Improving diagnostic practice and post-diagnostic support in the Gwent Integrated Autism Service:

The role of the Signposting Questionnaire for Autism-2 and the Repetitive Behaviours Questionnaire-3

A Service Evaluation produced by the Wales Autism Research Centre, School of Psychology, Cardiff University in collaboration with the Gwent Integrated Autism Service, Aneurin Bevan University Health Board, Wales

January 2025

Cardiff University / Prifysgol Caerdydd
Wales Autism Research Centre
Canolfan Ymchwil Awtistiaeth Cymru

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Aneurin Bevan University Health Board

UKRI Medical Research Council

Gwasanaeth Awtistiaeth Integredig • Integrated Autism Service •

Funding

This evaluation project was led by Dr Catherine R.G. Jones, Director of the Wales Autism Research Centre, Cardiff University, and funded by a UKRI Impact Acceleration Award (Medical Research Council) awarded to Dr Catherine R.G. Jones, Dr Claire Bowsher-Murray and Professor Sue Leekam.

Authors

Bowsher-Murray, C., Leekam, S., & Jones, C.R.G. (2025). Improving diagnostic practice and post-diagnostic support in the Gwent Integrated Autism Service: The role of the Signposting Questionnaire for Autism-2 and the Repetitive Behaviours Questionnaire-3. Cardiff University.

Contact

Dr Catherine Jones
Wales Autism Research Centre
School of Psychology
Cardiff University
Park Place
Cardiff
CF10 3AT

Tel: +44 (0)29 2087 0684
Email: jonescr10@cardiff.ac.uk

Acknowledgements

The authors would like to thank the following for their contributions to the project:

Our project partners, the Gwent Integrated Autism Service, Aneurin Bevan University Health Board.

Interviewees who spoke about their experiences of engaging with services at GIAS: Luke Doran, Jonathan Parker, Gaynor Pinnell Rice, SP, DT, Louise Taylor, and two others.

Interviewees who spoke about their professional experiences delivering assessment and/or support at GIAS: Gina Aubrey, Alexis Clayden, HC, Christine Fretwell, Dr Nicola Griffiths, Sian Matthews, Simone Washington, and four others.

Students from Cardiff University School of Psychology who assisted in data preparation and/or analysis: Ellie Holland, Maia Jones, Ellie-Mae Vickridge, Liam J. Williams.

Students from Cardiff University School of Psychology who helped in the development of Figure 1 and in proofreading the report: Emily Cleland, Millie Rees.

Professor Sue Bale OBE and the Research and Development Delivery Team, Aneurin Bevan University Health Board.

Contents

Acronyms

ABUHB	Aneurin Bevan University Health Board
ADI-R	Autism Diagnostic Interview – Revised
ADOS	Autism Diagnostic Observation Schedule
ADHD	Attention Deficit Hyperactivity Disorder
AQ-10	Autism Quotient-10
ASD	Autism Spectrum Disorder
DISCO	Diagnostic Interview for Social and Communication Disorders
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
GIAS	Gwent Integrated Autism Service
IAS	Integrated Autism Service
IS	Insistence on sameness
RBQ-3	Repetitive Behaviours Questionnaire-3
RQ	Relatives' Questionnaire
RRBs	Restricted and Repetitive Behaviours
RSMB	Repetitive Sensory and Motor Behaviours
SQ-A-2	Signposting Questionnaire for Autism-2
WARC	Wales Autism Research Centre

Executive Summary

This project relates to the use of two Cardiff University designed questionnaires in the Gwent Integrated Autism Service, Aneurin Bevan University Health Board, Wales.

We aimed to understand and evaluate how the two questionnaires were currently being used in the service's adult autism diagnostic assessment, and explored whether there was scope to expand their use within the service.

Introduction

Demand for adult autism assessment and support across the NHS in England and Wales is persistently high, consistently outstripping service capacity[1-4]. As a result, long waiting times between referral and assessment are increasingly common[1, 2]. The assessment process itself is complex and time consuming[2]. Assessments can be challenging for a range of clinical and organisational reasons[5] and are often a taxing experience for the person being assessed[6-8]. Both autistic traits and personal circumstances vary considerably between those who access services, meaning that the type and degree of support needed also varies greatly between individuals[9, 10].

The Gwent Integrated Autism Service (GIAS) provides autism diagnostic assessment and support within Aneurin Bevan University Health Board (ABUHB) for adults without learning disabilities and who are not receiving care from secondary mental health services. Autism assessments at GIAS draw upon information from a range of diagnostic tools, including diagnostic interviews, observational assessments, and questionnaires. The latter include two questionnaires developed by the Wales Autism Research Centre, Cardiff University: the Signposting Questionnaire for Autism-2 (SQ-A-2)[11] and the Repetitive Behaviour Questionnaire-3 (RBQ-3)[12]. The questionnaires are used both as self-report and as informant-report i.e. completed by someone who knows the person attending the appointment well. Existing data[11, 12] indicate their potential to provide valid, reliable and succinct profiles of an individual's autism-related characteristics. Optimising the use of these questionnaires within the GIAS, in both self- and informant-report versions, may contribute to increased efficiency in the assessment process. Further, because the questionnaires provide an individualised profile of autism-related characteristics, they may be useful beyond the assessment context. It may be possible to use them to help shape or direct the services offered to individuals, thus helping to meet the need for tailored, personally relevant support.

In this report we present:

(1) an evaluation of how the SQ-A-2 and RBQ-3 are being used in GIAS as part of the autism diagnostic process;

(2) recommendations for the future use of the SQ-A-2 and RBQ-3 in the GIAS service.

Methodology

To realise the full potential of the questionnaires in the service provided by GIAS, it was necessary to understand: (1) the experiences and opinions of the individuals who complete the questionnaires, including both the person attending the appointment and their informant, and the clinicians who use them as part of the assessment process, and (2) the current programme of support, including individuals' and clinicians' perceptions of any unmet need. Therefore, semi-structured interviews were conducted with eight people who have engaged with the GIAS service, and 11 professionals from the GIAS team. Service level data collated by the service for the quarter April to June 2024 was also examined.

Evaluation Findings

As part of the assessment process, the questionnaires had distinct uses and benefits for both individuals and clinicians. For individuals awaiting an autism assessment, completing questionnaires provided the opportunity for self-reflection and insight into their autistic characteristics, which would later be relevant to their assessment appointment. However, these individuals also felt that the questionnaires provided a limited or incomplete picture of their overall profile, because qualifications, context, or nuance could not be conveyed in their responses. The extent to which these individuals valued and benefitted from the use of informant questionnaires depended heavily on the quality of the relationships they had with their family members.

Clinicians made use of the questionnaires to supplement referral information as well as to aid diagnostic decision making. Questionnaires provided additional and/or corroborative information. This was particularly valuable when there was no informant at the assessment appointment, and when additional detail on individuals' restrictive and repetitive behaviours was provided. When considering diagnostic outcome, clinicians took a holistic approach. The role of the questionnaires were complementary, although subsidiary, to other sources of information. Overall, the questionnaires contributed to clinicians' confidence in the diagnostic outcome. Some inefficiencies were identified in the way questionnaire information was currently being collected.

In relation to the possibility of developing the use of questionnaires in the support context, a number of relevant factors emerged from the evidence. Currently, the service offers support with a wide range of needs at the post-diagnostic stage. Clinicians identified that there would be value in increasing services available at the pre-diagnostic stage, as well as by developing further alternative provision to group-based courses. It was recognised that family members' understanding of autism and/or the person being assessed was sometimes limited. Therefore, support that was also accessible to family members would be beneficial. There was a wide range of support needs among those using the service and the needs of individuals could be highly specific and personal, indicating a need for the provision of personalised support. However, the capacity within the service to expand its support services was limited. Individuals, particularly post-diagnosis, sought out material produced by autistic people for autistic people, and reported that the primary benefit of attending groups was connecting with other autistic people. Thus, autistic voices should be central to the content in any newly developed support tool.

Recommendations

Recommendation 1: The service should continue to use SQ-A-2 and the RBQ-3 in the diagnostic process.

Individuals benefited directly (in terms of insight gained) and indirectly (in terms of the robustness of the diagnostic decision) from the use of both questionnaires in the assessment process. Therefore, it is recommended that the service continues to use both questionnaires in the assessment process.

Recommedation 2: Individuals should be given additional information about the purpose and use of the questionnaires.

For individuals, the main challenge associated with completing questionnaires was feeling that the questionnaires presented an incomplete picture of their characteristics. Therefore, it may be helpful to explain the purpose of the questionnaires and their overall role in the process, i.e. that they present a snapshot of some relevant characteristics; there will be opportunity to give more detail in the assessment appointment; decisions are never made on the questionnaires alone.

Some individuals found completing the questionnaires emotionally challenging. It may be helpful to advise individuals to take account of

this when deciding when and where to complete the questionnaires.

Recommendation 3: Individuals should be provided with a free text response box at the end of each questionnaire for additional comments about their responses.

It would be helpful to provide a free text response box at the end of each questionnaire, so that individuals could record additional comments about their responses. This would support individuals' self-reflection and increase their confidence that the information conveyed was accurate and adequate.

Recommendation 4: Questionnaires should include space to record name of the person being assessed. Informant versions should also include space to record the relationship between the person completing the questionnaires and the person being assessed.

It would be helpful to identify the relationship between the person being assessed and the informant on the questionnaire. This is because clinicians often took into account the nature and quality of this relationship when interpreting the information the informant provided.

Recommendation 5: Questionnaires should include additional items on sensory differences.

Currently, the questionnaires provide minimal information about sensory differences. However, sensory differences were reported as common among people being assessed, and they often had sensory-related support needs. It would be helpful to include a small number of additional questionnaire items to capture this information. An extended version of the RBQ-3, containing eight additional items capturing sensory differences, would be appropriate for this purpose.

Recommendation 6: Individuals should be offered the option to complete the questionnaires via an online form.

Many people completed the questionnaires electronically using a Word document that was returned by email. The process could be made more user friendly by using an online form. There would also be associated efficiencies in having automated reminders; standardised response formats; and automated scoring of responses.

Recommendation 7: Questionnaires should be integrated into an online support tool, with bespoke resources provided according to individuals' questionnaire responses.

It would be helpful to develop an online support tool, whereby individuals completed the questionnaires and were provided with a package of support materials (e.g. videos, websites, or other information) that related to the particular items they endorsed. It could be accessed at any time before or after diagnosis; by people for whom group-based support was unsuitable; and by family members who may have a limited understanding of autism and/or the individual. Using questionnaire responses to determine what materials were shown to individuals would maximise the personal relevance of the support offered. The support tool could be widely distributed with minimal use of clinician time.

Introduction

Adults who seek an autism diagnosis display a varied and complex range of autism-related characteristics[2, 5, 13].

In recent years, there has been an exponential rise in referrals for assessment and for support following diagnosis, with resources struggling to keep pace with demand[1-4, 13]. Standardised questionnaires assessing autistic traits may be of particular use to adult autism services as they can offer an efficient means of understanding the particular profile of characteristics in individuals seeking assessment or support[12]. In the Gwent Integrated Autism Service (GIAS), an adult autism diagnostic service in Wales, UK, the Signposting Questionnaire for Autism (SQ-A-2) and the Repetitive Behaviours Questionnaire (RBQ-3) are currently used as part of the assessment process. Developed at the Wales Autism Research Centre, Cardiff University, previous research has established the validity and reliability of both questionnaires[11,12]. The current project seeks to understand the relevance and utility of the questionnaires from the perspectives of the individuals who complete questionnaires and the professionals who use them as part of the assessment process. This understanding will be used to inform recommendations for future use of the questionnaires, including proposals for how their use might be expanded to complement existing support services in GIAS.

To contextualise the understanding of the current and potential roles of the SQ-A-2 and RBQ-3, there follows a review of the current guidelines and wider literature relating to adult autism assessment and support. The development, format and content of the SQ-A-2 and RBQ-3 are outlined, followed by the history and composition of the GIAS. Finally, the objectives of the current project are described.

Adult Autism Assessment

Autism is a lifelong condition that impacts how people perceive the world around them and interact with others[14]. Autism spectrum disorder (ASD) may be diagnosed if a person experiences persistent difficulties in social communication, interaction, and/or developing and maintaining relationships, and also engages in restrictive, repetitive patterns of behaviour[15]. The latter may include repetitive motor movements, a strong preference for routines or sameness, intense interests, or significant sensory differences (e.g. being especially sensitive to specific sounds or textures, or being less sensitive than others to pain or temperature)[15, 16]. As such, there are a variety of characteristics and behaviours associated with being autistic. The range and severity of challenges autistic people experience vary considerably between individuals[14]. In addition, the impact of autism-related differences and difficulties can vary over time or in response to particular circumstances[16].

Note on terminology:

1. We refer to 'autistic people', to reflect evidence that many autistic people prefer 'identity first' language[17]. However, we have kept the original language used by interviewees when directly quoting from interviews.
2. Learning disability is the preferred label in the UK for people who experience global difficulties in learning new things, which impacts their everyday functioning. The term intellectual disability is used in other countries[18].

Guidelines for assessment and their implementation

Within the UK, guidelines for adult autism services were first published by the National Institute of Clinical and Health Excellence (NICE) in 2012[16]. To diagnose autism, the guidelines recommended a "comprehensive assessment" that draws on the expertise of a multidisciplinary team[16]. The assessment should cover the diagnostic features of autism; developmental history; other neurodevelopmental and mental health conditions; and day-to-day functioning. This information may be obtained via clinical interview or via a formal assessment tool. The recommended tools include structured diagnostic interviews and observational assessments. In a diagnostic interview, clinicians ask individuals directly about their behaviours and characteristics. In an observational assessment, individuals carry out a range of tasks that allow clinicians to observe and assess the presence of autistic traits. Differential diagnoses and co-occurring conditions should also be considered as part of the assessment. Where possible, family members or someone who knows the person well should be asked to provide additional evidence about the individual as part of the assessment process.

Within Wales, autism services adhere to a statutory Code of Practice on the Delivery of Autism Services[19] which was published in 2021. This Code of Practice stipulates autism diagnostic services must take account of the NICE best practice guidelines on autism diagnosis.

A recent survey of autistic adults and clinical teams in the UK found that around half of assessments were carried out by psychologists, 20% by psychiatrists and a smaller proportion by other health professionals such as nurses and speech and language therapists[13]. While it was generally standard practice to consult a friend or family as part of the diagnostic process, suitable informants were available in around only half of cases[20]. In addition, a majority included a standardised observation tool, the Autism Diagnostic Observation Schedule (ADOS)[20-22], and around half involved a standardised interview[20]. Between a third and a half of assessments included questionnaire measures of autistic traits[20, 22]. Estimates for the amount of clinician time required to carry out and report upon a single NICE-compliant assessment varied between nine and fifteen hours[2, 20]. In Wales, 64% of adults assessed in 2022-23 received a diagnosis of autism[23]. In England, rates of diagnosis in adults were reported in 2020 to vary between less than 50% to more than 80%[6].

The number of people receiving an autism diagnosis has risen substantially in recent years. In Wales there was an increase of 220% between 2001 and 2016[24]. The equivalent figure for England between 1998 and 2018 was 787%[25]. In both countries, the largest increases were seen in adults, and in women in particular. This has been attributed, in large part, to an increase in the number of people seeking assessment. Despite substantial efforts to increase capacity, services across England and Wales have experienced considerable difficulty in meeting this increasing demand. Long waiting times remain common[1-4, 13], with adults assessed in Wales in 2022-23 waiting an average of two years between referral and diagnosis[23].

Experiences of the assessment process

The experiences of individuals being assessed

People diagnosed with autism in adulthood frequently reported having experienced prolonged feelings of difference or disconnection from others[26-31], and may have experienced a 'hidden self' that differs from the persona they present to the world[31, 32]. Autistic traits may have been missed at an earlier stage due to their relatively subtle or atypical outward presentation, or misattributed to other conditions such as personality or mood disorders[20, 29, 30, 34, 35]. Indeed, previous contact with mental health services was common[20, 33]. For some, a referral for an autism assessment resulted from contact with health professionals. For others, it was prompted by a sudden change in circumstances, such as a bereavement or job loss, which challenged their ability to cope[2, 27, 36]. Others sought assessment after comparing their own characteristics to those of a recently

diagnosed family member or friend; as a result of increased awareness via the media; or on the suggestion of those close to them[29, 30, 35, 36]. Many were seeking to explain or validate their understanding of their own life experiences, or to help family members or employers to understand them better[6, 27].

Undergoing assessment was generally viewed as either a positive or neutral experience[6, 20]. Nevertheless, individuals have described the assessment process as challenging in a number of respects. Assessments were often experienced as heavily focussed on deficits, and recounting private matters and difficult childhood experiences could be particularly stressful[6-8]. Some aspects of observational assessments, such the requirement to tell a story or demonstrate a task, have been criticised as patronising or performative[6, 20, 27.] Some questionnaire based measures were described as difficult to understand[27] or unable to accommodate nuance, such as where behaviour was affected by compensatory or 'masking' behaviour[7, 27, 29]. Mixed views have been expressed on the role of informants. Many individuals who received an autism assessment in adulthood saw informants' contributions as useful, in that they could provide information about early development and relatively objective reports of individuals' current functioning. In such cases, it was felt that the inclusion of informants provided an enhanced understanding of the person being assessed[20, 29]. Others reported that informants lacked understanding either of the questions or of the experiences of the individual[29], while some perceived their involvement as infantilising[6].

Clinicians' experiences of the assessment process

Clinicians who carried out adult autism assessments reported being conscious that autistic traits vary considerably in their expression and intensity[5]. Adults exploring an autism diagnosis in adulthood were particularly likely to have adopted behaviours that mask or compensate for traits relevant to diagnosis. Consequently, it was thought that formal diagnostic tools, particularly those based on observation of the individual, might underestimate the presence of autistic traits. Conversely, such tools may overestimate the presence of autistic traits where characteristics are better explained by different or co-occurring conditions[5]. Therefore, although diagnostic tools were viewed as a useful part of the process, assessment required a broader appraisal that made sense of the individual's experiences. Practitioners' clinical experience and judgement was seen as central to this process[5].

Clinicians also reported being mindful of individuals' attitudes to diagnosis. They acknowledged the significance to individuals and their family members of receiving – or not receiving – a diagnosis[21]. Tensions could arise when an individual was particularly invested in getting a diagnosis, but practitioners concluded that characteristics were better explained by another condition, or did not reach the clinical threshold for diagnosis[5, 9]. In 'borderline' cases, some practitioners reported adopting a 'needs led' approach. For example, a diagnosis would not be 'forced' on an individual who did not identify with it, but would be given where diagnosis could enable access to services or financial support for which there was a genuine need[5, 21]. In contrast, others adopted a 'criteria led' approach, whereby such broader considerations were not taken into account. For those advocating a 'criteria led' approach, maintaining objectivity was seen as particularly important for being able to justify diagnostic decisions[5].

Long waiting lists and constraints on resources were challenging for clinicians[5, 22]. Complex and lengthy assessments as well as team discussion were seen as clinically necessary[36], but the time available to complete them was limited. Pressure on resources also meant it was not possible to carry out additional assessments, such as tests of cognitive function, that were not essential for diagnosis, even when it would be clinically useful[5].

Impact of Diagnosis

The impact of an autism diagnosis on an individual could often be substantial [28, 36-39]. While a minority of newly diagnosed adults rejected or failed to identify with the diagnosis[28, 36, 37], most received the diagnosis with feelings of relief and validation[6, 7, 28, 29, 36, 37, 40]. People often reported reevaluating their earlier life experiences and current circumstances in light of the diagnosis[27, 32, 35, 39]. This could lead to a new and enhanced understanding of the self[28, 31, 40, 41]. Reframing difficult experiences as related to autistic traits rather than shortcomings or deficiencies could elicit enhanced self-acceptance and self-compassion[7, 31, 32, 39-41]. However, the positive effects of diagnosis could be tempered with regret or grief that diagnosis and support had not come earlier in life[6, 7, 27-29, 35, 40]. Diagnosis was often perceived as marking the beginning rather than the end of a process, as individuals entered a period of uncertainty and adjustment[27, 29, 40]. For some, the realisation that the challenges they were facing were likely to be lifelong could be dispiriting[7, 29, 40]. Equally, an autism diagnosis might lead to a new sense of identity and belonging, along with a desire to forge connections with other autistic people[27, 31, 39, 42, 43]. The diagnosis could have a positive effect on relationships, often leading to increased understanding and accommodations from family members and in work or education[29, 40-42]. However, the reactions of others could also be problematic. Individuals reported that people around them sometimes dismissed or minimised the significance of the diagnosis[28], or overestimated its effects on their capabilities[40].

Many newly diagnosed autistic people reported a need for support in processing their diagnosis and its implications[28, 36-39]. Receiving a diagnosis could also act as a catalyst for seeking support with longstanding challenges, including those relating to social relationships, education or employment, and sensory needs[27, 28, 37, 39, 44].

Support

Guidelines for the provision of support and their implementation

The UK NICE guidelines calls for individuals who receive a diagnosis to be offered a follow-up appointment to discuss the implications of the diagnosis and their future support needs[16]. Intervention should consist of psychosocial support (i.e. support designed to increase people's understanding of autism and their own autistic characteristics), as well as self-management strategies[6]. The type and format of support offered should be tailored to the circumstances and needs of the individual. It should take account of the person's autism-related characteristics, such as sensory sensitivities; preference for predictability and structure; or difficulties with group-based interaction.

Within Wales, the Code of Practice on the Delivery of Autism Services[19] reflects NICE guidelines and specifies that autistic people must have access to post-diagnostic support, with an appointment offered within six weeks of diagnosis. The Code advocates a person-centred approach and states that a documented profile of the individual's strengths, difficulties and needs should be made available. Further, interventions that are offered should consider need and not be solely driven by diagnosis. A variety of formats are recommended to provide information, including written information, one-to-one sessions and workshops. Importantly, the Code recognises that support needs are not confined to people that receive a diagnosis. Services should consider if support, through provision of information or signposting to other services, could be useful to family or carers. Also, people awaiting a diagnostic assessment must be offered relevant types of support (e.g. information on the diagnostic process and autism), and signposting to relevant support and information should be provided to those who do not receive a diagnosis.

In 2022, the Welsh Government completed a review of the demand, capacity and design of neurodevelopmental services[2], which endorsed an evidence-informed approach to improving

autism services. The report found that the support offered to adults who received an autism diagnosis varied across services, and that services found it particularly difficult to find the capacity to offer support to family members and carers. The often unmet support needs of those awaiting diagnostic assessment were also recognised within the report, with a needs-led approach to support being favoured over a diagnosis-led approach. The review proposed that a key goal for reform was to improve the efficiency with which support was offered to autistic people, those awaiting assessment, and family members. An additional goal for reform was to ensure equity of access to support, so that characteristics such as age, gender, ethnicity or language preference did not affect access to support. A recommendation was made that a national support offer be developed, which would include clarity on what support could be accessed without a formal diagnosis.

Experiences of support

In a recent systematic review of post-diagnostic support for autistic adults in the UK, 83 services for autistic adults without a learning disability were identified[45]. Of these, 93% provided post-diagnostic support. The type of post-diagnostic support offered varied, encompassing initiatives such as signposting, low-level support provision, psychoeducation, and peer-support[45]. However, the experience of post-diagnostic support has been described as unsatisfactory by some autistic adults[10, 33,] with a lack of post-diagnostic support also reported[33, 46.]

The most common type of post-diagnostic support in the UK are follow-up appointments that provide feedback, information and/or signposting to other services[45]. However, autistic adults have reported dissatisfaction with this type of support[45], including finding the information negative and not personal to their specific experiences and needs[6, 10.] Further, following up with the signposted services was not within reach of some autistic adults, which they related to autistic differences and difficulties[6]. Low-level support offers more than basic information and signposting by providing specific resources in the context of support and advocacy from others. This can be either one-to-one or within a larger provision such as an autism 'hub'[45]. For example, autistic people may be able to access advocacy services, training sessions, or employment support. Autistic adults have described that a key benefit of low-level support initiatives is that they typically include the opportunity to interact with other autistic people[47, 48]. This was thought to benefit confidence and communication skills, as well as foster a sense of belonging and create new friendships[47]. Psychoeducation offers a standardised way of providing education about autism, although this standardisation is typically service-specific and not manualised[38]. Autistic adults described psychoeducation as leading to improved self-acceptance and self-esteem[6], and the development of adaptive strategies[6, 49, 50]. As with low-level support, the presence of autistic voices were considered important and ranged from sharing experiences with other autistic attendees[6], through to the programme being autistic-led[49, 51]. Reflecting this, autistic people are positive about the potential for peer support to enhance post-diagnostic support, considering it to play an important role in developing self-acceptance[10].

The SQ-A and RBQ-3 Questionnaires

Signposting Questionnaire for Autism-2 (SQ-A-2)

The SQ-A-2 was originally developed as an informant-report questionnaire for measuring autism signs in children, known as the SQ-A [52]. The 14 items used in the SQ-A were drawn from the Diagnostic Interview for Social and Communication Disorders (DISCO)[53], a clinical interview for caregivers and adults that informs autism diagnoses in children and adults. The 14 items were selected as they were the 14 most discriminating items from the DISCO DSM-5 algorithm set[54, 55,] and therefore considered to have utility in identifying people likely to be autistic. The 14 items were transformed to support a questionnaire format, with a 4-point

rating scale assessing agreement with the 14 statements. Across samples in both Wales and Latvia, the SQ-A showed good construct validity, including the discrimination of autistic children from non-autistic children and from children with a range of additional learning needs[52].

Subsequently, the SQ-A was developed into the SQ-A-2, in consultation with autistic people[11]. This second iteration produced a revised, lifespan version with 18 items that was available in self- and informant-report formats. Four autistic consultants gave detailed feedback on the wording of the items, with a focus on their validity and acceptability. This was complemented by input from six expert autism clinicians, who considered how well any proposed changes aligned with the original DISCO items. As a result of this consultation process, two versions of the SQ-A-2 were produced, one with the original wording from the SQ-A and one with items adapted to increase their perceived validity and acceptability to autistic people. Using the self-report format, subsequent research showed that the adapted version was a more discriminating measure of autism, producing a greater difference in scores between autistic and non-autistic adult respondents[11]. The adapted version was also preferred by autistic adults. The 18-item SQ-2-A also showed excellent convergent validity, correlating significantly with the AQ-10[56], which is another brief measure of autistic traits. It also showed excellent internal consistency, indicating the items were measuring the same underlying construct[11]. However, further research is needed to fully evaluate the SQ-A-2 across different types of respondent (self and informant) and for both autistic adults and children.

The 18 items of the SQ-A-2 are statements about autistic traits and the responder chooses one of four response options to indicate agreement ('Definitely Agree', 'Slightly Agree', 'Slightly Disagree', 'Definitely Disagree'). Responses to each item can be allocated a score of 0 or 1, with a score of 1 indicating the presence of an autistic trait. Scores can be added to generate a total score of between 0 and 18 (with a higher score indicating more autistic traits).

Repetitive Behaviours Questionnaire-3 (RBQ-3)

The RBQ-3 focuses on the restricted and repetitive behaviours (RRB) subdomain of the autism diagnosis[15]. This is a complex domain that encapsulates a broad spectrum of behaviours including motor stereotypies, the need for routine, special interests, and sensory sensitivities. The RBQ-3 is a 20-item measure that incorporates two subscales corresponding to two distinct sub-domains of RRBs that have been consistently found across previous research[57-60]. Repetitive sensory and motor behaviours (RSMB) refers to rocking, repetitive hand/finger movements, spinning and sensory reactivity, whilst insistence on sameness (IS) refers to behaviours that include the need for activities, routines or objects to remain the same. Like the SQ-A-2, the RBQ-3 has its roots in the DISCO[53] and has had various iterations before the RBQ-3 was published as a lifetime version in self- and informant-report versions[12].

The RBQ-3 is unique among measures of RRBs in that it has been validated for both self- and informant-report[12]. This research included routinely collected data from the GIAS, where people attending the clinic and a person who knew them well completed the self- and informant-report versions, respectively. Both the self- and informant-report versions of the RBQ-3 showed convergent validity by significantly correlating with clinicians' DISCO-Abbreviated[61] RRB domain scores. Cross-informant reliability was also established, indicated by significant correlations between the self- and informant patterns of response. Good-to-excellent internal consistency was found for the RBQ-3, and the measure also significantly discriminated a separate sample of autistic and non-autistic adults who completed the self-report version. As with the SQ-A-2, further research is required to more fully explore the psychometric properties of the instrument.

For the RBQ-3, items 1 to 19 are scored on a four point scale (e.g. 1 = 'never or rarely'; 2 = 'mild or occasional'; 3 = marked or notable; 4 = serious or severe) that varies according to the nature of the question. Item 20 relates to range of self-chosen activities and has a different, three-point response format. The mean RSMB and IS subscales can be calculated, along with a mean total score.

The RBQ-3 is freely available on the WARC website, and has been translated into multiple languages[a].

The Gwent Integrated Autism Service

The GIAS is one of seven regional Integrated Autism Services (IASs) in Wales, which were set up following the Welsh Government Autism Spectrum Disorder Strategic Plan of 2016[62]. They were designed to provide autism diagnostic assessment and support for adults who were not eligible to access such services elsewhere. The service is provided by a multidisciplinary team of clinicians and support workers. Figure 1 represents the procedure followed for diagnostic referrals at GIAS.

Referrals are accepted for autism assessment or support for adults without a learning disability and who are not currently receiving care from secondary mental health services. In the case of referrals for assessment, the referral must also contain sufficient evidence of autistic traits to merit diagnostic assessment. In the case of referrals for support only, the individual must have previously received a formal autism diagnosis. Referrals may be made by the individual themselves (self-referral), by a professional such as a GP, or by a parent or carer.

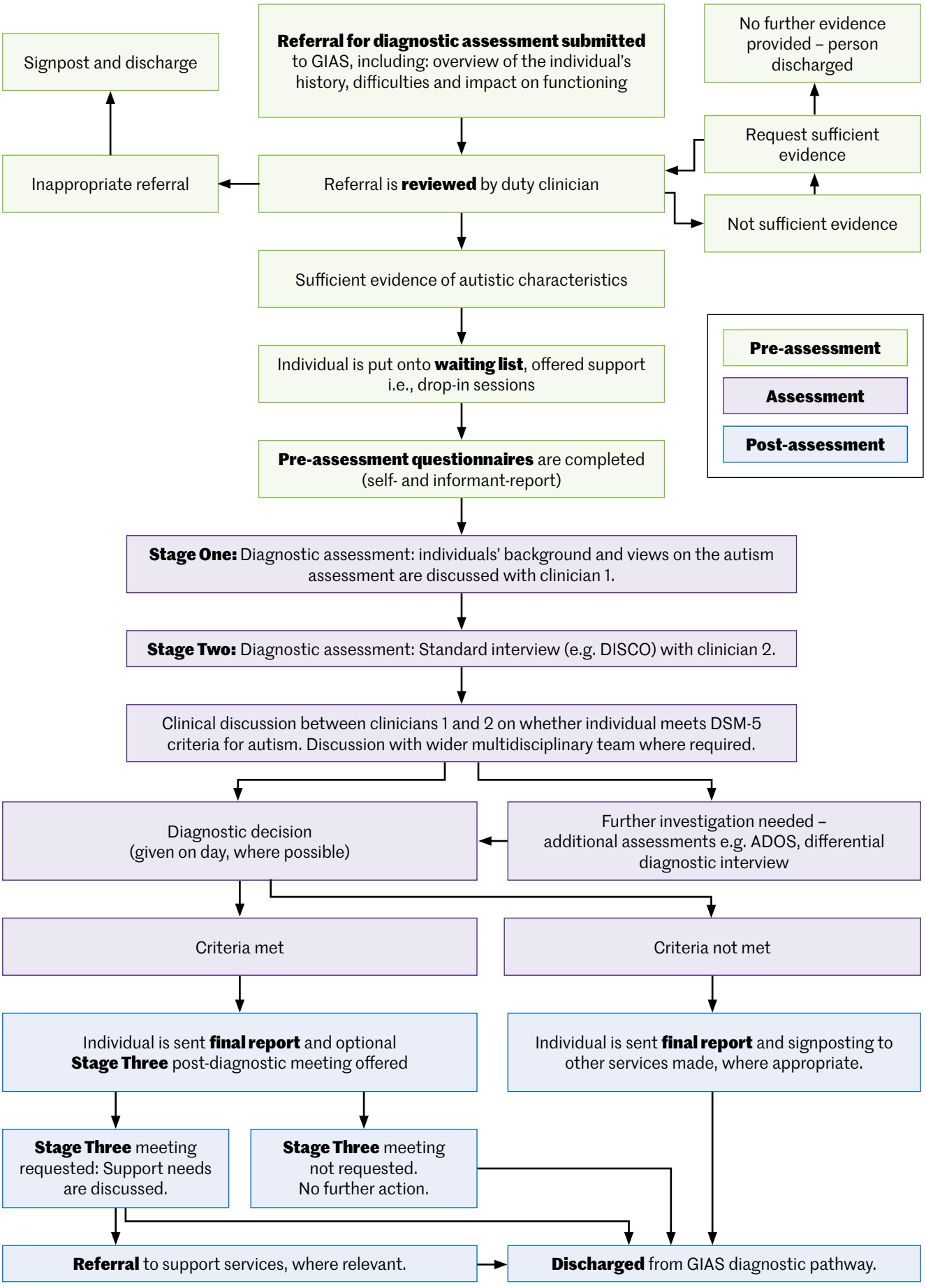
Before the assessment appointment, individuals are asked to complete a set of questionnaires. In addition to the self- and informant-report versions of the SQ-A-2 and RBQ-3, individuals complete self- and informant-report versions of the Autism Quotient-10 (AQ-10)[56], and the informant completes a Relatives' Questionnaire (RQ). The AQ-10[56] is a ten-item questionnaire designed for screening purposes. The RQ is designed to capture information about an individual's early development, and should be completed by someone who knew the individual being assessed when they were a child. It is based on the Childhood Autism Spectrum Test (CAST)[63], appended with additional free-text questions about early development.

At the assessment appointment, the primary diagnostic tool used by the service is the abbreviated version of the DISCO (DISCO-Abbreviated)[61]. It contains 25 questions about characteristics that relate to social communication and 23 that relate to restricted and repetitive behaviours. During the interview, the information provided by the individual and/or relative is interpreted by the clinician, who rates each question according to a coding scale. These ratings are used to support the diagnostic decision that is made. If needed, clinicians may seek additional information. For example, they may carry out a clinical interview or use a further assessment tool such as the ADOS[64], in which individuals are asked questions and complete tasks.

If a diagnosis is given, or if a formal diagnosis has already been received elsewhere, individuals may access the support services provided by GIAS. There are a range of psychoeducational group-based courses that are run both in person and online. Drop-ins or more extended one-to-one support with a support worker are also available. The GIAS also signposts individuals to other agencies for issues beyond the scope of the service, e.g. housing or benefit matters.

[a] https://www.cardiff.ac.uk/psychology/research/impact/measuring-repetitive-behaviours-across-the-lifespan

Figure 1: Referral process for diagnostic assessment at the GIAS



The Current Project

In providing brief and accessible measures of autistic traits via both self- and informant-report, the SQ-A-2 and RBQ-3 have the potential to support adult autism diagnostic assessment. Both questionnaires have been used in assessments at GIAS since 2019 but there has been no formal exploration of their usefulness. To understand more about the use and usefulness of the SQ-A-2 and RBQ-3 in the GIAS, we explored:

- individuals' experiences of completing the questionnaires as part of the diagnostic process
- how these experiences fitted in with individuals' wider experience of the diagnostic process
- how clinicians used the questionnaires in the diagnostic process
- clinicians' views on the overall utility of the questionnaires

This evaluation was designed to establish the value of the SQ-A-2 and RBQ-3 to diagnostic assessments at GIAS, and to determine if and how their utility could be further improved.

The second aspect of this the project related to support. It is well known that the presentation of autistic traits, and associated support needs, can vary considerably from person to person[13]. For this reason, previous reviews[2] and research[9,10] relating to adult autism services have called for a personalised approach to delivering support. Currently, the SQ-A-2 and RBQ-3 are used in GIAS only for the purposes of assessment. However, in providing a personalised profile of the autistic traits of each person assessed, they may be of use in tailoring the support that individuals receive. To understand how the questionnaires may be best used for this purpose, this project sought to understand the current range of support being offered at GIAS, as well as individuals' experiences of seeking and receiving support. Based on these findings, it presents a proposal for the development of a support tool that capitalises on the personalised information provided via questionnaire responses.

Methodology

We explored service level data and collected information via nineteen semi-structured interviews, conducted with people who had engaged with the service or were members of the GIAS team.

The project was a service evaluation that received approval from the Research and Development Department, Aneurin Bevan University Health Board.

Service level data

The service level data was generated by GIAS for the period April to June 2024, and included information on the number and type of referrals received; wait times; diagnostic outcomes; and numbers of assessment and support sessions delivered.

Semi-structured interviews

Participants

All interviewees provided written informed consent before taking part. Eight interviews were with people who had engaged with GIAS. Five had received an autism assessment and support; one had received support only; and two were family members who had acted as informants in the assessment process. Three of the eight were female and five were male, with a mean age of 35 years (range 23-52 years). All described themselves as either White British or White Welsh. Five of the eight interviews took place by video call and three by voice call, according to interviewee preference. Interviewees were asked about their experiences of assessment and diagnosis at GIAS, with a particular focus on their experiences of and views about the questionnaires, as well as about their experiences of seeking and receiving support. Interviews lasted a mean of 60 minutes (range 24-83 minutes).

Eleven interviews were with professionals from GIAS: eight clinicians, two support workers and the team administrator. Nine interviews took place via video call and two took place in person at the GIAS offices, according to interviewee preference. Professionals were asked about their experiences of delivering autism assessment and/or support at GIAS, with a particular focus on the use of the SQ-A-2 and the RBQ-3. Topics included the referral and screening process; assessment appointments; clinical decision making; and delivery of support. Interviews lasted a mean of 64 minutes (range 25-98 minutes).

It was made clear to participants that there were no right or wrong answers, and that both positive and negative experiences were important to share. This was particularly emphasised for discussions about the SQ-A-2 and RBQ-3, which had been developed by the research team, although not by the specific interviewer.

Analysis

All interviews were recorded and subsequently transcribed verbatim. Following a close reading of the transcripts, themes in the data were generated by the lead author. In parallel, two researchers analysed the data by following the principles of reflexive thematic analysis[65]. This thorough process included data familiarisation, coding the interview data for individual units of meaning, and then grouping codes together in an iterative process to generate themes. The themes generated by the two sets of analyses were compared in order to generate the finalised set of themes, in consultation with the last author. The final set of themes were also informed by two members of the research team with lived experience of receiving a diagnosis of a neurodivergent condition in adulthood. They provided reflections on a sample of the transcripts and on the final themes; both researchers felt that the data resonated with their own experiences.

Feedback from the GIAS

The preliminary findings and recommendations were presented to the GIAS in November 2024. This enabled the findings and recommendations to be discussed with the GIAS at an early stage, enabling opportunity for any feedback to be integrated into the final report.

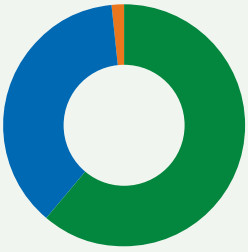
Findings

The findings of this service evaluation are presented in two parts.

The first part provides an overview of GIAS diagnostic and support services. It summarises the processes used, incorporating quantitative information about the current operation of the service. The second part, underpinned by the interviews, focuses on experiences of the diagnostic and support services provided by GIAS, with a particular focus on the role of the SQ-A-2 and RBQ-3.

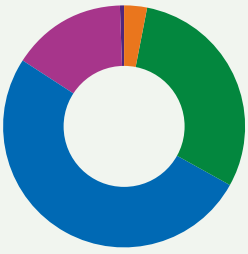
Service Overview

In the most recent three month period for which data were available (April to June 2024), 280 individuals were referred to the service. Approximately 60% of the referrals were from women, with about half of referrals between the ages of 26 and 45 years. See Figures 2-4 for the demographics of the individuals who were referred. Although most referrals were self-referrals (see Figure 5), clinicians reported that a high proportion of self-referrals were made on the advice of a professional e.g. a GP.



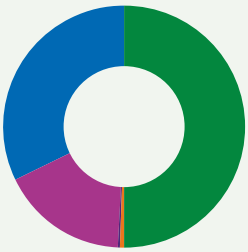
Female	61.4%
Male	37.1%
Other gender identities	1.4%

Figure 2: Gender of referrals between April and June 2024 (n = 280)



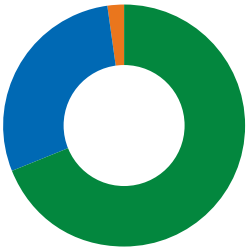
16-17 years	3.2%
18-25 years	30%
26-45 years	51.1%
46-64 years	15.4 %
65 years+	0.4%

Figure 3: Age of referrals between April and June 2024 (n = 280)



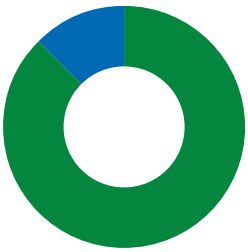
White	50%
Mixed/multiple ethnic origins	0.7%
Asian/Asian British	0.4%
Other ethnic group	16.8%
Prefer not to say	32.1%

Figure 4: Ethnicity of referrals between April and June 2024 (n = 280)



Referral route:

Self-referral	68.6%
Professional referral	28.6%
Relative referral	2.1%



Reason for referral:

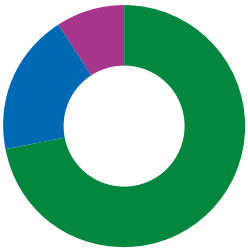
Diagnostic assessment	87.5%
Requesting support	12.5 %

Figure 5: Route and reason for referrals between April and June 2024 (n = 280)

Stages of the referral and assessment process

Review of referral form: Referrals are made via a standard form used across IASs in Wales. The form includes details about the individual's current situation; their strengths and difficulties; medical and family history; education and employment history; and developmental history.

All referrals are reviewed by a clinician, on average within a week of receipt, to assess whether individuals meet the service's eligibility criteria (see Figure 6). In the case of referrals for diagnostic assessment, there is consideration of whether there is sufficient evidence of autistic characteristics to merit an assessment. Clinicians estimated that in around 50% of cases it was necessary to obtain further information before deciding whether to accept the referral.



Accepted	72.1%
Accepted pending more information	18.9%
Not accepted	8.9%

Reasons for not accepting:

Not appropriate	48%
Insufficient information	52%

Figure 6: Referral rates between April and June 2024 (n = 280)

Pre-assessment waiting list: If a referral is accepted, individuals go on the waiting list for assessment or support, as appropriate. People on the waiting lists may attend the service's drop-in sessions with a support worker, or speak to a support worker over the phone for advice on an ad hoc basis. The service plans to increase the services currently offered to those awaiting assessment.

Individuals are typically invited for assessment in the order they were placed the waiting list, although they can opt to be contacted at short notice because of a cancellation. In April to June 2024, the mean wait from referral to assessment was 18 months.

Pre-assessment booking and paperwork: Individuals are invited to book their assessment appointment around six weeks in advance. At this point they are asked to complete the self-report versions of three questionnaires: the SQ-A-2, the RBQ-3, and the AQ-10. They are also asked to arrange for the completion of the informant-report versions of each of these questionnaires. Informants also complete the RQ, which is designed to be completed by someone with knowledge of their characteristics and behaviour during childhood.

Quantitative data on current return rates of questionnaires was not available. However, clinicians reported that return rates were high; almost all individuals were said to return the self-report questionnaires, with the return rate for the informant-report questionnaires only slightly lower. This is broadly consistent with previous research spanning 2019 to 2023, in which return rates for the self and informant versions were 88 and 80% respectively[12].

Diagnostic assessment (Stage One and Stage Two): Individuals are encouraged to attend the assessment appointment with a person who knew them well as a child. Up-to-date quantitative data about whether or not people were accompanied was not available. Previous research[12] indicates that 79% of people were accompanied during appointments in September 2019 to March 2020, and 57% were accompanied during October 2022 and March 2023. Clinicians estimated that, currently, between 30 and 60% of individuals are accompanied at the appointment.

Nine clinicians are currently involved in carrying out diagnostic assessments. Their professional backgrounds cover nursing, occupational therapy, speech and language therapy, and clinical psychology. The assessment appointment takes place across two stages, with a short break in between. A different clinician takes each stage:

Stage One: The clinician asks about the individual's early life; their current home, work, health, and social circumstances; and their views on the autism assessment and the possibility of diagnosis. The Stage One meeting lasts about an hour.

Stage Two: The clinician conducts a semi-structured clinical interview. Until recently, some used the DISCO-Abbreviated[61] and others used the Autism Diagnostic Interview-Revised (ADI-R)[66]. The latter have now received training on the DISCO and DISCO-Abbreviated, with a view to using the DISCO-Abbreviated in future assessments.

Both between and after the Stage One and Two assessments, there is a clinical discussion between the two assessing clinicians. If both agree that the DSM-5[15] criteria have been met, a diagnosis of ASD will be given. The decision will be communicated to the individual shortly afterwards, either the same day or in the following few days. Alternatively, clinicians may decide that further investigation is needed. For example, additional observational information may be required following an online assessment, which might lead to an in-person ADOS[64] assessment. In cases where an individual has a history of significant trauma, a clinical interview with the clinical psychologist may be required to explore whether their characteristics are better explained by a differential diagnosis. The ultimate diagnostic decision is made by consensus between the assessing clinicians, with additional input from other members of the multidisciplinary team, where required. Clinicians' impression was that the number of cases requiring further

investigation had increased over recent years and now stood at around 50%.

In April to June 2024, 100 diagnostic assessments were carried out, 76 of which resulted in a diagnosis of autism. In the remaining 24, a diagnostic decision had not yet been reached at the time of report. It was therefore not possible to establish the current overall rate of diagnosis. The consensus among clinicians was that a large majority of assessments currently resulted in a diagnosis of autism.

Post-diagnostic meeting (Stage Three): After being informed of the diagnostic outcome, individuals are sent a letter summarising the information obtained from the assessment, restating the diagnostic outcome, and outlining the reasons for the decision reached. Individuals who receive an autism diagnosis are offered a 45 minute Stage Three meeting. Individuals who do not receive an autism diagnosis may be signposted to other services.

At the Stage Three meeting, individuals are able to discuss any issues arising from the report or diagnosis with a clinician, and are given details of the post-diagnostic support provided by the service. No quantitative data was available on the proportion of people who take up the offer of a Stage 3 meeting, but it was believed to be around 40-50% of those who were offered it.

Support: A major component of the services available after the Stage Three appointment are a range of group-based psychoeducational courses. There is an initial post-diagnostic course consisting of six weekly two-hour sessions, originally developed by the Cardiff IAS and used across Wales. It is designed to increase individuals' knowledge and understanding of autism and to advise on practical issues, such as disclosing diagnosis. There is an equivalent course for family members and carers of recently diagnosed individuals. After having attended the post-diagnostic course, individuals may attend additional courses that cover a range of topics, such as emotional regulation, sensory needs, and planning and decision making. In April to June 2024, the service ran three group-based courses which were attended by 25 individuals.

Individuals may also access one-to-one support from a support worker. Support is provided over a defined period, typically of a few weeks, to help an individual achieve a particular goal, e.g. to travel independently to and from their home to go shopping, or to attend an activity. Once the goal has been achieved, the individual is discharged. The service also runs peer- or support-worker-led social and outdoor groups.

The average wait to receive support from the service in April to June 2024 was just over four months.

Experiences of individuals and professionals

This section describes experiences of the diagnostic and support services provided by GIAS, with a particular focus on the role of the SQ-A-2 and RBQ-3. It draws on the perspectives of individuals who have been assessed as well as the professionals who provide the service. The data are presented by theme, with sub-themes used to further illustrate patterns in the data.

Quotes from interviews are provided, with an anonymous code used to label different contributors. Codes beginning with I indicate the comment is from an individual who attending the GIAS for diagnosis and support. Codes beginning with a P indicate the comment is from one of the GIAS team, with all quotes being from clinical staff.

(1) Assessment is challenging but worthwhile for individuals

Managing the wait

All individuals experienced a lengthy wait between the referral being accepted and the assessment appointment. This period was typically experienced as very difficult, with individuals reflecting they could feel "hopeless" (I1) or in a "frustrating limbo" (I4). The uncertainty of whether a diagnosis would be given was a key driver of these challenging emotions:

> It was really hard... I felt like I was on eggshells until this diagnosis come round... (I1)

Table 1: Themes and sub-themes from the semi-structured interviews about the GIAS and the use of the SQ-A-2 and RBQ-3

1	**Assessment is challenging but worthwhile for individuals** ▪ Managing the wait ▪ Challenging but well-supported assessments ▪ Complex reactions to diagnosis
2	**Family attitudes and understanding affect the assessment experience**
3	**Questionnaires provide opportunity for self-reflection** ▪ Contemplation and insight ▪ Qualifications and item-adjacent behaviour
4	**Questionnaires are one part of a bigger picture** ▪ Use at different stages of the assessment process ▪ An aid to diagnostic decision making
5	**Support: Individual differences and the need for connection** ▪ Variation in support needs ▪ Connection with autistic people ▪ Barriers to support ▪ Pre-diagnostic support gap

The challenges of the pre-assessment period were sometimes exacerbated by how other health services responded to the individual's needs during this period. For example, practitioners might put certain care on hold until a diagnostic decision was made. There was also the frustration of individuals wanting help and support with their autistic features but, instead, having mental health symptoms treated and the underpinning autistic features ignored. The frustrations of waiting were succinctly captured by one individual, who remarked:

> It is difficult, the waiting list, because you don't really get sent for an [assessment] if you're not struggling..." (I6)

Individuals and clinicians both highlighted the degree of investment felt by individuals about getting a diagnosis, which was often exacerbated by the lengthy wait. Clinicians remarked that individuals sometimes expected a diagnosis, which could lead to significant upset if a diagnosis was not given. Individuals spoke in emotive terms about their search for validation, to have confirmation that they have not been exaggerating and that it is not "all in your mind" (I4). A diagnosis was seen by some as a "light at the end of the tunnel" (I3), which led to anxieties about what would happen if a diagnosis was not provided.

Many individuals also reported a sense of uncertainty about what the assessment itself would entail, or a desire to know more. Uncertainties spanned issues such as what the room would look like, through to the format of the assessment and what would be discussed.

Challenging but well-supported assessments

The assessment appointment was described as long and tiring by the individuals. The questioning prompted self-reflections that were emotionally challenging at times, which was often related to thinking about difficult situations or circumstances in the person's life. Challenges also came from being uncertain about what to say and from being confronted with issues that the individual did not typically think about:

> It was actually exhausting... It was so focused and intense... Some of the questions... I froze because I was like 'I really don't know what to say'. Because there was things I just wasn't expecting them to ask me... [things] I hadn't really thought about until I started to talk about it, and then I found it a bit upsetting. (I4)

However, individuals also commented that the clinicians were supportive and able to put them at ease. In particular, one individual described how the approach of the clinicians had a significant impact on their ability to engage with their interview:

> I was so fortunate to have two ladies that were just great, and they really knew how to... put both of us at ease, and they asked things in a way that... made it easy to answer, and... I was surprised because I'm not usually that comfortable talking in that depth, but... when I was talking, I was able to... open up. (I4)

Complex reactions to diagnosis

Individuals described a mix of emotional responses to receiving their diagnosis. Commonly, diagnosis elicited a sense of relief and validation, coupled with an increased sense of self-understanding and self-compassion:

> It takes a lot of weight off, when you've carried a lot of stuff for many years that you haven't really understood... [Having a diagnosis] allows you to give yourself the allowance that your brain works differently, or your processing is different... like it fills the void of every time I've looked back at life and thought 'Why did that happen to me?' or 'Why did I feel that way when that happened?' (I1)

However, positive responses to diagnosis were always accompanied, or followed, by a sense of grief, anger, or sadness in relation to difficult past experiences. Individuals reflected that aspects of their life, such as their schooling or social life, may have been different if they had been given a diagnosis when they were younger.

For some, diagnosis elicited a period of poor mental health. This sometimes related to feelings of uncertainty over whether their life would improve and a sense of 'What now?' (I3). One individual had to take three months of work:

> I thought I wanted [the diagnostic decision] to be 'Yes', but when I found out, I absolutely went into a meltdown. ... My head was all over the place. I really struggled with being newly diagnosed. I really found it harder than what I thought it would be. (I6)

However, despite a mix of emotions, in the longer term, diagnosis had driven positive change. This was often underpinned by an active approach to understanding the self, including looking at tools and strategies that could provide support:

> If I know I'm getting overwhelmed, or if things in my head's getting a bit bad... now I'm getting to learn my triggers, whereas if I didn't I would still be where I was. (I6)

(2) Family attitudes and understanding affect the assessment experience

The challenges and benefits that individuals experienced at each stage of the assessment process were strongly influenced by their family members' attitudes and understanding. Clinicians reflected that some individuals were emphatic in not wanting family members involved in the assessment process. This sometimes related to difficulties within the family, such as a lack of support for the diagnosis, and sometimes to concern about family members' understanding of the individual.

For the individuals we interviewed, there was considerable variation in the quality of the family relationships described. Some individuals reported that there were people who knew them well, while others felt that the people around them had a limited understanding of their inner world:

> I sadly feel like my family don't really know me. They know the version of me that I've created... There was always that extra, what was inside...I didn't really share stuff with family, so I always was very isolated. (I1)

Individuals and clinicians reported that family members often had a limited or outdated understanding of autism, such as assuming someone cannot be autistic if they have been to university, or assuming that autistic traits would always present similarly in children and adults. Where family members' understanding of the individual or of autism was limited, there could be tension in the family about the prospect of assessment and/or diagnosis:

> I had a lot of people telling me that it was nonsense, that I was just depressed, or I was just anxious... there was a lot of controversy in my family around it. (I2)

This tension was sometimes related to parents' feeling that they were responsible, or that they were being blamed, for failing to recognise the signs of autism in their child at an earlier stage.

Family members' attitudes and understanding were strongly linked to how individuals felt about involving them in the assessment process. For some, the request for input from an informant highlighted sensitivities in their familial relationships. One person reported not having anyone to call upon as an informant, whilst another did not want to tell their family members that they were being assessed. Where family relationships were problematic, individuals felt that family members' involvement would either have little value, or would undermine their own recounting of their experiences:

> I couldn't help reading those questions [on the informant versions of the questionnaires] and, because it's personal to me, thinking 'Well I can answer that better than anybody.'... I felt like I could... provide more insight than what, say, a family member might be able to. (I1)

Even when family relationships were otherwise close and supportive, recounting difficult personal experiences in front of family members could be a vulnerable experience:

> Asking someone to [act as an informant]... it is intrusive, in a way, because it is so personal to talk about. I don't talk about my feelings in that depth a lot so, yeah, it was a big thing. (I4)

One clinician reflected that such discussions could also be difficult to negotiate for informants, who could be mindful of the need to recount their family members' difficulties but who were also keen to avoid portraying them in an excessively negative light.

Nevertheless, individuals with positive family relationships reported clear benefits from their family members' involvement. These included helping the individual recount information if they were uncertain or confused, being able to provide them with emotional support, and reassurance that their informants' 'second opinion' could be used to maximise accuracy.

Finally, family relationships influenced the impact of diagnosis on individuals. For some, diagnosis facilitated increased understanding or acceptance between family members:

> For my [partner] and myself, it's the level of honesty about how I feel... My mum said it's like a sort of a light bulb – things have clicked... she said 'I can totally understand now why that happened, or why you don't want to do that, or why you've reacted in that way.' (I4)

However, negative or dismissive reactions from others could be challenging to receive, and included family members not being supportive of the diagnosis or not understanding what it means to be autistic. Notably, these negative reactions were often described as still persisting, rather than having evolved since the initial diagnosis.

(3) Questionnaires provide opportunity for self-reflection

Individuals reported thinking carefully about their responses when completing the questionnaires. The questionnaires prompted a sense of recognition, but individuals also identified qualifications or limits to the extent to which questionnaires reflected their autism-related characteristics.

Contemplation and insight

Individuals and informants reported completing questionnaires largely independently, although some subsequently viewed and discussed each other's responses. Individuals often reported a degree of recognition when completing the questionnaires, which reassured them that an autism assessment was appropriate:

> Everything they're asking is me... so there was almost that niceness about it. Because it's on your journey of getting a diagnosis... they're those first little moments of light that start to make you think 'Well yeah... this stuff is what makes sense to me'... confirming a lot of stuff that I think and feel... I'm in the right direction... it was a nice reconfirmation that I was doing the right thing. (I1)

Others noted similarities between their own and the informant's responses, which could be validating, particularly the sense that "other people could see it too" (I4).

Individuals also recognised that completing the questionnaires in their own time offered the opportunity for self-contemplation, with time to process what was being asked of them. The opportunity to take time to think about their autistic characteristics was described as a "benefit" (I3) of questionnaires.

However, the degree of self-reflection elicited by the questionnaires could also be emotionally challenging:

> For anybody completing it, I would say putting aside time just to be kind to yourself... it can be a negative rabbit hole... and you think 'All my life I must have been doing these things and people must have been thinking, why is she doing these?' So I think, yeah, it's having time to just sort of reflect on that and just be nice to yourself about it I guess. (I4)

Notably, contemplating the questionnaire items was described as leading to new insights about the self. This could be driven by appreciation of autistic characteristics that the individual had not previous though about. However, new insights were often derived from reviewing the responses of their informant. For example, the informant sometimes endorsed characteristics that the individual had not recognised in themselves.

Some individuals also thought that the degree of self-reflection prompted by completing the questionnaires served as a useful primer for the assessment appointment:

> Once the questions [in the interview] started... because I'd been asked similar formats to these questions before [in the questionnaires], I wasn't surprised when they asked them again. (I2)

Qualifications and item-adjacent behaviours

Individuals felt strongly that the applicability of many of the questionnaire items depended on multiple factors. For example, whether an individual engaged in a particular behaviour might depend on the sensory environment; the setting (e.g. work vs. home); or the level of challenge they were experiencing in other aspects of their life.

They also identified elements of nuance or qualification that could not be conveyed via the available response options:

> I think I've learned a lot of the social things... But actually, if you ask me whether I feel it then it would be a different answer. (I3)

Additionally, some of the RBQ-3 items brought to mind behaviours that might be described as item-adjacent, i.e. behaviours that were analogous to those described, but not strictly captured by the item wording:

> One of my sort of repetitive behaviours is chewing my tongue... that's not included with fiddling ...so that wasn't captured. (I3)

The sense that there were item-adjacent behaviours not captured by the RBQ-3 was linked to individuals' observations that many of their autistic characteristics manifested in singular or subtle ways. By contrast, they felt that the questionnaire items described typical or obvious manifestations of autism:

> They're generically structured based on- I don't want to say stereotypical, but that's the only word I can think of, understanding of what autism is. (I2)

Because of the limitations they identified, individuals felt that the completed questionnaires presented an incomplete and therefore potentially misleading profile of their autism-related characteristics. They described wanting to add qualifiers, such as using an asterisk to denote "Only [on] this occasion" (I3), or have the opportunity to explain their experience more fully:

> Some of them... made me think, like, it's not all the time. So I wish I could explain to them which times. You know, not just a like 'Strongly' or whatever, because it can give a little bit of a false picture. (I6)

However, individuals also recognised that the assessment appointment later provided an opportunity to present a fuller picture:

> I'm not sure whether [the questionnaires] quite gave an accurate description of how things are, but then I think I was reassured by that in the assessment when, like, they did ask so much more detail. (I3)

Despite the sense that questionnaire responses omitted relevant information, individuals did not report annotating questionnaires. Clinicians also reported that it was uncommon for individuals to provide supplementary information about their responses. Clinicians did, however, share individuals' views about the importance of nuance and contextual information:

> You don't just want to know if someone likes to touch different textures, you kind of want to know, well, what do they touch? To what extent do they touch it? How often do they touch it? You want that qualitative [information], rather than just a 'Yes they do', because you need to back it up for your diagnostic assessment in more detail than just a 'Yes' or a 'No'. (P8)

(4) Questionnaires are one part of a bigger picture

Clinicians reported using the questionnaires at different stages of the assessment process, and identified a range of ways in which they contributed to decision making. The overall utility of the questionnaires lay in how they related to other evidence obtained as part of the assessment process.

Use at different stages of the assessment process

A number of clinicians reported asking for the questionnaires to be completed when there was not enough information in the referral form to make a referral decision. In these instances, the questionnaire responses might elicit additional information that allowed the referral to be accepted:

> [On the referral form] people... might go 'No, I don't actually have any problems with social interaction,' or, 'I don't really have any restrictive repetitive behaviours'... You send out the questionnaires, they come back, and their mother has ticked every single box... (P7)

This additional information could also lead to increased confidence in the decision to accept the referral, which was important in light of the long wait for an assessment and the resource-intensive nature of the assessment process.

For one clinician, providing a profile of the individual at the referral stage was the key function of questionnaires:

> In my head, it's part of the referral... before we've seen people... to get a whole person picture... I would rarely I would rarely go back and look at those questionnaires after I've then completed the assessments. (P3)

However, most clinicians did review the questionnaires when making the diagnostic decision. Where this was the case, some felt it was important not to look at questionnaire

responses until the appointment had taken place, so as not to bias their view of the individual when meeting them in person. In contrast, some considered that the questionnaires could be useful throughout:

> **The nice thing about [the questionnaires] is they can be used at any part of the assessment, you know, from triage right through to diagnostic outcome. (P7)**

An aid to diagnostic decision making

Clinicians described how diagnostic decision making involved interpreting multiple sources of information, with a view to creating an overall picture of an individual's presentation. Clinicians' observations of the individual and their overall clinical judgement were critical elements in this process:

> **I think it's using all of it. It's using all of the information we have and looking at everything... I guess what you're looking for is people telling you bits of the same story in slightly different parts of the assessment. (P7)**

Clinicians reported that questionnaires were one element in this wider sense making process. They were subsidiary to other sources of information, in that the diagnostic decision never turned on information provided in the questionnaires.

However, there were a number of ways in which questionnaires were described as supporting the decision making process:

Maximising informant involvement: Clinicians noted that the NICE guidelines[16] call for assessments to incorporate informant information about current behaviour where possible. Yet, clinicians estimated, between 40 and 70% of individuals attend the assessment appointment alone[b], although virtually all individuals returned both the self- and informant-report versions of the questionnaires. Thus, in a substantial proportion of cases the informant versions of the SQ-A-2 and the RBQ-3, together with the informant version of the AQ-10, were the only available sources of informant information about individuals' current presentation.

In the small number of cases where no informant information was available, clinicians sometimes needed to use alternative, more resource-intensive means of obtaining additional information, such as an ADOS assessment.

Corroboration across sources: Clinicians described how questionnaires could be used as corroboration for information obtained by other means. Before making a diagnostic decision, most clinicians reflected on whether the informant questionnaires corroborated the information provided by individuals. Such corroboration was felt to be particularly important where there had been no informant at the assessment appointment.

Clinicians identified that sometimes there was not clear corroboration across the individual and their informant. Where informants endorsed items that individuals did not, clinicians gained additional information about the individual's characteristics, and were also prompted to reflect on the individual's level of insight:

> **[Where scores on the self questionnaires are low]... the [informant questionnaire] might score very highly ... we'll discuss then 'Well actually, is this person struggling to see their difficulties?' So... we can use it from that perspective and that could be quite helpful. (P4)**

Conversely, informants sometimes reported fewer autistic characteristics than individuals. Clinicians identified many possible reasons why this might be the case, including the informant not being attentive to the features being measured, the informant being neurodivergent and not recognising the behaviours as different, or the individual masking their autistic features. Such reasons generally caused them to give reduced weight to the informant questionnaires.

[b] Up to date quantitative data in relation to accompanied status was not available. Existing research data indicates that 21% of people were unaccompanied during appointments in September 2019 to March 2020 and 43% were unaccompanied during October 2022 and March 2023[12]

To a lesser extent, the self-report questionnaires also had a corroborative role, linked to the fact that the questionnaires would have been completed under different conditions to those of the assessment, and/or could demonstrate consistency over time:

> It's just that corroboration, that actually, yeah, this absolutely backs up everything that we've heard from what you've said and what was on your referral form... which they probably filled in a couple of years ago. So is the story still the same? (P8)

Providing additional information: Clinicians noted that the RBQ-3 could help identify behaviours not mentioned elsewhere. Clinicians felt that it was often challenging for individuals to recognise the presence or intensity of RRBs, or their relevance to the assessment. Therefore, individuals may not volunteer information about a particular characteristic or behaviour in the referral form or even at the assessment appointment, but would nevertheless endorse a specific questionnaire item that described the behaviour:

> The questionnaires can be really helpful sometimes in just pulling out what sometimes people don't think is necessarily autism... some people don't necessarily understand what restrictive repetitive behaviours are... I don't know that people think about them in as much detail as we would look for to be able to give a diagnostic outcome of ASD... the way [the RBQ-3] breaks those down is actually really, really helpful. (P7)

Highlighting that relevant characteristics are not present: When considered in conjunction with other sources of evidence, the questionnaires may also serve to highlight that the diagnostic criteria were not met in a particular case:

> Actually, it might suggest, well no, there's still big gaps. Maybe there's nothing in the repetitive behaviours [questionnaire], there's nothing in the [referral] form... there's nothing much come out in the DISCO, so that's a big gap. (P4)

Confidence in the diagnostic decision: Clinicians described that some diagnostic decisions were relatively clear cut, and they could be confident in their decision based on the information obtained at the assessment appointment alone.

However, generally, clinicians were keen to ensure that all possible sources of evidence were considered before a diagnostic decision was made, particularly if it was likely that no diagnosis would be given. This process of exploring all avenues led to increased confidence in the diagnostic outcome:

> It's just another layer that helps to kind of solidify things... it wouldn't feel enough to not have the questionnaires. I guess it would feel a bit like there was a bit missing. (P5)

Finding the RBQ-3 more useful than the SQ-A-2: A minority of clinicians reported that the RBQ-3 and SQ-A-2 were equally valuable to the assessment process. However, most felt that the RBQ-3 was more useful. First, as described above, the RBQ-3 played a particular role in differentiating, mapping out, and quantifying particular subcategories of RRBs. It could elicit additional information that did not emerge at the assessment appointment, which was not the case for the SQ-A-2. Second, diagnostic decision making often required consideration of differential diagnosis. In this context, RRBs, and therefore the RBQ-3, could be particularly important in determining whether an autism diagnosis was merited:

> I don't think [the SQ-A-2] is less useful... it gives an overview, as opposed to something more specific, so I don't think it's any less useful. I think it just gives us that broader picture, whereas the [RBQ-3] is specific, and very often that's where people don't give us the information on the referral forms. (P7)

> I find the RBQ much more useful. The SQ-A... it doesn't give me what I feel like I need information wise. So I already know that the people that are coming in and have

> already had their assessment, they've got quite significant social communication differences in their relationships – all of those type of things that are covered in the SQ-A. But it's always the rigid and repetitive behaviours and the insistence on sameness that's a differentiator between other disorders. (P2)

(5) Support: Individual differences and the need for connection

Clinicians reported that many individuals who accessed the service had support needs connected to their autistic characteristics. Various features of accessible, appropriate and relevant support were discussed.

Variation in support needs

Clinicians identified broad topics that were relevant to autism-related support. These included: wanting to understand the self better and enhance self-identity; support with activities of daily living; support with social connections and reducing isolation; and support in managing sensory differences. However, at an individual level, both individuals and clinicians expressed that people tended to have a specific, individualised profile of needs. Additionally, there was felt to be variation in the time at which it was most helpful for individuals to access support. Clinicians reflected that some people could take a long time to process their diagnosis and it could take a while before they were ready for support, whereas for others the need was more immediate.

Both individuals and clinicians felt that the personalised nature of support needs meant that providing support that was relevant could be challenging:

> How do you make a course digestible and understandable for everyone, but also, you know, interesting for other people?... There was a mix of people [on the post- diagnostic course], and I guess that [it] has to kind of be relevant for everybody, regardless of what stage or what age they are. (I1)

> I think it's about having something for everybody, which is hard because everybody is so different. (P3)

Connection with autistic people

Individuals described benefitting from attending the service's post-diagnostic course, which provided psychoeducation in a group setting. The primary benefit they identified, or anticipated, was connecting with other autistic people on the course:

> [On the post-diagnostic course] I'm... meeting other people who have an autism diagnosis and also hearing other people like are struggling too, and that's helpful I think. So not necessarily, like, the content as much. (I3)

Similarly, either while awaiting assessment or after diagnosis, all individuals had independently sought out autism-related resources. They felt that the most helpful materials were those devised and delivered by autistic people whose experiences were comparable to their own, e.g., late-diagnosed autistic women. Individuals described learning more about themselves from the experiences of others:

> [I got] some books on Amazon of autism in women, listen to TED talks, I found them really helpful. I would be in tears listening to some of them thinking 'Oh my God, that is me.' If only I'd watched these years ago. (I6)

Clinicians echoed the need for, and value in, such connection:

> [At post-diagnostic appointments] Often people ask 'Do other people do that?' 'Have you met another person that does that thing?' or 'Do other people feel like this?' And it's like, 'Yeah, they definitely do!'... It's that reassurance... saying that, actually, everything you're experiencing is normal. (P5)

Barriers to support

A major component of the support provided by the service was their range of group-based courses, which individuals were eligible to attend if they had an autism diagnosis. While the variety of topics covered by the courses was felt to be comprehensive, a range of reasons were identified why individuals were unable to access them. These included: a dislike of group situations; difficulty travelling to in-person sessions; or sessions held at inconvenient times (e.g. during work hours). Clinicians were aware of barriers to attendance and the commitment that attending a five or six week course required. One clinician described a need to develop alternative support for people for whom groups were unsuitable:

> **I think if you don't want to do the courses that's where it falls down, because there's nothing then.... I think that's why it would be important to put together some kind of post-diagnostic pack, so you still get access to the information... it's accounting for those people that don't want be in a group, but also probably don't need one-to-one support, but they want to learn more. It's not a group, and it's not one-to-one support, it's somewhere in the middle. (P5)**

Pre-diagnostic support gap

Individuals on the waiting list for assessment could contact the service for advice on an ad hoc basis, but there was no wider programme of pre-diagnostic support. In line with the Code of Practice[19] requirement that access to support should not depend on diagnosis, clinicians shared that the service intended to increase its pre-diagnostic support provision. They also recognised that individuals' level of autism knowledge and understanding was highly variable at the assessment stage.

Clinicians saw clear benefits to providing pre-diagnostic support within the service. There was a sense that this could contribute to individuals' wellbeing whilst navigating the challenges of being on the waiting list. It was also acknowledged that individuals struggle just as much pre-diagnostically as they do after diagnosis, such that "everything we provide post-diagnostically might be helpful pre-diagnostically" [P7].

Clinicians also discussed that the service had given consideration to running group support sessions for those currently awaiting assessment. However, it was felt that such groups may be impractical for addressing highly personalised support needs, and would divert resources from other parts of the service. In contrast, there was greater support for providing written and/or pre-recorded resources for those on the waiting list. Such materials were felt to be more accessible to individuals and to better meet the needs of the service. However, clinicians emphasised that the current demands on the service meant that there was limited time available to step back and reflect on different ways of working, or to develop or deliver additional resources.

Practical considerations

There were also some practical considerations, relating to collection of questionnaire information, that did not fit within the five main themes. Although there were no major difficulties in the way information was collected, clinicians identified some practical difficulties with the process.

First, it sometimes emerged on the day of the assessment appointment that the questionnaires had not been completed. Clinicians might then ask the individual and/or informant to complete the questionnaires during the appointment, taking up clinician time. Alternatively, they might provide additional copies of the questionnaires and ask for them to be returned at a later date. The questionnaires were then unavailable during the clinical discussion directly after the assessment, potentially delaying the diagnostic decision.

Second, because questionnaires did not include space to record the name of the person completing it or, in the case of the informant versions, their relationship to the person being assessed, it was not always clear who had completed the questionnaires.

Third, questionnaires sent out electronically as Microsoft Word documents could occasionally be difficult to interpret when returned. For example, responses may have been marked in an ambiguous way, or changes to the formatting may have resulted in responses becoming misaligned with the response options.

Fourth, questionnaire scores had to be calculated manually. Because a number of SQ-A-2 items are reverse scored (i.e. the presence of an autistic trait is indicated where the item is not endorsed), this could be a time consuming process with potential for error.

Discussion

This project evaluated the use of the SQ-A-2 and RBQ-3 questionnaires within the GIAS assessment process, and explored ways in which the questionnaires could help supplement its support services.

Interviews revealed that individuals accessing the service and clinicians delivering the service derived distinct benefits from the questionnaires. For individuals, completing the questionnaires provided insight into their autistic characteristics, but felt limiting because questionnaire items were unable to capture additional relevant information or context. For clinicians, questionnaires supplemented referral information and supported diagnostic decision making, although questionnaires complemented rather than determined the decisions made in the assessment process. Some inefficiencies in the way in which questionnaire information is collected were also identified. The evidence revealed a number of factors that should be taken into account when developing support based on the questionnaires. They related to: the current support provision; barriers to take up; plans and capacity to expand provision; and the support needs and priorities of those accessing the service. Overall, the evidence suggested the questionnaires should be retained as part of the assessment process with some minor modifications. If developed into an accessible and personalised online support tool, the questionnaires could additionally be used to complement the service's current support.

Understanding and evaluating the current use of the questionnaires

Use of the questionnaires by individuals

Individuals typically completed the questionnaires after a long wait, at a time when they may be anxious about the diagnostic outcome, as well as about what the upcoming assessment appointment will entail. Completing the questionnaires could also be emotionally challenging for individuals, potentially contributing to the overall challenges associated with pursuing an autism assessment. The extent to which individuals welcomed and benefitted from the inclusion of informant versions of the questionnaires depended on their family circumstances and the quality of their relationships, which varied considerably between individuals.

The benefits of completing the questionnaires derived from the striking degree of contemplation and reflection by individuals when completing the questionnaires. Together with reviewing the responses of informants, where helpful, this process contributed to individuals' insights into their autism-related characteristics. In part this benefit came from recognising the characteristics described in the questionnaire items as applicable to them. Greater insights came from instances where the questionnaire items did not quite capture a relevant behaviour, for example, because the item applied only in certain contexts, fluctuated over time, or brought to mind an analogous behaviour that did not fall within the wording of the questionnaire item. Completing the questionnaires brought to mind information that was relevant for their upcoming appointment.

At the time they completed the questionnaires, however, individuals felt limited by the fact that it was not possible to communicate nuances, qualifications and additional information via their questionnaire responses, which they felt presented an inaccurate or incomplete profile as a result. These feelings were consistent with those reported in the wider literature relating to autistic people's experiences of completing questionnaires for diagnostic[29], healthcare[67], and research[68] purposes.

It is worthwhile noting that we only spoke to individuals who had attended GIAS and received an autism diagnosis. It is possible that reflections on completing the questionnaires, including any benefits or drawbacks, may have been different for those who did not receive a diagnosis.

Use of the questionnaires by clinicians

Clinicians differed as to whether they principally used questionnaires at the referral stage, the assessment stage, or both. As identified by clinicians and elsewhere, an alternative possible use is for clinicians to review the questionnaires before the assessment appointment and used them to guide interview questioning[12], although clinicians did not report using them for this purpose at GIAS. Overall, the evidence highlighted that questionnaires can be used flexibly across different contexts and according to clinician preference.

At the referral stage, questionnaires were used as an efficient means of gathering information to supplement that provided in the referral form. Questionnaires could sometimes elicit more information than the referral form alone, in that individuals and/or informants were specifically prompted to think about characteristics and behaviours they may not previously have been aware of, and/or associated with autism. Questionnaires contributed to clinicians' confidence in their referral decisions, which was important in light of the long wait for assessment to take place and the level of resources required to deliver each assessment.

At the assessment stage, informant questionnaires could corroborate information provided by individuals themselves. There were a substantial number of cases where individuals were unaccompanied at the appointment, but nevertheless returned informant questionnaires, helping to fulfil the NICE requirement for corroborative information where possible. Questionnaires could sometimes obviate the need to carry out a more resource-intensive supplementary assessment such as the ADOS. Restricted and repetitive behaviours and their relevance to the assessment were often less well understood than the social communication criteria for autism diagnosis. For this reason, the RBQ-3 had a distinct role in highlighting and quantifying behaviours that were captured neither in the referral form or assessment appointment, and most clinicians indicated that the RBQ-3 was the more useful of the two questionnaires as a result. Finally, where evidence of autistic traits was lacking across all diagnostic tools, including the questionnaires, they played a contributory role in justifying a 'no diagnosis' outcome.

The role of the questionnaires in the diagnostic process should not, however, be overstated. There were some instances where a diagnosis was clearly justified based on the information obtained during the assessment appointment alone, in which case the questionnaires did not contribute to the diagnostic decision. Questionnaires were also unable to capture the level of detail and nuance that was required for a diagnostic decision to be reached. Thus, the primary source of diagnostic information was the detailed information and clinical observations obtained via the assessment. Nor was it always possible to take the information contained in the questionnaires at face value. There were instances in which either the informant or the individual themselves lacked insight into the relevant behaviour and characteristics, in which case autism-related traits tended to be underreported on the questionnaires. Ultimately, diagnostic decisions were based on a holistic formulation that used clinical judgement to

interpret all of the available information. The questionnaires played a complementary albeit subsidiary role in this process, contributing to clinicians' overall confidence in the diagnostic decision reached.

Given the benefits to individuals and the contribution made to referral and diagnostic decisions, there would be clear value in retaining the questionnaires as part of the assessment process at GIAS. However, there are inefficiencies in the way in which questionnaire information is currently collected. Ensuring that questionnaires were returned sometimes took up an undue amount of clinical or administrative time; the format in which questionnaires were returned sometimes made them difficult to interpret; the name of the person completing the questionnaire or their relationship with the person being assessed was not recorded on the questionnaire itself; and scoring had to be carried out manually. Increased automation of the process, e.g. creating an online form for questionnaire completion, could help address these problems.

Developing the contribution of the questionnaires to the support service

Expanding existing services

The post-diagnostic support currently offered by the service is wide-ranging in terms of the topics and issues it addresses, and support is provided in a variety of formats (group-based, one-to-one, in person and online) depending on individual needs. However, there were three particular ways in which the evidence indicated that it would be helpful to expand the existing support provision.

The first related to the pre-diagnostic stage. The wait for assessment is long and characterised by ongoing difficulties. Individuals often experienced uncertainty about their autistic identity, which could be challenging. Clinicians recognised the benefits of providing additional support to people awaiting assessment, as well as noting the requirement in the Code of Practice for support than was not dependent on diagnosis. The service has already begun to consider the options for expanding pre-diagnostic support. However, the resource available within the team to develop and/or deliver such services is limited.

The second related to the accessibility of group-based courses. The quantitative data indicated that the numbers of people assessed by the service (100 people in April to June 2024) are much higher than the numbers of people to whom it provides group-based support (25 people in the same period). Interviewees identified a number of reasons why group-based courses were not suitable for all, relating to travel; timing; dislike of group-based situations and the level of ongoing commitment required. Thus, although not everyone who is assessed will want or need support, it seems likely that many people would benefit from further alternative provision to group-based courses.

The third related to family members. The evidence indicated that people receiving assessments often felt that their relatives had a limited understanding of them and their experiences, and/or had an outdated understanding of autism. Family members could be sceptical or even opposed to diagnosis. Where this was the case, the pre-assessment period could be particularly challenging for individuals, and the benefits of receiving the diagnosis could be limited. Thus, although the service already runs a post-diagnostic group-based course aimed at family members, it may be helpful to supplement this provision with a resource that: (1) can be accessed pre-diagnostically; (2) supports a personalised understanding of the individual being assessed, as opposed to an understanding of autism in general; (3) requires a lower level of commitment than group-based courses, which may be off-putting to some family members.

Personalisation and connection

Consistent with findings elsewhere[9, 10], there is a wide range of support needs among those using the service. They encompassed a variety of topics including increased self-understanding and enhanced self-identity; support with activities of daily living; social relationships; and managing sensory differences. At an individual level, however, people tended to have a specific, individualised profile of needs, such that delivering relevant support in a group context was particularly challenging.

Another important point in relation to support was connection. Individuals sought out, and benefitted the most from, autism-related resources produced by autistic people, whose characteristics and experiences they could relate to. Similarly, the primary benefit of attending groups was connecting with other people. Shared experiences played a role in fostering individuals' developing autistic identity. This valuing of autistic connection reflects the findings of may other investigations of support for autistic people[6, 47-50].

Principles for developing support

Based on the evidence, there are five criteria that should guide the development of any new support tool:

- **Timely:** The tool should be available at a time when the individual was ready to access it, whether pre- or post-diagnostically, and outside working hours;
- **Accessible:** The tool should be accessible to those for whom group-based support is not suitable because of the group context, travel demands, or commitment required;
- **Shareable:** There is a particular need to support understanding of individuals' autism-related characteristics among family members, who may be less inclined to seek out relevant resources independently, and/or reluctant to commit to a group-based course. A resource that can be easily shared with family would be beneficial;
- **Personalised:** The tool should seek to maximise relevance to individuals, and foster a sense of shared experience and connection with other autistic people;
- **Feasible:** Delivery of support via the tool should take into account constraints on service resources.

Recommendations

We provide seven recommendations that relate to the use of the SQ-A-2 and RBQ-3 within GIAS.

The evidence we collected touched upon broad and varied topics relating to the provision of services at GIAS. However, in accordance with the scope of the current project, our recommendations are specific to the use of the SQ-A-2 and RBQ-3 within GIAS. It is, of course, entirely up to the service whether or not to adopt the recommendations made.

Recommendation 1	The service should continue to use SQ-A-2 and the RBQ-3 in the diagnostic process.
Recommendation 2	Individuals should be given additional information about the purpose and use of the questionnaires.
Recommendation 3	Individuals should be provided with a free text response box at the end of each questionnaire for additional comments about their responses.
Recommendation 4	Questionnaires should include space to record name of the person being assessed. Informant versions should also include space to record the relationship between the person completing the questionnaires and the person being assessed.
Recommendation 5	Questionnaires should include additional items on sensory differences.
Recommendation 6	Individuals should be offered the option to complete the questionnaires via an online form.
Recommendation 7	Questionnaires should be integrated into an online support tool, with bespoke resources are provided according to individuals' questionnaire responses.

Table 2: Table of recommendations for the GIAS based on the Service Evaluation

Use of questionnaires in the assessment process

Recommendation 1: The service should continue to use SQ-A-2 and the RBQ-3 in the diagnostic process.

Questionnaires add value both to the experiences of people undergoing assessment and to the diagnostic decision making process. Particularly given the fact that questionnaires are free to use and efficient to administer, we recommend that they continue to be used as part of the assessment process at GIAS.

In light of the majority view among clinicians that the RBQ-3 was felt to be more valuable than the SQ-A-2, we considered whether to recommend the continued use of the RBQ-3 only. However, the benefits reported by individuals in relation to self-reflection and insight were not specific to the RBQ-3. Asking individuals to complete only the RBQ-3 in advance of the assessment appointment would also risk giving an unbalanced picture of the topics to be covered in the appointment itself. Further, the SQ-A-2 added a tangible benefit to diagnostic decisions in cases where there was no informant, providing corroborative information and supporting compliance with NICE guidelines.

We make no recommendations as to the point of the process at which questionnaires should be used, i.e., whether they are best used as part of the referral or diagnostic decision. Rather, their flexibility is a strength, and they should continue to be used according to clinician preference and the needs of each individual case.

Recommendation 2: Individuals should be given additional information about the purpose and use of the questionnaires.

Individuals commonly express anxiety about their upcoming assessment, and/or a desire to know more about what it will entail. Individuals felt some frustration that the questionnaires did not present a complete picture of their characteristics. Completing the questionnaires could also bring up strong emotions. These difficulties might be mitigated by providing additional information at the point at which they are asked to complete the questionnaires. For example, in the covering letter or email, individuals could be advised that:

- the purpose of the questionnaires is to give a snapshot of their current characteristics and behaviour, not a complete picture;
- if they were unsure how to answer a question, they should give their best guess or pick the response closest to how they feel;
- they will have the chance to give more details about themselves at the appointment;
- no decisions will be made based on the questionnaires alone – they will be considered alongside all the other information gathered as part the assessment; and
- completing the questionnaires may bring up difficult thoughts or feelings, so it is recommended that they complete them when they are in a private place, when they have plenty of time to do so and, if possible, when emotional support is available.

Recommendation 3: Individuals should be provided with a free text response box at the end of each questionnaire for additional comments about their responses.

Individuals felt strongly that there was additional relevant information that they were unable to convey via the questionnaires, such as context about their response or behaviours that were not quite captured by the item wording. Being able to provide this additional information would give individuals increased confidence in the accuracy and/or completeness of their responses.

It is also important not to lose the distinct benefits of the questionnaires as brief measures of autistic traits. A proportionate means of recording additional information would be to include an optional free text response box at the end of each questionnaire, with an instruction such as: “If you would like to, you can provide any comments about your responses in the box below.”

Recommendation 4: Questionnaires should include space to record name of the person being assessed. Informant versions should also include space to record the relationship between the person completing the questionnaires and the person being assessed.

Currently, neither the name of the person being assessed nor, in the case of informants, their relationship to the person being assessed, are recorded on the questionnaire itself. It will not always be clear at the appointment who completed the questionnaire: many people are not accompanied at all, and those who are may have had the questionnaires completed by someone different e.g. a parent may attend the appointment to provide information about a person's early life, but a partner may have filled out the questionnaires about the person's current behaviour. However, the identity of the person completing the questionnaire and their relationship to the person being assessed was often important in interpreting the information it contained. Therefore, it would be helpful to record the name of the person being assessed and the relation of the informant to that person on the face of each questionnaire.

Recommendation 5: Questionnaires should include additional items on sensory differences.

Significant sensory differences and associated support needs were reported to be common by individuals and clinicians alike. Yet, as one individual pointed out, the SQ-A-2 and RBQ-3 contain limited coverage of sensory differences. An extended version of the RBQ-3 contains twelve additional items, eight of which relate to sensory differences as well as four relating to repetitive language. Including these additional items would be an efficient means of gathering relevant information for both assessment and support purposes.

Recommendation 6: individuals should be offered the option to complete the questionnaires via an online form.

Currently, individuals complete questionnaires either on paper or electronically in a Microsoft Word document. It is important to keep the option of completion by paper for people who prefer to do so. However, there would be several advantages to setting up an online version of the questionnaires, via a platform such as Microsoft Forms, to use where possible.

First, online versions of the questionnaires can be easily viewed and completed on a range of devices e.g. smartphones, tablets, computers. Copies of responses can also be sent automatically to respondents. They are therefore likely to be more convenient for individuals who fill them in.

Second, using automated processes, individuals who have been invited to complete the questionnaire can be automatically sent an email reminder to do so, if needed. This would reduce the need for questionnaires to be filled out at assessment appointments and/or requests followed up at a later date, saving time for both clinicians and administrators.

Third, online forms can be set up to require responses to all items; to ensure that only one response is given per item; and to provide standardised PDF versions of responses. This would make reading and interpreting questionnaire responses easier for clinicians.

Lastly, online forms could help automate questionnaire scoring. For example, questionnaire responses can be set up to be imported automatically into a spreadsheet, which in turn can generate questionnaire scores. Automated questionnaire scoring would save clinician time and reduce the possibility of error involved in manual scoring.

Use of questionnaires in a support tool

Recommendation 7: Questionnaires should be integrated into an online support tool, with bespoke resources are provided according to individuals' questionnaire responses.

Together, the SQ-A-2 and RBQ-3 itemise a range of autism-related characteristics and behaviours. It would be possible to identify support material relating to each item, or a group of items. The online tool could be set up so that, after an individual enters their questionnaire responses, they can access a package of resources relating to the items they endorsed. It could be viewed in sections or all at once, and re-viewed as needed.

The material in relation to each item could cover both its positive and challenging aspects, from the perspectives of other autistic people. For example, if an individual endorsed the RBQ-3 item relating to collecting or hoarding objects, the package of material provided could include a video in which autistic people talked about their experiences of the same thing e.g. what they collected and how their interest came about; the ways in which they enjoyed or benefited from doing so; whether they felt their approach to collecting differed to others, and if so how; any challenges associated with having a large collection, and how they navigated them. The material associated with each questionnaire item could either be co-produced with autistic people, or sourced in consultation with autistic people from pre-existing resources available online.

The tool could be distributed with minimal use of service resources. It could be accessed at any stage of the assessment process once the questionnaires had been completed, including pre-diagnostically, providing early help for those awaiting assessment and helping compliance with the Code of Practice requirement that support should be decoupled from diagnosis. The tool could be accessed by those for whom group-based courses were not appropriate e.g. because of the group context, timing, or travel requirements. The personalised nature of the content included would maximise the relevance of the information and support offered. Together with the focus on the similar experiences of others, the tool would help promote self-understanding and connection. If shared with multiple family members, a personalised package of material would also help individuals to explain the particular ways in which their autistic characteristics affected them, as well as to communicate ways in which they could be best supported. Its low commitment format may make it more likely to be accessed by family members reluctant to engage with group-based courses, or do their own independent research.

Concluding comments

This service evaluation explored the role of the SQ-A-2 and RBQ-3 in the GIAS.

Information from individuals accessing the service and professionals working within the GIAS converge to support the continued inclusion of the questionnaires in the service. Potential for the SQ-A-2 and RBQ-3 to play a role in the support provided to those accessing the service also emerged.

A set of seven recommendations provide a practical framework for enhancing and expanding the role of the questionnaires within the GIAS.

References

1. NHS Digital. Autism Waiting Time Statistics. 2024.
2. Holtom DL-J, S. Review of the Demand, Capacity and Design of Neurodevelopmental Services: Full Report. Cardiff: Welsh Government; 2022.
3. People & Work. Evaluation of the Code of Practice on the Delivery of Autism Services: Phase One (a practitioners' assessment of compliance). Cardiff: Welsh Government; 2024.
4. Cahill T, Dowling C, Banks R. A national framework to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards. 2023.
5. Hayes J, Ford T, McCabe R, Russell G. Autism diagnosis as a social process. Autism. 2022;26(2):488-98.
6. Beresford BA, Mukherjee SKM, Mayhew ET, Park A-L, Stuttard L, Allgar VL, et al. Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. Health Services and Delivery Research. 2020.
7. Wilson RB, Thompson AR, Rowse G, Freeth M. The experience of seeking, receiving, and reflecting upon a diagnosis of autism in the UK: A meta-synthesis of qualitative studies conducted with autistic individuals. Research in Autism Spectrum Disorders. 2023;103:102135.
8. Beresford B, Mukherjee S. Incorporating Psychoeducational Care in the Autism Diagnosis Pathway: Experiences, Views, and Recommendations of UK Autistic Adults and Autism Professionals. Autism in Adulthood. 2024.
9. Crane L, Batty R, Adeyinka H, Goddard L, Henry LA, Hill EL. Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. Journal of autism and developmental disorders. 2018;48:3761-72.
10. Crompton CJ, Hallett S, McAuliffe C, Stanfield AC, Fletcher-Watson S. "A group of fellow travellers who understand": Interviews with autistic people about post-diagnostic peer support in adulthood. Frontiers in psychology. 2022;13:831628.
11. Livingston LA, Davies G, Shah P, Layinka O, Carrington SJ, Leekam SR, et al. The Signposting Questionnaire for Autism-2 (SQ-A-2): Using Input from Autistic Adults to Inform Questionnaire Development. In prep. 2025.
12. Jones CR, Livingston LA, Fretwell C, Uljarević M, Carrington SJ, Shah P, et al. Measuring self and informant perspectives of Restricted and Repetitive Behaviours (RRBs): psychometric evaluation of the Repetitive Behaviours Questionnaire-3 (RBQ-3) in adult clinical practice and research settings. Molecular Autism. 2024;15.
13. National Institute for Health and Clinical Excellence. Surveillance of Autism: Surveillance Report. 2021.
14. Fletcher-Watson S, Happé, F. Autism: A New Introduction to Psychological Theory and Current Debate (2nd ed.). Routledge. 2019
15. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. 5th ed. Arlington, Va.: Arlington, Va.: American Psychiatric Association; 2013.

16. National Institute for Health and Care Excellence (NICE). Clinical Guideline 142: Autism spectrum disorder in adults: diagnosis and management. 2014, updated 2021.

17. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. Autism. 2016;20(4):442-62.

18. Cluley V. From "Learning disability to intellectual disability"—Perceptions of the increasing use of the term "intellectual disability" in learning disability policy, research and practice. British Journal of Learning Disabilities. 2018;46(1):24-32.

19. Welsh Government. Code of Practice on the Delivery of Autism Services. 2021.

20. Wigham S, Ingham B, Le Couteur A, Wilson C, Ensum I, Parr JR. A survey of autistic adults, relatives and clinical teams in the United Kingdom: And Delphi process consensus statements on optimal autism diagnostic assessment for adults. Autism. 2022;26(8):1959-72.

21. Rogers CL, Goddard L, Hill EL, Henry LA, Crane L. Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. Autism. 2016;20(7):820-31.

22. Spain D, Stewart GR, Mason D, Robinson J, Capp SJ, Gillan N, et al. Autism diagnostic assessments with children, adolescents, and adults prior to and during the COVID-19 pandemic: a cross-sectional survey of professionals. Frontiers in Psychiatry. 2022;13:789449.

23. National Autism Team. National Autism Team Annual Report 2022-23. Cardiff; 2024.

24. Underwood JF, DelPozo-Banos M, Frizzati A, John A, Hall J. Evidence of increasing recorded diagnosis of autism spectrum disorders in Wales, UK: An e-cohort study. Autism. 2022;26(6):1499-508.

25. Russell G, Stapley S, Newlove-Delgado T, Salmon A, White R, Warren F, et al. Time trends in autism diagnosis over 20 years: a UK population-based cohort study. Journal of Child Psychology and Psychiatry. 2022;63(6):674-82.

26. Huang Y, Arnold SR, Foley K-R, Trollor JN. Diagnosis of autism in adulthood: A scoping review. Autism. 2020;24(6):1311-27.

27. Cage E, Botha M, McDevitt L, King KN, Biscoe L, Tucker K, et al. Diagnosis as a new beginning not an end: A participatory photovoice study on navigating an autism diagnosis in adulthood. Autism. 2024:13623613231220418.

28. Lewis LF. Realizing a diagnosis of autism spectrum disorder as an adult. International journal of mental health nursing. 2016;25(4):346-54.

29. de Broize M, Evans K, Whitehouse AJ, Wray J, Eapen V, Urbanowicz A. Exploring the experience of seeking an autism diagnosis as an adult. Autism in Adulthood. 2022;4(2):130-40.

30. Stagg SD, Belcher H. Living with autism without knowing: receiving a diagnosis in later life. Health Psychology and Behavioral Medicine. 2019;7(1):348-61.

31. Hickey A, Crabtree J, Stott J. 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. Autism. 2018;22(3):357-67.

32. Lilley R, Lawson W, Hall G, Mahony J, Clapham H, Heyworth M, et al. 'A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. Autism. 2022;26(6):1395-408.

33. Jones L, Goddard L, Hill EL, Henry LA, Crane L. Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom. Journal of autism and developmental disorders. 2014;44:3033-44.

34. Kentrou V, Livingston LA, Grove R, Hoekstra RA, Begeer S. Perceived misdiagnosis of psychiatric conditions in autistic adults. EClinicalMedicine. 2024;71.

35. Ghanouni P, Seaker L. What does receiving autism diagnosis in adulthood look like? Stakeholders' experiences and inputs. International Journal of Mental Health Systems. 2023;17(1):1-10.

36. Holtom DL-J, S. Evaluation of the Integrated Autism Service and Refreshed Autism Spectrum Disorder Strategic Action Plan. 2019.

37. Arnold SR, Huang Y, Hwang YI, Richdale AL, Trollor JN, Lawson LP. "The single most important thing that has happened to me in my life": Development of the Impact of Diagnosis Scale—Preliminary Revision. Autism in Adulthood. 2020;2(1):34-41.

38. Beresford BA, Mukherjee SKM. Providing psychoeducation after an autism diagnosis: findings from an evidence-based consultation project. University of York. 2023.

39. Tan CD. "I'm a normal autistic person, not an abnormal neurotypical": Autism Spectrum Disorder diagnosis as biographical illumination. Social Science & Medicine. 2018;197:161-7.

40. Powell T, Acker L. Adults' experience of an Asperger syndrome diagnosis: Analysis of its emotional meaning and effect on participants' lives. Focus on Autism and Other Developmental Disabilities. 2016;31(1):72-80.

41. Rutherford M, Boilson M, Johnston L, MacIver D, Curnow E, Utley I. Neurodevelopmental Pathways: Report on Actions, Outcomes and Recommendations from Pathfinder Sites in Scotland. In: Team NAI, editor. 2023.

42. Scottish Government. National Autism Post-Diagnostic Support Service: Evaluation of pilot programme 1st Dec 2020 -1st June 2021. 2022.

43. Rutherford M, McKenzie K, Forsyth K, McCartney D, O'Hare A, McClure I, et al. Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children. Research in Autism Spectrum Disorders. 2016;31:53-65.

44. Powell LJ, Spelke ES. Human infants' understanding of social imitation: Inferences of affiliation from third party observations. Cognition. 2018;170:31-48.

45. Norris JE, Harvey R, Hull L. Post-diagnostic support for adults diagnosed with autism in adulthood in the UK: A systematic review with narrative synthesis. Autism.0(0):13623613241273073.

46. Wigham S, Ingham B, Le Couteur A, Wilson C, Ensum I, Parr JR. Consensus statements on optimal adult post-autism diagnosis support and services: Delphi process following a UK survey of autistic adults, relatives and clinicians. Autism. 2023;27(2):344-55.

47. Southby K, Robinson O. Information, Advocacy and Signposting as a Low-Level Support for Adults with High-Functioning Autism Spectrum Disorder: An Example from the UK. Journal of Autism and Developmental Disorders. 2018;48(2):511-9.

48. McConkey R, Cassin M-T, McNaughton R, Armstrong E. Enhancing the social networks of adults with ASD: a low level community intervention. Advances in Autism. 2021;7(4):322-34.

49. Crane L, Hearst C, Ashworth M, Davies J, Hill EL. Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. Journal of Autism and Developmental Disorders. 2021;51(3):892-905.

50. Hatton VA, Lee MX. An evaluation of the online post-diagnostic groups facilitated by the autism spectrum condition service at Gloucestershire Health and Care NHS. Advances in Autism. 2022;8(4):319-31.

51. Crane L, Hearst C, Ashworth M, Davies J. Evaluating the online delivery of an autistic-led programme to support newly diagnosed or identified autistic adults. Autism & developmental language impairments. 2023;8:23969415231189608.

52. Jones CRG, Barrett SL, Bite I, Legzdina M, Arina K, Higgins A, et al. Development of the Signposting Questionnaire for Autism (SQ-A): measurement comparison with the 10-item Autism Spectrum Quotient-Child and the Strengths and Difficulties Questionnaire in the UK and Latvia. Molecular autism. 2020;11(1):64.

53. Wing L, Leekam SR, Libby SJ, Gould J, Larcombe M. The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. J Child Psychol Psychiatry. 2002;43(3):307-25.

54. Carrington S, Leekam S, Kent R, Maljaars J, Gould J, Wing L, et al. Signposting for diagnosis of Autism Spectrum Disorder using the Diagnostic Interview for Social and Communication Disorders (DISCO). Research in Autism Spectrum Disorders. 2015;9:45-52.

55. Carrington SJ, Kent RG, Maljaars J, Le Couteur A, Gould J, Wing L, et al. DSM-5 Autism Spectrum Disorder: In search of essential behaviours for diagnosis. Research in Autism Spectrum Disorders. 2014;8(6):701-15.

56. Allison C, Auyeung B, Baron-Cohen S. Toward brief "Red Flags" for autism screening: The Short Autism Spectrum Quotient and the Short Quantitative Checklist for Autism in toddlers in 1,000 cases and 3,000 controls [corrected]. Journal of the American Academy of Child and Adolescent Psychiatry. 2012;51(2):202-12 e7.

57. Barrett SL, Uljarevic M, Baker EK, Richdale AL, Jones CR, Leekam SR. The Adult Repetitive Behaviours Questionnaire-2 (RBQ-2A): A Self-Report Measure of Restricted and Repetitive Behaviours. J Autism Dev Disord. 2015;45(11):3680-92.

58. Arnott B, McConachie H, Meins E, Fernyhough C, Couteur AL, Turner M, et al. The Frequency of Restricted and Repetitive Behaviors in a Community Sample of 15-Month-Old Infants. Journal of Developmental & Behavioral Pediatrics. 2010;31(3).

59. Lidstone J, Uljarevic M, Sullivan J, Rodgers J, McConachie H, Freeston M, et al. Relations among restricted and repetitive behaviors, anxiety and sensory features in children with autism spectrum disorders. Research in Autism Spectrum Disorders. 2014;8:82-92.

60. Barrett SL, Uljarević M, Jones CRG, Leekam SR. Assessing subtypes of restricted and repetitive behaviour using the Adult Repetitive Behaviour Questionnaire-2 in autistic adults. Molecular autism. 2018;9(1):58.

61. Carrington SJ, Barrett SL, Sivagamasundari U, Fretwell C, Noens I, Maljaars J, et al. Describing the Profile of Diagnostic Features in Autistic Adults Using an Abbreviated Version of the Diagnostic Interview for Social and Communication Disorders (DISCO-Abbreviated). J Autism Dev Disord. 2019;49(12):5036-46.

62. Welsh Government. Refreshed Autistic Spectrum Disorder Strategic Action Plan 2016.

63. Scott FJ, Baron-Cohen S, Bolton P, Brayne C. The CAST (Childhood Asperger Syndrome Test): preliminary development of a UK screen for mainstream primary-school-age children. Autism. 2002;6(1):9-31.

64. Lord C, Risi S, Lambrecht L, Cook EH, Leventhal BL, DiLavore PC, et al. The Autism Diagnostic Observation Schedule—Generic: A standard measure of social and communication deficits associated with the spectrum of autism. Journal of autism and developmental disorders. 2000;30:205-23.

65. Braun V, Clarke V. Thematic Analysis: A Practical Guide: SAGE Publications; 2021.

66. Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. Journal of autism and developmental disorders. 1994;24(5):659-85.

67. Nicolaidis C, Raymaker DM, McDonald KE, Lund EM, Leotti S, Kapp SK, et al. Creating accessible survey instruments for use with autistic adults and people with intellectual disability: Lessons learned and recommendations. Autism in Adulthood. 2020;2(1):61-76.

68. Stacey R, Cage E. "Simultaneously Vague and Oddly Specific": Understanding Autistic People's Experiences of Decision Making and Research Questionnaires. Autism in Adulthood. 2023;5(3):263-74.