered, and;
- understand the operation of the interface of the IAS with other services.

1.2 The evaluation also captured the experiences of individuals, families and professionals in accessing the IAS and their views on the impact of the services delivered, and as a secondary objective, undertook an assessment of how the refreshed ASD SAP is meeting its aims.

2. Preliminary findings

The development of the IAS

This independent evaluation finds that there was almost unanimous support among stakeholders for creating an integrated autism service. The findings demonstrate a strong case for national leadership in establishing the Integrated Autism Service (IAS) to drive up standards and ensure the consistent application of good practice. Although there were challenges implementing the IAS, these have now largely been overcome in areas where the IAS is now well-established. It is difficult to say to what extent these challenges stemmed from having a national (standardised) model. Opting to implement a national and integrated service may have slowed the process of implementation because it reduced the scope for local flexibility and adaptation. This led to disagreements between the National Autism Team and Local Health Boards (LHBs) and Local Authorities (LAs) because its integrated nature required LHBs and LAs to work together. This had the effect of complicating leadership and governance arrangements, and also recruitment and IT activities necessary to support implementation. Managing the expectations of parents, families and professionals with respect to the scope of the IAS, particularly in relation to provision for children and young people and long-term support which is currently out of scope, continues to be key challenge. Individuals, parents and family members who had been anticipating the roll out of the IAS expressed disappointment and frustration that the IAS would not provide a solution for all of the challenges for which they seek and often struggle to secure support, but upon engagement with the IAS increasingly reported positive experiences.

With respect to the initial phase of development of the IAS model, the evaluation reports that having a standardised model caused communication difficulties and disagreements that delayed implementation of the IAS in Cardiff and Vale, Cwm Taf and Gwent. However, the evaluators note that a standardised model was likely the right approach and the difficulties that arose could be attributed to matters of leadership, stakeholder engagement, communication and the timeframe imposed for implementation. Relationships between IASs and the National ASD Team have improved markedly, enabling a more collaborative approach and supporting greater regional ownership and innovation. However, despite a national model and standards, some stakeholders voiced concerns about inconsistencies,

largely driven by i) differences in funding, which originate from different sources and may be distributed in ways that fail to reflect demand, ii) differences in the pace of development, iii) differences in service provision in each area, affecting capacity for collaboration with other services and iv) differences in the structure, professionals, skills and ethos of different teams. These differences can still result in variations to service provision that is influenced by geography as services evolve locally. There are indications that the Community of Practice is encouraging sharing of practice and there are examples of Local Health Boards (LHBs) learning from and adapting the practices of each other, for example Cwm Taf has sought to emulate the models and practices of Cardiff and Vale.

The implementation of the IAS

The evaluation finds that there has been considerable progress establishing the national IAS. After overcoming challenges recruiting appropriately skilled staff, particularly psychologists and most keenly in rural areas, Cardiff and Vale, Cwm Taf, Gwent and Powys have consolidated their teams, implemented assessment and diagnostic and support services and begun working with other services. There is evidence that these teams are working in person-centred ways and developing their service to meet the needs of individuals and groups. These established services do face challenges in managing the demand on capacity to undertake assessment and diagnosis and post-diagnostic support for individuals, family members and carers. There were concerns that demand for assessment and diagnosis may risk drawing resources away from providing post-diagnostic support in future. The service in North Wales is now operational, following some delays, and good foundations have been laid for the service in Western Bay and West Wales.

Interface between the IAS and other support services

The evaluation finds that IAS is working collaboratively with other services including mental health services, learning disability services and the voluntary sector. Positive relationships are being built, and engagement is felt to have improved services and managed demand. However, the process is time-consuming and often requires skill to manage challenging relationships. The efforts of IASs have also been constrained by the pressure on almost all other services, particularly the limited capacity of the voluntary sector, though good examples of partnership working exist. Engagement with other services including education,

employment, leisure and housing have largely focused on delivering advice and training and there are positive indications that this work may develop further in future. Broadly speaking, IASs in Cardiff and Vale, Gwent and Powys are furthest ahead in what the evaluators note is “a work in progress” working with other services. Given the other competing demands on the capacity of IASs with regard to assessment and diagnosis, the important role the IASs potentially have to play in helping people with autism to access and navigate services may be compromised.

Assessment and diagnosis

Investment in the IAS and children’s Neurodevelopmental (ND) services has improved the quality of assessment and diagnosis. The report finds that although long waiting times have developed for both children and adults, there is now a service for them and the level of demand is evidence of previously unmet need. Diagnosis remains important for children, adults, family members and carers, although the impact differs and experiences are not always positive. The evaluation findings suggest that the impact and value of a diagnosis depends to a large degree on the availability of post-diagnostic support, not only from the IAS and children’s ND services, but also from education, health, social care services and the voluntary sector. The evaluation also notes that in some areas, concerns about the confidence of some staff in mental health services to undertake assessment and the robustness of the adult assessment and diagnosis process in these services were raised.

Support services

Established IASs in Cardiff and Vale, Cwm Taf, Gwent, Powys and North Wales have demonstrated marked improvements in i) the provision of support for adults with regard to managing emotional and behavioural needs and ASD specific issues, developing life skills and accessing social and leisure activities and ii) the provision of support for family members and carers. The evaluation identifies however that some individuals accessing the IAS were in crisis and presented with more complex needs than those originally envisaged in the development of the IAS. Reportedly there is a risk that focusing the resources of the IAS in this area may be drawing resources away from more preventative work. Findings suggest that there may be a need to consider how best to resource the IAS to provide

support for individuals and families across the life-course to help them negotiate significant life events and transitions, such as entering employment.

Working with other services

Evidence suggests that by working with other services, supporting and signposting people to them, and in a small number of cases, working jointly with them, the IASs have helped to ensure that people can access the other services they need and are entitled to. Reportedly the impact has been greatest with mental health services, and to date, quite limited with learning disability (LD) services, where there is seen to be less need, and social care, where a small group of adults have struggled to have their longer term needs assessed and provided for. Evidence suggests that, despite some examples, there is still a need to work with other services, such as employment, housing and leisure services. The evaluators note that the IASs have neither the capacity, nor always the expertise to engage with all statutory and voluntary sector services. There may be a risk that attempting to engage with too broad a range of services may dilute the support provided.

Impact of the IAS

The evaluation makes clear that it is still too early to judge the impact of the IAS; those services that are operational are still developing, data collection has been problematic, and many impacts of the collaborative work the IASs undertake with other services, should be invisible to but may be beneficial to service-users. Early evidence about the impact of the IAS is encouraging and shows that it has markedly increased the capacity of adult assessment and diagnosis services. Though demand has outstripped supply, in doing so it has highlighted latent unmet demand for diagnosis and assessment for adults. Evidence shows that it has also improved the quality of assessment and diagnosis by ensuring compliance with NICE guidelines and the provision of a multi-disciplinary assessment.

The findings show that the IAS has provided a vital service for adults without a diagnosed learning disability or severe mental health difficulties, where provision had previously only been partially available in some areas and not at all in some areas. Findings also show that the IAS has provided an important service for family members and carers and helped, to some extent, compensate for the pressures on children's ND services, which have very

limited capacity to provide post-diagnostic support to parents and carers. Though parents and families who participated in the evaluation expressed disappointment and frustration that the IAS does not directly provide services, primarily post-diagnostic support for children and young people.

Evidence also suggests that the IAS has provided a focal point for sharing and consolidating autism expertise, which previously been dispersed across services and a forum for promoting joint working, consultancy, advice and training to raise awareness and educate other services, activity which had been piecemeal and limited before the IAS was established.

The wider experiences and expectations of children and autistic adults and their families and carers

The report recognises the wider context in which the IAS has been implemented and acknowledges that the experiences of autistic adults were often poor, and sometimes extremely fraught, prior to the establishment of the IAS. The evaluators note that many of the adults who contributed to this study were not diagnosed as children, and had not accessed a service until they hit a crisis, and then consequently came into contact with mental health services. Others, who had been diagnosed in childhood, had found that diagnosis had not unlocked the support they wanted, particularly after leaving education. Similarly, the experiences of family members and carers who contributed to this evaluation were also poor, and sometimes extremely distressing. Most reported a constant battle to access services and support for their children and themselves. Some had sacrificed their own aspirations to meet their children's needs and many were concerned that their adult child was not engaged in planning for the future. The evaluators acknowledge that it is difficult to assess how representative these experiences are, and note that there were those who reported positive experiences. It is also possible that selection bias means that those with more polarised experiences (good or bad) were more motivated to share them with the evaluation. However, the difficulties reported were consistent with other research, and at the very least point to severe difficulties that some adults, and some families and carers experience. Given the context, the evaluation finds that the IAS is helping to improve the experiences of individuals, families and carers, who generally cited that they welcomed and

valued the knowledge and expertise of IAS staff and the positive and empowering approach taken towards an autism diagnosis.

The IAS is largely delivering what it was intended to deliver, but the evaluators note that given the challenges many parents, families and carers face, what is offered often initially fell short of the hopes and expectations that had been built in anticipation of the roll out of the IAS. The report finds that there is often a gulf between the expectations of families and carers in particular, but also of some adults, and the services and support offered. Part of the problem is rooted in the severity of the impact of autism on children and adults and their parents and carers, and the effects of living with their sometimes unmet needs. There were examples of people IASs and other services struggled to support, as no agreement could be reached with service users on how best to meet their needs. However, the report notes that challenges are more multifaceted, and though many parents and carers were realistic about what they wanted and apparently reasonable in their requests, system failures were often the cause of frustration. These typically arose as a consequence of severe financial constraints, inflexibility, rising demand and sometimes, limited awareness and understanding of autism, which influenced the degree to which services were able to adapt to accommodate the needs of service users.

Since 2016, in the context of the wider autism agenda, much focus has been directed towards the implementation of the IAS, but the evaluators highlight that a specialist service like the IAS needs to be viewed and developed alongside the transformation of mainstream services and form an integral part of a broader approach to supporting people with autism. The evaluation findings do not provide a clear indication of where responsibility for this wider agenda should lie, but they highlight some challenges to consider with regard to the future strategic oversight and governance of autism services. The report suggests establishment of a collaborative body with responsibilities that cut across service boundaries in health, social care and education. It identifies a number of possible candidates, among them Public Service Boards (PSBs) and Regional Partnership Boards (RPBs), but notes that autism remains a smaller part of the agenda of these bodies, relative to care for older people. Evidence suggests that action to address other priority areas identified in the Refreshed ASD Strategic Action Plan, such as access to education, employment and social care is required.

Long-term sustainability of the IAS

The evaluation finds that the IAS is largely delivering what was intended, and although it took time to become operational, the experiences of people accessing the IAS has generally improved as services have developed. At this stage, the evaluation reports that prospects for the future are encouraging, provided services can cope with demand, retain staff and secure funding for the service beyond 2021.

3. Recommendations

1. The Welsh Government and the National Autism Team should review the communication strategy, to provide clarity about the IAS role and remit.
2. The Welsh Government and the National Autism Team should identify how, in the future, more information about the progress in establishing the IAS, the challenges encountered, and its performance, can be appropriately shared with (i) stakeholders involved in the development and establishment of the IAS (e.g. through the national advisory implementation group and the community of practice) and (ii) autistic adults, children and young people and their families, and the general public, through, for example, ASDInfoWales and local ASD steering groups.
3. The Welsh Government, National Autism Team and RPB ASD Champions¹ should continue to monitor the continuing development and performance of the first five IASs (Cardiff and Vale, Cwm Taf, Gwent, Powys and North Wales) and the establishment of the two remaining services (Western Bay and West Wales).
4. The National Autism Team should ensure that monitoring consistency through compliance with the IASs national standards, is complemented by a benchmarking of outcomes achieved (e.g. differences in resources and context). Improvements in the measurement and reporting of outcomes using Outcome Stars will be crucial to enable this. This should be complemented with more qualitative research with service users.
5. The Welsh Government, National Autism Team and RPBs should review the adequacy of overall funding for the IAS, given the demand across Wales for assessment and diagnosis, support and collaborative work with other services.
6. The Welsh Government and National Autism Team should review the apportionment of funding for each IASs in light of the evidence of demand for each service.

¹ In the draft Code of Practice, the role of Regional ASD Champions includes “Reporting to the regional partnership board on the delivery of autism services” (p. 37)

7. The Welsh Government should review funding for children's assessment and diagnosis services in light of the forthcoming review of waiting times, which finds that current demand exceeds capacity and that the scope to generate further efficiencies (in order to increase capacity) is constrained.
8. Each IAS should periodically review its work with other services to ensure that a strategic approach is taken, and that engagement with different services is prioritised and planned. Opportunities to involve autistic adults and also family members in this review should be taken.
9. The Welsh Government, National Autism Team and RPB ASD Champions should examine how the interface between the IAS and other services develops, including, in particular, its impact upon access to mental health services and social care and upon outcomes for autistic adults and parents and carers.
10. As outlined in the draft autism Code of Practice, "local Health Boards must ensure healthcare professionals have the knowledge and training in autism they need to undertake their roles". As part of this, Local Health Boards (LHBs) should review assessment and diagnosis practice in adult mental health and learning disability services and, where needed, invest in workforce development to address confidence and skill gaps.
11. IASs should continue to monitor the profile of autistic adults accessing the service in order to assess how well suited the IASs' support offer is to the needs of different groups, such as men and women with autism, those with mental health difficulties and those with sensory needs. This should be informed by analysis of the data on outcomes. This analysis should inform Population Assessments, which under the Draft autism Code of Practice, must include autism as a core theme.
12. IASs should assess the capacity of the service to respond to changes in people's circumstances and needs; for example, this could include monitoring the numbers of autistic adults who receive a short-term, outcome focused intervention, and who subsequently re-engage with the IAS at a later point, when their circumstances or needs change.

13. The National Autism Team and IASs should continue to monitor and evaluate the extent to which interventions and support they offer adults and parents and carers meets their needs. Where gaps in support are identified, consideration should be given to whether IASs should develop their offer and/or work with other services to meet the need.

14. The National Autism Team should work with IASs, RPBs, voluntary sector and service users, to consider the scope and ambition of the IAS; for example, should the IAS i) focus its work upon a small number of services such as mental health, learning disability and social care services, or ii) should it seek to take on a more ambitious agenda, to work systematically with other services such as leisure, employment and housing services. This should consider both which organisations are best placed to deliver this, and their capacity to do so.

15. The Welsh Government and National Autism Team should work with other stakeholders to explore where responsibility for regional and local ASD policy development should lie.

16. As the IAS becomes firmly established, the Welsh Government, National Autism Team, RPBs ASD Champions, PSBs and Local ASD Leads should work with autistic adults and their families, and the voluntary sector, to identify the next priorities for action; for example, support in education, for transitions and employment appear to be unmet needs, but it is too early to judge if the actions in the refreshed autism strategy or the draft autism Code of Practice will be sufficient to address this.

17. The Welsh Government should ensure that the impact of the new Code of Practice for autism is evaluated² and that, for example, the impact upon access to social care is considered.

18. As far as possible, future evaluations of other elements of the autism strategy, such as the Employability Programme and ALN Transformation Programme, should be required to identify and report on their impact upon people with autism.

² The Welsh Government has committed to evaluate the impact of the Autism Strategy, which will include an assessment of the impact of the Code of Practice

19. Local Health Boards and Local Authorities hosting IASs should monitor staffing and the impact of decisions about terms, conditions and pay upon services' budgets and their ability to recruit and train staff.

20. IAS should work with the National Autism Team and RPB ASD Champions to ensure the evidence needed to inform decisions about the long-term funding is available.

21. The Welsh Government should make its expectations about long-term funding for the IAS clear; for example, whether the expectation is that if the model is proved cost effective, it will continue to be funded through the ICF, or if, for example LHBs and LAs will be expected to fund the service after March 2021.