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Consultation – summary of response

# The Refreshed Autistic Spectrum Disorder Strategic Action Plan

30 November 2016

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.  
This document is also available in Welsh.

# **Response to the Consultation on the Refreshed Autistic Spectrum Disorder Strategic Action Plan 2016**

## **Introduction**

The draft refreshed Autistic Spectrum Disorder Strategic Action Plan was published for public consultation on the Welsh Government's website [www.wales.gov.uk](http://www.wales.gov.uk) between the 4 March and 26 May 2016. The consultation document was provided in English, Welsh and Easy Read. 76 written responses were received, of these 30 were from individuals with ASD or their parents and carers. 46 responses were received from a broad range of statutory and voluntary organisations and from professional groups. Welsh Government officials also met with a range of parent and stakeholder groups across Wales to raise awareness of the consultation and to discuss their views on the document.

Many of the written responses received from individuals, parents and carers provided us with valuable information about their experiences of accessing services. As this feedback will help us to identify where there may be specific issues which can be addressed, we sought their agreement to pass on their responses to the ASD National Lead for discussion with local service providers.

A list of individuals and organisations which agreed to have their names published is at appendix one. A list of consultation meetings and events attended by officials is at appendix two.

## **Summary of Feedback Received**

Overall the responses received supported the Welsh Government's strategic approach and the stated priorities for action. There was widespread agreement with the development of the National Integrated Autism Service, and improvements being sought to diagnostic services through the Together for Children and Young People Programme, although there were questions about implementation. The responses from individuals, parents and carers tended to raise concerns about local provision. For children's services there was feedback about difficulties experienced in getting a referral for assessment and the lack of support available in schools, including access to specialist staff. There were also calls for more information and guidance for parents pre and post diagnosis including advice on interventions. The responses reflected the need for more support for young people during post 16 transitions and for improved services for adults with autism. In particular many responses asked for more support for individuals to help them achieve and maintain employment.

The majority of responses from organisations highlighted the need to provide autism training across a range of professions including health, education, social care and GP's as well as employers and leisure centre staff. Training should be tailored to meet the specific needs of people with autism and it was recommended that autism training should be included in initial professional training, for example for teachers and nurses and in continuing professional

development. The response from the National Offender Management Service specifically raised the need to improve awareness and support in prisons.

## **Key Findings**

The responses to the consultation were analysed in relation to the key priorities for action set out in consultation document. The information provided was varied but several themes emerged in relation to each priority area.

### **Awareness Raising, Information and Training**

Parents and carers reported difficulties in finding information about autism diagnostic pathways, interventions and how autism services operated in their areas. It was apparent that many were not aware of the wide range of information and advice available on the ASDinfo.wales website which is a key element of the delivery of the ASD SAP. Some also pointed out that advice and information should be available for those without access to the internet.

There was a great deal of support for improving awareness of autism and particularly to provide on-going training for a wide range of professional groups. This would need to be tailored to individual roles and responsibilities which had a standardised approach to ensure good quality training provision. Many also stated that people with autism and their parents should be included in training development and delivery.

### **Assessment, Diagnosis and Support**

In recent years many stakeholders have raised concerns about long waiting times for referral into assessment and diagnostic services for children, and the scarcity of diagnostic services for adults. Although measures are now being put in place to improve services, there are continued concerns about accessing a referral to diagnostic services and the need for a standardised diagnostic pathway.

The Welsh Government as part of the Together for Children and Young People Programme has invested in neurodevelopmental disorder diagnostic services and the improvements are now being seen in service delivery. The refreshed ASD SAP will be updated to reflect that a national diagnostic pathway has been agreed and action is being taken to reduce diagnostic waiting times.

Improvements are also being made to adult diagnostic services. Building on the improvements achieved by the Adult Diagnostic Pre/Post Counselling Network, a task and finish group considered how a sustainable adult diagnostic service could be developed. The Group concluded its work in March 2016 and has provided advice to Ministers, which supports the development of the National Integrated Autism Service. Its recommendations will inform future service development and will be reflected in the refreshed ASD SAP. The groups report will be published.

Of particular note were concerns expressed by parents in some areas about difficulties in getting a referral to assessment services through schools or via primary health services. Many parents are concerned that they can't get a referral for their child for a diagnostic assessment and that without a formal diagnosis they are unable to secure additional support their child needs in school.

### **Addressing Support Needs**

There was widespread support for the development of a National Integrated Autism Service, which involves collaborative working across agencies. Only one response advocated allocating the resources to local areas for smaller scale services. The consultation document did not contain detailed information about the delivery of the National Integrated Autism Service, so many responses asked for more information about the evidence base for the new service, what it will provide, how its links to existing services and how true integration will be achieved.

There were a variety of recommendations on how to improve support services across the age range. Many parents raised concerns about post 16 transitions in education and transitions between children and adult social care services. More support was considered to be needed for adults, including improvements in mental health services, social skills and anxiety training, social care pathways for autism, housing support, therapies and family resilience.

Difficulties were reported in service providers not being flexible when considering the specific needs of individuals with autism. For example when a local authority changed school transport provider a child with autism was not willing to travel with an unfamiliar driver, but there was no flexibility to engage the previous driver who was available. This resulted in the family having to make alternative arrangements which impacted on the parent's ability to work and created significant additional personal expense.

### **Education and Employment**

Many of the responses from individuals and families raised concerns about difficulties in securing support in schools. As stated above, many parents reported that children were being refused a referral to diagnostic services, stating that in one area schools alone could make a referral to diagnostic services. There were also concerns about the lack of specialist support such as the availability of educational psychologists and some questioned whether there was sufficient specialist knowledge about autism. A typical response was that children would be well behaved in school but their behaviour would deteriorate at home. Parents felt that there should be flexibility to consider behaviour at home to inform decisions about whether a child should be referred to assessment services.

Several parents also raised issues around attendance, as some were coming under significant pressure to ensure their child attended school regularly. There was no recognition of the difficulties experienced by the young person with

autism and as a result some parents have de-registered their children from school to provide home schooling. The support provided at home did not meet the child's educational needs.

Considerable concerns were raised about the provision of post 16 education and employment opportunities, with more needing to be done in colleges and universities to support young people with autism. Many responses raised the lack of employment opportunities for people with autism, for all abilities. There was a need for more engagement with agencies such as Job Centre Plus and the provision of tailored support to find and maintain paid work. There needed to be more work with employers to raise awareness and to provide employment opportunities.

### **Delivering Priorities for Action**

Most of the responses supported the intention to publish a delivery plan and most highlighted the need to closely monitor implementation, this included ensuring there was evaluation of the National Integrated Autism Service. There was also widespread support for the inclusion of people with autism on the planned ASD Implementation Advisory Group. Many were concerned to ensure that effective outcome measures were agreed and reported on regularly.

### **Other Comments**

When visiting parent and stakeholder groups it was evident that many of those attending had not had time to read the consultation document, particularly as it was 46 pages long and quite complex. It was therefore important to ensure the refreshed action plan was accessible for all.

A response from the National Offender Management Service, reflected the recent joint work being carried out with Monmouthshire County Council and local prisons which could be expanded. This has included awareness raising amongst staff to better understand the needs of individuals in the criminal justice system that may have autism.

Two written responses sought autism legislation, one from the National Autistic Society and one from an individual. NAS describes the purpose of legislation would be to improve accountability amongst public services to ensure the provision of autism services. This was particularly true of local authorities which receive a funding allocation for autism, which is no longer ring fenced as the ASD Infrastructure Grant was placed into the Revenue Support Grant in 2015. The National Autistic Society also calls for greater collaborative working, particularly around its Too Much Information Campaign to improve understanding and tolerance of people with autism in the community.

### **Equality Impact Assessments**

The responses received were also analysed to identify gaps in services and support which may have a disproportionate impact on individuals from protected groups in relation to the Equality Act 2010 and in promoting the use of the Welsh Language. Several responses highlighted the specific needs of girls with autism, looked after children and the need to explore awareness and provision for individuals from minority ethnic groups. Two responses were received in Welsh and some responses raised the need to ensure services and support were available in Welsh.

## **Actions**

To respond to the feedback received during the consultation we will update the refreshed action plan by:

- Ensuring the refreshed ASD SAP and planned Delivery Plan are easy to access and understand.
- Developing a communications strategy to improve awareness of autism and publicising the resources available on the ASDinfoales website.
- Making it easier to find out about local services, including the National Integrated Autism Service through the ASDinfoales website.
- Taking forward plans to work with the National Offender Management Service to work collaboratively to raise awareness of autism in prisons and the wider criminal justice system.
- Taking a strategic approach to the development and provision of training for a wide range of professional groups, including those who require specialist knowledge.
- Using the feedback we have received to inform awareness raising and training provision.
- Raising the need to adapt service provision to meet the specific needs of individuals with autism.
- Considering what more can be done to improve employment opportunities and support for adults with autism
- Considering the feedback provided on support in schools in our reform of Additional Learning Needs services and to continue to develop and roll out our Learning with Autism programmes for schools.
- Considering the feedback provided on supporting children in school including post 16 transition support in the development of the Additional Learning Needs reform.

- Ensuring we involve people with autism and their families and carers in the ASD Implementation Advisory Group to monitor the implementation of the refreshed ASD Strategic Action Plan and Delivery Plan.

## Appendix A

### List of respondents which agreed to have their names published

Professor Alka Ahuja	The Royal College of Psychiatrists in Wales
Mrs Bennett	Parent
Rodney Berman	British Medical Association
Kerrie Berroyer	Parent
Stewart Blythe	Welsh Local Authorities Association
Sarah Capstick	Cardiff Third Sector Council
	Chief Officer of the Pembrokeshire People First members
Karen Chandler	Cwm Taf ASD Steering Group
Darrell Clarke	Cwm Taf ASD Parents Group
Darrell Clarke	Parent
Joanna Davies	Parent
Helen Dodoo	Mental Health
Dr Jane Fenton-May	Royal General Practitioners Wales
DT Fisher	Individual
Liz Foden-Shroff	Welsh Dietetic Leaders Advisory Group
Tracey Good	NHS Centre for Equality and Human Rights
Dr Dougal Hare/Professor Sue Leekam	Wales Autism Research Centre
Lindsay Haywood	Swansea City Parents Support Group
Nicola Heady	Parent
Ann Hodgson	City of Cardiff Council Autism Support Team
	Centre for Evidence based Early Intervention Bangor University
Dr Judy Hutchings	SNAP Cymru
Denise Inger	Individual
Caryn James	Powys Children and Young People Framework Partnership
Rebecca James	Monmouthshire ASD Stakeholder Group
Teresa James	Abertawe Bro-Morgannwg University Health Board Learning Disability Service
Wendy James/Rebecca Saltmarsh	Rhondda Cynon Taf Asperger's Syndrome Support Group
Christine Jenkins	Parent
Lisa Jenkins	Parent
Non Jenkins	Parent
Robert Jenkins	Individual
Paul and Ann Joyner	Parents
	Consultant Community Paediatrician, Abertawe Bro-Morgannwg University Health Board Learning Disability Service
Dr Tamsin Josty	



San Leonard	Social Firms Wales
Sandra Morgan	Parent
Mark Owen	Career Wales
Anna Parton	Individual/Parent
Stephen Pickett	Individual/Adult
Mary Rendall	Ceredigion Stakeholder and Steering Group
Libby Ryan	Hywel Dda Health Board
Pembrokeshire People First members	Pembrokeshire People First
Jan Roberts	Wrexham Local Authority Education Inclusion Department
Becca Sayers	Wales Arts Therapy Advisory Forum
Sandra Spratt	Individual
Dr Alison Stroud	Head of Wales Office, Royal College of Speech and Language Therapists
South Powys NAS Branch	
Meleri Thomas	National Autistic Society Cymru
C Wendy Thomas	Carmarthenshire ASD Steering Group
C Wendy Thomas	Carmarthenshire Local Authority Education and Children's Services
Patricia Thompson	Parent
Karen Thompson	Adult with ASD
Christine Trevett	Rhondda Cynon Taf Asperger's Syndrome Support Group
Lisa Turnbull	Royal College of Nursing Wales
Catherine Vaughan	Abertawe Bro-Morgannwg UHB, Looked After Children's Team
Mel Whitter	Women and Equalities Officer, Unite Wales Office
Rob Williams	Policy Director National Association of Headteachers
Sarah Payne	Director of National Offender Management Service in Wales

## Appendix 2

### List of Consultation Meetings

21 March	Monmouthshire County Council ASD Stakeholder Group
23 March	ASD Leads National Forum, Newtown
7 April	Powys ASD Information Day for Parents, Carers and Professionals
25 April	Flintshire ASD Stakeholder Steering Group
9 May	Torfaen Parents Group
11 May	Swansea City Council – parent drop session
16 May	Pyle ASD Parents Group
17 May	Newport City Council extra ordinary ASD Stakeholder Group.