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SUPPORTING GUIDANCE

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Background

There is clear evidence that many autistic people particularly those without a co-occurring learning disability or significant mental health issue who are not eligible for tier 2 and 3 services, often fall into gaps between statutory mental health and learning disability services. As a consequence, they are unable to access emotional, behavioural, low level mental health and life skills support.

Many will have often low level support needs which if not addressed could escalate into more serious mental health problems.

The ASD Strategic Action Plan has been refreshed with the assistance of an expert advisory group and the issue of unmet need has been identified as a priority for action. As part of its development in 2015 a scoping exercise to examine existing provision to address the gap in services in Wales was undertaken.

In December 2015, the scoping exercise report was presented to Ministers with options on the possible models to address the issues for consideration. The preferred option was to develop an integrated autism service, which would involve further development of adult diagnostic assessment provision and lifelong support for individuals with ASD and those who support them. Funding for the service will be provided by the Welsh Government's Intermediate Care Fund.

The development of this service is the main delivery objective of the refreshed ASD Strategic Action Plan.

2015 consultation report

In order to support the Welsh Government Interim ASD Delivery Plan and its work streams a number of surveys and focus group events were undertaken in order to ascertain the issues that individuals with ASD, their carers and family members were currently experiencing. In addition to this data from the ASD Community Monitoring and Support Projects was used.

Parents, carers and individuals with ASD frequently tell us that their support needs are not being met, and this exercise aimed to identify the areas within which gaps in provision remain.

Many parents, carers and individuals with ASD spared their time to share their views with us. However, it is worth noting that it is quite clear that individuals are feeling very frustrated by contributing to numerous consultations and surveys and not seeing outcomes from these. We now have substantial information about the needs of individuals with ASD and their carers and must seriously consider whether future consultations are really necessary.

Gaps in provision and issues that are experienced were broadly similar for children and adults, and there is a similar pattern of unmet needs reflected across all activities undertaken.

In relation to ongoing support and provision the most frequently reported areas of unmet need across children and adults were:

- Support for emotional / behavioural issues
- Support for ASD specific issues and life skills
- Access to social and leisure opportunities within own community

In addition to these lack of supportive ASD aware education provision was a frequently reported issue for autistic children and lack of support for employment was a frequently reported as an unmet need for adults.

Parents and carers also report unmet support needs. Again these are consistent across those caring for children and adults, with the most frequently reported being:

- Inability to access advice in a timely manner
- Lack of social activities leading to social isolation
- Lack of training, information and support to manage problems and behaviours

Parents / carers also clearly find ambiguous information, timescales and advice very difficult. Across all areas of need and all ages, there appear to be three themes emerging:

- Staff within many generic and community services lack the skills and knowledge to support individuals with ASD
- Eligibility criteria for tier 2 and 3 services mean that individuals with higher functioning ASD (and their carers) fall into gaps between mental health and learning disability services and so cannot access emotional, behavioural, low level mental health and life skills support.
- Existing generic community support and services need to be adapted in order to be suitable for many individuals with ASD due to their specific needs.

It should be noted that developments to address many of the issues raised within the consultation are already underway, directed by the Refreshed ASD Strategic Action Plan.

Funding

In March 2016, the Minister for Health and Social Services announced a £6 million investment in the development of an IAS for Wales. In April 2017, the Minister for Social Services and Public Health announced additional funding taking the total funding to £13 million. This funding is provided to Regional Partnership Boards via the Intermediate Care Fund (ICF) and will fund the service until March 2021. Please refer to ICF guidance for allocations.

An Integrated Autism Service for Wales

It is clear that autistic individuals are not able to access the support that they require. The Welsh Government have committed this funding to the development of a national service that:

- Is equitable across Wales
- Provides consistent accessible information
- Provides consistent accessible support

[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. 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. Where staff lack experience or confidence in working with autistic individuals they may seek advice and guidance from the Integrated Autism Service or training coordinated by the National Autism Team.]

Ethos of the Service

The aim of the service is to ensure that autistic individuals, their family and carers are able to access the advice, support and interventions needed to enable them to reach their full potential where these are otherwise unavailable.

Social Services and Well-being Act

Working with the underlining principles of the Social Services and Well-being Act the service will focus on improving well-being of autistic individuals whilst taking into account the adaptations to usual practice that these individuals require. The guidelines for the service have been developed following extensive consultation with service users and reviews of best practice and best available evidence.

Key principles for the Integrated Autism Service

The principles should be used to guide service development and operational delivery.

Principle 1

With the exception of diagnostic assessment of adults, the service may only be accessed by those who have received a formal autism diagnosis. However, the IAS may work with adults on their waiting list for Diagnostic Assessment.

Principle 2

The Integrated Autism Service will work directly to support autistic adults (and their family and carers) who are unable to access advice or support from statutory services due to **eligibility exclusion**.

Principle 3

The Integrated Autism Service will provide consultation, advice and support to professionals working with autistic individuals who are accessing statutory/non statutory services.

Principle 4

The Integrated Autism Service provides advice and support to parents and carers of autistic children and young people.

Principle 5

The Integrated Autism Service provides a time limited outcome focused intervention.

Principle 6

The service will provide diagnostic assessment for those aged 18 and over who are not eligible for diagnostic assessment from LD or MH services due to eligibility exclusion. There will be local flexibility between the IAS and ND service in relation to young adults.

Principle 7

The IAS aligns with existing provision for autistic individuals to prevent duplication and to ensure seamless support. The IAS will promote collaborative working with other agencies to the benefit of the autistic individual and parent and carer.

Principle 8

The IAS is an additional resource and will not replace any existing service, nor result in the cutting of existing services.

Principle 9

The IAS will ensure the voice of autistic individuals and their parents and carers, are listened to through pro-active engagement.

Interventions

Adults

For autistic adults who are unable to access advice or support from statutory services due to **eligibility exclusion**, (and **where the provision is not available elsewhere**) the IAS will provide:

- diagnostic assessment
- post diagnostic information and support
- social learning programmes based on developing social interaction
- structured and predictable training programmes based on behavioural principles focussed on improving daily living skills
- support to access leisure activity programmes to reduce social isolation
- emotional awareness and regulation interventions, adjusted to the needs of autistic adults.
- anti-victimisation interventions based on teaching decision-making and problem-solving skills
- evidence based interventions for distressing behaviour based on behavioural principles.
- access to National autism programmes which promote awareness and acceptance in the community, for autistic adults at a local level
- information, advice, training and support to family and carers of autistic adults

(Please refer to NICE Guideline CG142: Autism in adults: diagnosis and management)
[\[http://www.nice.org.uk/guidance/cg142\]](http://www.nice.org.uk/guidance/cg142)

www.ASDinfoWales.co.uk/practitioner-toolkit-support-and-interventions-for-adults-with-asd

Parents and Carers

Whilst not working directly with children and young people, the service will work in partnership with other organisations to support parents and carers.

(Please refer to NICE Guideline CG170: Autism in under 19s: support and management)
[\[http://www.nice.org.uk/guidance/cg170\]](http://www.nice.org.uk/guidance/cg170)

www.ASDinfoWales.co.uk/practitioner-toolkit-support-and-interventions-for-children-with-asd

Young adults

Young adults may need a combination of adult/child approaches which may be facilitated by the IAS. This needs to be discussed and agreed locally in each region with Neurodevelopmental Services.

Data collection

Accurate data will be collected and monitoring of outcomes will enable us to learn more about the needs of autistic individuals, in order to improve and adapt our practice. This will also inform future service planning in conjunction with additional data collected through the area Population Needs Assessments.

We need to ensure that data:

- is consistent and therefore comparable
- is meaningful to autistic people
- is meaningful to health, LA and 3rd sector services
- reflects the areas the IAS aims to address

Reporting arrangements

Areas will be required to report quarterly using the national reporting framework and utilising information from the Outcomes Star.

Reporting consistency

It will be important that there is consistency in reporting across Wales, therefore points of measurement will be as follows:

Diagnostic Assessment - Adults

Referrals should be counted from the date '**an appropriate referral is received**'.

A referral will be deemed 'appropriate' when it includes information about;

- signs and/or symptoms
- developmental/childhood history (if known)
- relevant medical history and investigations
- information from previous assessments
- score from AQ10 (if used)

and indicates **at least one** issue from each of the two following lists:

One or more of the following:

- Persistent difficulties in social interaction
- Persistent difficulties in social communication
- Stereotypic (rigid and repetitive) Behaviours, resistance to change or restricted interests

And

One or more of the following:

- Problems in obtaining or sustaining employment or education
- Difficulties in initiating or sustaining social relationships
- A history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

Should there be insufficient information to make a judgement about appropriateness the referrer should be contacted and referral advice given. This will not count as a referral at this stage.

Should the referral contain sufficient information, but not indicate ASD the referrer should be advised, this will not count as an appropriate referral (*A referral form can be viewed in Appendix 1*).

'First appointment' should include pre diagnostic discussion appointments.

Support

Referrals should be counted from date that an appropriate referral is received. An appropriate referral should include sufficient information for the team to be able to clarify:

- Age
- Whether the individual is eligible for LD / MH services
- The advice or support the individual is requesting
- That the individual has consented to the referral
- The area in which the individual lives

And should be accepted by the team if the individual:

- has a diagnosis of autism (or in the case of children is a parent / carer of a child with a diagnosis of autism)
- does not have a moderate to severe learning disability or mental health difficulty
- is unable to access advice or support from statutory services due to eligibility exclusion, (and where the provision is not available elsewhere)

'First appointment' should be counted as **'the first contact a member of the team makes with the intention of providing assistance to the individual'**

This will include advice, signposting or direct interventions, depending on the type of support that has been requested and the support that has been deemed appropriate by the team. The nature of the intervention should be recorded for reporting and monitoring purposes.

(A referral form can be viewed in Appendix 2)

Standards

Standards for diagnostic assessment

Following on from the work of the All Wales Adult Diagnostic Network agreed standards for diagnostic assessment are as follows:

Standard 1:

There is a single point of access for diagnostic assessment of all autism spectrum disorders

Standard 2:

The decision as to whether to accept a referral or not is made on the quality of information provided (as outlined in NICE guidelines). Where there is adequate information to support concern, access should not be subject to permitted referrers, the use of screening questionnaires or other specifications. The IAS should liaise with other services in relation to referrals for diagnostic assessment, so that the most appropriate service undertakes the assessment.

Standard 3:

When referrals are not accepted the referrer is provided with rationale for this, alongside advice on how to improve the referral or which other service to refer to as appropriate.

Standard 4:

Assessments are planned in a person centred way ensuring sufficient information to create a profile of the individual's need is gathered (as outlined in NICE guidelines), whilst ensuring a prudent, flexible approach to the use of resources.

Standard 5:

There is a timely discussion involving all those involved in the assessment process which leads to a decision about the outcome of the assessment, a profile of the individual's strengths and difficulties and recommendations for future support.

Standard 6:

A professional who has been involved in the assessment process will communicate the outcome of the assessment with the individual. This is followed up in writing, and where consent is given, should be shared with the GP.

Standard 7:

Information and guidance should be provided to the individual, alongside advice on where and how to access future support.

Standards for post diagnostic information provided

Consistent feedback from parents and carers shows inconsistency in the information provided following diagnosis. Therefore, the IAS and or ND (diagnostic team) should provide the following:

Parents and Carers

Provide information on:

- Support and resources
- Key organisations in the local area
- What training is available in the local area

Adults

Offer all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss:

- the implications of the diagnosis
- any concerns they have about the diagnosis
- any future support they may require

If required carry out a one-page profile or outcomes star plan to identify areas to work on.

Provide resources as required communicated through the available on the www.ASDinfoWales.co.uk

Diagnostic Assessment Referral form



www.ASDinfoWales.co.uk

**Integrated Autism Service
Diagnostic Assessment Referral Form**

Referrer Details

Date	
Name	
Address	
Telephone Numbers	
Email address	
Relationship to the referred person	

Details of Individual Referred

Surname	
Forenames	
Gender (circle)	Male Female Other
Date of Birth	
Current Address	
Telephone numbers	
Email address	

Carer Details (if relevant)

Surname	
Forenames	

Address	
Telephone numbers	
Email address	

GP Details

Name	
Surgery Address	
Telephone Number	

Please outline the SIGNS / Symptoms the individual is experiencing:

The examples below have been designed to help support your referral. For referral guidelines see NICE Guideline CG142: Autism in adults: diagnosis and management [Link: <http://www.nice.org.uk/guidance/cg142>] and Royal College of GPs Autism Spectrum Disorder Toolkit <http://www.rcgp.org.uk/clinical-and-research/toolkits/asd-toolkit.aspx> or www.ASDinfoWales.co.uk/recognise-ASD-adult

Social interaction and verbal communication

Examples may include problems with use/understanding of language; lack of interest in social interaction; difficulty with social-communication, social relationships, friendships, awareness of/ response to others' feelings

Please detail the impact of difficulties (including areas of life impacted)

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Please circle if difficulties experienced with:

language (limited, repetitive, echoed (echolalia) or literal)	Interaction with age-peers (avoidant, passive or indifferent)	Approaches to others (one-sided, non-reciprocal)	Making or keeping friendships	Awareness of or response to others' feelings	Comfort seeking or comfort giving	Sharing of interests/ enjoyment with others
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Imagination, ideas and creativity

Examples may include lack of pretend play with toys in childhood, solitary imaginary activities, lack of generating or sharing of creative ideas with others (all ages), ability in older children and adults to foresee consequences of own actions or expectations, intentions of others

Please detail the impact of difficulties (including areas of life impacted)

Please circle if difficulties experienced with:

Generating spontaneous creative, ideas

Sharing imaginative activities with others

Predicting others' expectations, intentions

Imagining consequences of own actions on others

Gestures and non-verbal communication

Examples may include: infrequent use of pointing to show objects, gestures that lack spontaneity, or appropriateness, particularly gestures expressing emotion; facial expression, tone of voice, eye contact, body language, proximity

Please detail the impact of these symptoms (including areas of life impacted)

Please circle if difficulties experienced with:

Pointing to show /share objects

Emotionally expressive gestures

Tone of voice, facial expression or eye-contact

Body language, proximity

Narrow range of interests, routines and repetitive behaviours

Examples can include limited pattern of self-chosen activities, arranging objects in patterns, repetitive motor behaviours (e.g. hand flapping, spinning) repetitive routines/rituals, over-focused interests

Please detail the impact of these symptoms (including areas of life impacted)

:

Please circle if difficulties experienced with:

Limited pattern of self-chosen activities

Arranges objects in patterns (may dislike their disturbance)

Insists on routines being unchanged

Repetitive motor behaviours

Over-focused interests

Sensory Responses

Examples can include heightened sensitivity to or avoidance of particular sensations (sights, sounds, touch, smell, or taste; unusual seeking out of sensory sensations; reduced sensory reaction to pain or temperature

Please detail the impact of these symptoms (including areas of life impacted)

Circle all that apply:

Unusual responses to particular sounds, sights,

Unusual responses to taste, smell, touch

Reduced sensory reaction to pain or temperature

Has the person experienced any of the following?

Please provide details of any problems in obtaining or sustaining education or employment:

Please provide details of any difficulties in initiating or sustaining social relationships:

Please provide details of any previous or current contact with mental health or learning disability services:

Please provide details of any history of neurodevelopmental condition or mental disorder:

Does the individual have family member with a diagnosis of ASD or other neurodevelopmental condition?

Additional Information

Please return to:

Consent

The Integrated Autism Service provides support in conjunction with a range of organisations to help autistic individuals (and adults who suspect they may be autistic and wish to be assessed).

I understand that by consenting to this referral I am agreeing to access support from the service and the organisations that work alongside it.

I understand that the information recorded will be used to help professionals understand what help I need and that it may be shared with other agencies as part of the process.

I understand that where I do not agree to sharing information with other agencies then this may affect the service provided and that I may not receive any service.

I understand the information that is recorded will be stored according to the Integrated Autism Service Information Sharing Protocol and used for the purposes of providing the support requested. I also understand that anonymised data will be shared with external partners for the purpose of monitoring and evaluation.

If you do not consent to this information being shared please do not sign the form. If you wish to share information with particular agencies only or not share information with agencies, please specify below.

I understand the process and I consent to this information being shared

I understand the process and I consent to this information being shared with only the following agencies

--

Individual name	
Individual signature	
Date	

Appendix 2– IAS Support Referral Form



Integrated Autism Service Support Referral Form

Referrer Details

Date	
Name	
Address	
Telephone Numbers	
Email address	
Relationship to the referred person	

Details of Individual Referred

Surname	
Forenames	
Previous Names	
Gender (circle)	Male Female Other
Date of Birth	
Current Address	
Telephone numbers	
Email address	
Language preference	

Carer Details (if relevant)

Surname	
Forenames	

Address	
Telephone numbers	
Email address	

As part of our referral process we will require additional information about the individual / carer in order to ascertain the most appropriate response. This helps us provide a more efficient service.

Please indicate contact method preference (please note, without this we will not be able to process the referral):

Further information can be obtained from:	
Individual	
Parent / Carer	
Referrer	
Preferred method of contact:	
Telephone call	
email	
By post	
If telephone call, please specify best time to call:	
(team to insert options here)	

GP Details

Name	
Surgery Address	
Telephone Number	

School Details (If relevant)

Name of School	
School Address	
School Contact Name	

**School Contact
Details**

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Is the individual currently being supported by any of the services below? (tick all that apply)

CAMHS	<input type="checkbox"/>	LD	<input type="checkbox"/>
Community mental health	<input type="checkbox"/>	Education	<input type="checkbox"/>
Social care	<input type="checkbox"/>	Third sector	<input type="checkbox"/>
Primary mental health	<input type="checkbox"/>	Child health	<input type="checkbox"/>
OT (Outside IAS)	<input type="checkbox"/>	SaLT (Outside IAS)	<input type="checkbox"/>
Portage	<input type="checkbox"/>	ND team	<input type="checkbox"/>
Flying Start	<input type="checkbox"/>	Families First	<input type="checkbox"/>

Other (please specify):

Please Outline Main Reason for referral

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Please specify desired outcomes for the individual being referred

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Please return to:

Consent

The Integrated Autism Service provides support in conjunction with a range of organisations to help autistic individuals (and adults who suspect they may be autistic and wish to be assessed).

I understand that by consenting to this referral I am agreeing to access support from the service and the organisations that work alongside it.

I understand that the information recorded will be used to help professionals understand what help I need and that it may be shared with other agencies as part of the process.

I understand that where I do not agree to sharing information with other agencies then this may affect the service provided and that I may not receive any service.

I understand the information that is recorded will be stored according to the Integrated Autism Service Information Sharing Protocol and used for the purposes of providing the support requested. I also understand that anonymised data will be shared with external partners for the purpose of monitoring and evaluation.

If you do not consent to this information being shared please do not sign the form. If you wish to share information with particular agencies only or not share information with agencies, please specify below.

I understand the process and I consent to this information being shared

I understand the process and I consent to this information being shared with only the following agencies

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If the child or young person is able to understand then they may provide their own consent. Where a child or young person is unable to understand then the responsible parent or guardian may provide consent on their behalf.

Individual name	
Individual signature	
Date	

OR

Parent/guardian name	
Parent/guardian signature	
Date	