

Children's ASD diagnostic services in Wales

**Methods of diagnostic practice
and clinicians' views of service effectiveness**

December 2010

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Executive Summary

An evaluation study of children's diagnostic services was undertaken by the Wales Autism Research Centre between June and October 2010. The study aimed to contribute to the delivery of the Welsh Assembly Government's ASD Strategic Action Plan by providing information about diagnostic systems and methods of practice and by identifying areas for future improvement in service provision and organization.

The study had two main objectives. The first was to obtain information on existing children's diagnostic services. The questions here included how and by whom services are delivered, the methodologies used, and the resources available, especially with regard to the funding and delivery of specialist/ tertiary services. The second objective was to gain clinicians' own evaluation about the effectiveness of current diagnostic services, including their evaluation of strengths, weaknesses and potential for improvement.

These objectives were met in a two-part study carried out over five months. First, a focus group was held to gain the views of nine participants drawn from five different professional groups and regions in Wales. The focus group study elicited participants' views about a number of issues. These included; factors influencing the diagnostic process, their experience of the diagnostic process and their views about post-diagnostic support. The focus group also discussed two key issues raised as recommendations for practice within the Strategic Action Plan for ASD; that is, multidisciplinary working and consistency in services. Results from the focus group study helped to guide question design for a questionnaire survey that was targeted at all clinicians in Wales who were involved in diagnosing children with ASD. The questionnaire survey gathered factual information from individuals about how services are delivered in their own service and by whom, the methodologies used in assessing and diagnosing children, and how specialist services are funded. Clinicians' views on barriers and improvements to best practice were also elicited in the questionnaire study.

In addition to the formal focus group and questionnaire study, meetings were held with professionals within WAG such the regional support officers and the regional coordinator for the WAG ASD Strategic Action Plan and lead of CAMHS strategy for WAG, in a plan to trace information on the diagnostic services available in each local authority area and identify lists of clinicians involved in diagnosis. Initial service user comments were also sought and additional information was obtained from independent clinical consultants in England who provide diagnostic services in Wales.

With respect to the first objective, to obtain information about the delivery of existing diagnostic services, findings showed that children's ASD diagnoses are predominantly delivered by multidisciplinary teams in line with the guidelines of the WAG Strategic Action Plan for Autism and the National Autism Plan for Children. However there were striking differences evident in organisational structure and processes. Multidisciplinary team working included different configurations of professionals and different organisational procedures across different regions. Furthermore, although the responsibility for diagnostic processes and decision making belonged to a group of professionals, only approximately half of cases were reported as dealt with in a 'truly' multi-disciplinary way (defined by clinicians in terms of involvement of team members in joint decision making). This percentage was significantly lower than the percentage that questionnaire participants reported as desirable. In many cases, the structure and organisation of team working was reported to be inadequate to allow for time-efficient practices, effective communication or joint decision making.

Investigation of the methodologies used in diagnostic practices showed that clinicians used observation and developmental history assessments in the vast majority of cases and for about 2/3 of cases these were standardised assessments. Approximately half of the respondents used and had received training one of the following published diagnostic measures (ADOS, ADI-R, DISCO, 3di), though a much smaller proportion had met the 'passing-out' criteria following training, with

little scope for trained users of these tools to train others within teams. The most used instrument was the observation tool, the ADOS.

Study of the provision of specialist services showed that most if not all health boards have a specialist service but that, as far as respondents were aware these are not funded as tertiary services. These specialist services rely on the goodwill of clinicians who contribute to them. They are not receiving the appropriate funding and are therefore severely under resourced, contributing to the strains and difficulties reported throughout this report. The study also showed that diagnostic consultancy is also bought in from outside Wales by at least one health board to deal with complex, difficult to diagnose cases.

The second objective was to gain clinicians' own evaluation about the effectiveness of current diagnostic services, including their evaluation of strengths, weaknesses and potential for improvement. Clinicians' showed recognition of the value of both multidisciplinary working and consistency of practice, balanced against the challenge of severe time and resource restrictions and need for autonomy in clinical judgement when making a diagnosis. They also recognised the value of the objectivity and consistency offered by standardised diagnostic methods such as the Autism Diagnostic Observation Schedule. However, barriers and disadvantages also existed including time, confidence to use them, and lack of language translation. Autonomy of clinical judgement and assessment of child's needs beyond the use of these tools for diagnostic decision making was also emphasised. Clinicians proposed that improvements can be made to services by building clinical expertise and resources, streamlining diagnostic processes and improving structural and organisational systems.

While recommendations arising from this study should address long-term concerns, it is understood that at the current time any additional funding resource for follow-on work can only be limited to one year. As a result, the recommendations have been prioritised so that they incorporate short term actions at low cost that will be likely to have longer-term implications.

These recommendations are;

1. To develop a *network of expertise and mentoring* be developed that will support multi-agency clinics at a regional level and make links with adult diagnostic services. The goal is to enlarge the community of expertise with Wales, to enhance training and skill in diagnostic work for complex cases and to provide a forum to support the optimal delivery of multidisciplinary team working practice.

2. To facilitate *changes to organisational systems for diagnosis* including a) clearer mapping of service organisation, b) identification of referral pathways and tracking of individual services and c) a service delivery framework with operating guidelines and procedures. The goal is for a framework of practice, the content and consistency of which is negotiated between clinicians, NHS and Welsh Assembly Government.

The recommendations that follow from this study will help to inform policy direction in the area of children's ASD diagnostic services, especially with respect to specialist services for complex and difficult to diagnose cases. The recommendations also enable the Welsh Assembly Government to identify how plans for future improvements in children's diagnostic services can be connected with planning already in place for the provision adults' diagnostic service, and to compare diagnostic services and methods in Wales with those elsewhere in the UK and internationally.

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Children's ASD diagnostic services in Wales: Methods of diagnostic practice and clinicians' views of service effectiveness

1 Introduction

A study was carried out by the Wales Autism Research Centre between June-October 2010 in response to a Welsh Assembly Government tender to evaluate diagnostic services for children with Autism Spectrum Disorders (ASD) in Wales. The issue leading to the tender was the need to gain a definitive understanding of the scope and nature of children's ASD diagnostic services including specialist and tertiary level services in Wales. This issue is of key importance to the delivery of the Welsh Assembly Government's ASD Strategic Action Plan. Response to this issue will enable the Welsh Assembly Government to identify strengths and weaknesses within these services, inform policy developments in this area, especially with respect to specialist and tertiary services, enable potential linking with recommendations for adult services and facilitate comparisons between diagnostic services in Wales and elsewhere in the UK and internationally.

1.1 Aims and objectives

To address the specifics of this issue, the evaluation study aimed to provide information about diagnostic systems and methods of practice and identify areas for future improvement in service provision and organization as identified by clinicians.

The objectives of the evaluation study were to:

1. Obtain information on (a) how and by whom diagnostic services are delivered (b) the methods used in the diagnosis process and (c) how specialist services are delivered and funded
2. Obtain clinicians' views about the effectiveness of current diagnostic services, including their evaluation of strengths, weaknesses and potential for improvements.

1.2 Project team

The project team was led by Professor Sue Leekam, Chair in Autism Research, Cardiff University (Principal Investigator).

- Dr Jane Lidstone, Research Associate
- Dr Dawn Wimpory, Clinical Psychologist, BCUHB & University of Bangor (Co-Investigator)
- Dr Chris Ramsden, Evaluation and organisational consultant (Focus group facilitator)
- Hugh Morgan, OBE, Welsh Assembly Government ASD Implementation Manager
- Social Services Improvement Agency (SSIA) Regional ASD Support Team, David Poole, Jo Manikiza, Sharon Walters and Mary Rendell.

The total cost of project was £24,999, drawn from the existing annual ASD Grant of £1.8m and the work was carried out during the five month appointment of Dr Lidstone.

1.3 Background

Autism Spectrum Disorder (ASD) is the term used to refer to the spectrum of conditions otherwise described in international diagnostic classification systems as Pervasive Developmental Disorders. Autism spectrum disorder includes classic forms of autism and related conditions including Asperger's syndrome and atypical autism. ASD is a life-long condition. Symptoms are usually apparent in the first three year of life and diagnosis most commonly place from two to four years of age although it can take place later. Prevalence figures for the UK show a prevalence rate of up to 1% of the population (Office for National Statistics, 2004; Baird et al., 2006). The most recent prevalence study for Wales was carried out in 2007 in South Wales and reported prevalence rate of 60 per 10,000 (Latif & Williams, 2007).

National clinical guidelines for assessment and diagnostic practice were issued in the UK in 2003 (National Autism Plan for Children, 2003). The guidelines were published by The National Autistic Society (NAS) in collaboration with the Royal College of Paediatrics and Child Health and the Royal College of Psychiatrists and included a comprehensive set of recommendations regarding assessment and diagnosis of children. Separate guidelines were written specifically for Scotland (Scottish Intercollegiate Network Guidelines, 2007).

In 2008 the ASD Strategic Action Plan was published in Wales. This is a ten year action plan setting out the strategic direction for services for children and adults with ASD. The Strategic Action Plan included specific recommendations for identification, assessment and diagnostic practice. These recommendations followed recommendations for standards set by the National Autism Plan for Children regarding the assessment and diagnosis of children with ASD. The ASD Action Plan proposes that diagnosis should take the form of a multidisciplinary assessment including both generic and specialist components, although in less complicated cases assessment by a single discipline is adequate. It also recommends an all-Wales approach to services for ASD, favouring coordination across regions and consistency in practice where possible.

While the recommendations of the WAG Strategic Action Plan have now been in place for eighteen months, no information has yet been collected on the specifics of children's assessment and diagnostic services in terms of how they operate in practice. For example, how they are delivered, by whom, the methodologies used, and the provision for specialist diagnostic services. Baseline survey data collected by WAG for the ASD Action Plan reported initial information from local authorities about the numbers of individuals with ASD and the provision of services. Also in 2002, a report of Children's Diagnostic Services in Wales was published (Lowe, 2002). This report provided an outline of specialist diagnostic services available at that time. The report predated the ASD Strategic Action Plan and changes to these data were expected. The goal of the proposed evaluation work was to build on these earlier studies, by providing information on the delivery of children's diagnostic services at the current time.

The remit of the study was to obtain specific information and views regarding the scope and nature of children's diagnostic services with respect to the diagnostic process itself. Related issues of pre and post-diagnostic support and the referral process were not included in this remit. However, these issues are closely linked and some information was also gathered in the process of the study about diagnostic referrals and about post-diagnostic support and result are reported briefly in the results section only. This particular study was also directed specifically towards clinicians to obtain information about their practices and gain their own evaluation about the effectiveness of services in Wales. Future work should focus on others' perspectives, particularly the parent perspective and some initial information has been collected and reported in preparation for this which is included in the discussion section.

The report below outlines the method and results of the two linked studies. A further point concerns reference to professionals. Both health and education professionals are involved in children's ASD diagnoses. Professionals involved may include psychiatrists, paediatricians, clinical psychologists,

educational psychologists, speech and language therapists, occupational therapists, social workers, nurses Throughout the report we use the term 'clinician' to refer to all professionals delivering clinical diagnostic services, while acknowledging that a proportion of these team members are not clinicians (e.g., educational psychologists or social workers).

1.4 Overview of method

There were two main elements of the investigation, both of which aimed to gather information from a sample of clinicians involved in children's ASD diagnosis to address the following objectives

Objectives:

1. To obtain information on (a) how and by whom diagnostic services are delivered (b) methods used in the diagnosis process, and (c) how specialist services are delivered and funded
2. To obtain clinicians' views about the effectiveness of current diagnostic services, including their evaluation of strengths, weaknesses and potential for improvements.

The elements of the investigation were:

- 1) A focus group session of 8-10 participants, designed to: (a) gain an understanding of the diagnostic process, and the strengths and weaknesses of diagnostic services, in relation to the ASD Strategic Action Plan, and; (b) facilitate the development of a questionnaire (see below).
- 2) A questionnaire, to be sent to as many relevant health and education professionals as possible that would ask questions relating to the study objectives.

1.5 Preliminary data searching

Following approval from Cardiff University's School of Psychology Ethics Committee (Feb 2010), preliminary data searching began. The initial goal was to obtain a list of all clinicians involved in children's ASD diagnosis in Wales, from which a focus group could be recruited and a questionnaire mailing list constructed. The approach planned was to be both 'bottom-up' and 'top down'. The goal for a top down approach was to gain information about the organisation of diagnostic teams, through heads of services, in order to compile a 'map' of the structure and organisation of diagnostic services across the regions within Wales. Such a map, giving information on multidisciplinary team structure, could help to inform the specifics of questions for the questionnaire so that questions would be relevant to different regional areas. Meanwhile the goal for the 'bottom up' approach was to compile lists of individual clinicians through contacts; on the ground' enabling clinician numbers to be checked against numbers collected through other sources.

The regional coordinator of the ASD Strategic Action Plan and the three regional support officers contributed to the data searching relevant to both approaches. However any method that was used to access records through heads of services did not yield the information needed. A subsequent meeting with the lead of the CAMHS strategy for WAG, revealed that the organisational and management structure that encompasses ASD diagnostic services for children is highly complex and variable, making the communication of organisational arrangements opaque not only across Wales but also even within Health Boards. Therefore this study relied solely on information gained through 'bottom up' sources.

Information for the contact list using these sources was compiled in stages. This work started three months before the beginning of the 5-month project, and continued for two months after its start date until the questionnaire was sent out. The initial list was compiled by the regional support officers. This was added to with help from local ASD leads. Then clinicians named on this list were contacted by the researcher, to ask if they could provide contact details of their colleagues and if they could add anyone they thought was missing. The final list of clinicians used in the study is summarised in Table 1.

Table 1: Number of professionals identified as being involved in children’s ASD diagnosis

Professional group	Number
Clinical psychologists	37
Educational psychologists	64
Paediatricians	51
Psychiatrists	28
Speech and language therapists	15
Other*	30
Total	253

*e.g., Occupational therapists, specialist nurses

2 Focus Group Study

2.1 Method

There were nine participants representing the health and education professions involved in the ASD diagnostic process: one psychiatrist, two paediatricians, two clinical psychologists, two educational psychologists and two speech and language therapists (SaLTs). These participants came from regions across north, south, west and mid-Wales. The participants were selected from an initial list, compiled by the regional support officers (see section above). In most cases a senior representative of each professional group was selected.

A set of semi-structured questions were designed in accordance with the objectives and main evaluation questions. The goal of these questions was to gain an understanding of the diagnostic process, and elicit clinicians' views the effectiveness of current diagnostic services, particularly in relation to the ASD Strategic Action Plan. The focus group also provided an opportunity to explore experiential issues and clinicians perceptions and attitudes. Background information sent to participants before the meeting is shown in Appendix A.

In summary, the first half of the session elicited participants' accounts of;

1. The factors that influence the diagnostic process and/or decision,
2. Their experience of making diagnoses,
3. The perceived value of diagnostic instruments.

These questions helped to provide insights on how and by whom diagnostic services are delivered and the methods used in the diagnostic process. Although the remit of the study was confined to the diagnostic process, two other questions were asked at the beginning and end of the first part of the session, in order to gain understanding of the contextual factors influencing diagnosis. These related to the referral process (how referrals come in to their team) and post-diagnostic support for parents (how referrals for post-diagnostic support work in practice).

In the second half of the session, participants' views were elicited on their interpretation of themes of the Strategic Action Plan, namely *multidisciplinary working* and *consistency of practice and structures* across health boards.

As well as providing detailed qualitative data, focus group questions also facilitated and informed the design of questions for the subsequent questionnaire. A semi-structured proforma was prepared to facilitate group discussion and focused dialogue.

2.2 Results

Sections 2.2.1 to 2.2.5 below summarise responses to the questions asked by the facilitator for the first half of the session and Sections 2.2.6 and 2.2.7 summarise responses for the second half.

Initial discussion revealed that the configuration of teams dealing with diagnostic assessment and diagnosis was variable across welsh regions, from one dedicated multi-disciplinary team including a consultant psychiatrist, clinical and educational psychologist and SaLT, to a generic social and communication team. Configurations also included Participants also included more independent individuals (e.g. SaLTs), who were drafted into case meetings and not otherwise part of the diagnostic team. Overall, however, it was not possible to discern a model of a core diagnostic or assessment team from the focus group data.

2.2.1 How do referrals come into your team/profession?

Participants reported that referring agents could be multi-agent based, including other teams (e.g. CDTs: Child Development Team) or individuals, including SaLTs, schools, parents, educational psychologists and paediatricians. Indeed, initial referral processes and 'roll-on' pathways for diagnostic assessment were quite variable both within and among Welsh regions and there was clear recognition of this. The focus group also evidenced that there were both open-referral systems for diagnostic assessment (e.g. from parents, schools and paediatricians) and more closed 'screening systems' which used a gate-keeping approach; accepting only referrals from certain known sources which had already engaged in some prior screening or assessment of the child. This was particularly evident in tertiary teams, where the referral would only come formally in writing from the paediatrician.

2.2.2 Factors influencing the diagnostic process

Participants were asked to prepare the answer to the following question prior to coming to the focus group meeting: *What are the most important external factors that influence the diagnostic process and/or decision?* Participants were asked to rank the following answers according to their importance, and to add any others they felt to be important.

- Child's need for services
- Opinions of parents and school
- Policy
- Resources (time, money) in comparison to demand for services
- Targets / performance indicators

Answers were subsequently discussed at the focus group meeting. The top three answers were: the child's need for services; the opinions of parents and school; and resources (time, money) in comparison to the demand for services. The first two are intrinsically linked and therefore are reported together.

Child's need for services and opinions of the parents and school

Participants reported that, in a broad sense, the child's need for services influences the diagnostic process in cases where the child is in crisis at school or where the family is in crisis at home. Where there is a pressing issue of this nature, this influences "what you do or where you go to gather information – you go where things are falling apart because you want to make things better. That's what we're here for – not just a diagnosis of autism or not." In this respect the multidisciplinary approach to assessment was described as being particularly useful, for gaining a complete and rounded understanding of the child's and family needs and the provision of optimally effective interventions.

However, participants indicated that the child's need for services also influences whether or not children are placed on the autism spectrum, considering that this may make them eligible or ineligible for particular services. "If you have a child who is not typically autistic but they have the same needs at school as someone who does have autism, you think, 'What do I call this child in order for them to have a happy life and to get the services they need?' A PDD-NOS label serves that purpose." Another participant indicated that, in her locality, having an ASD label is detrimental, considering that provision for language disorders is good whereas provision for ASD is not, and having an ASD diagnosis precludes a child from entering a language provision. This all stems from the fact that "resources fund diagnoses," within both education and health: "A child with identical need, if they have ASD they get a service, and if they haven't, they won't." Participants reported being in a great dilemma as a consequence: "It puts pressure where pressure shouldn't be,

because our job should be to describe the child as best we can, and to have their needs met,” whether or not they get a diagnosis. This was described by one participant as producing a poorer service for children with complex difficulties, because these children do not fall neatly into any diagnostic category.

Participants reported that parents are sometimes aware of these issues, and that some parents are keen to get a diagnosis and a statement of special educational needs so their child can access an appropriate intervention. Additionally, parents’ views necessarily influence the diagnostic process considering that they provide the main source of the developmental history. Participants acknowledged that it’s very difficult for parents to remember the precise details and dates that milestones were reached; one participant noted that some parents are very well informed about autism and this can sometimes influence their reporting of their own child’s developmental history.

Resources

The group reported that the resource they lacked most was time, and they identified the biggest unnecessary drain on their time as resulting from the lack of dedicated administrative support. Health professionals tended to give their own time to fulfil administrative obligations. One participant stated that, when they lost their ASD coordinator for six months, “really [they] didn’t operate for that period of time.” There was general agreement, that, especially in multi-agency teams, coordination was a crucial aspect of effective work. Key administrative tasks that currently consume a lot of clinicians’ time include organising meeting times and spaces, making phone calls and typing letters, and collating information.

One participant stated that his team was affected by CAMHS waiting targets, “an absolute disaster. The only thing anyone’s interested in is getting them off [the waiting list] – the fact that people’s assessments might run for 8 to 12 months doesn’t seem to come into it, just as long as you get everyone off.” It seemed to the participants that “the diagnosis becomes unimportant – it’s all about giving the diagnosis *now*.” This is a particular issue considering that children’s access to services depends on their having a label. If there were systems in place for dealing with children’s *needs* (as opposed to their diagnoses), then the diagnostic process could be done more thoroughly.

2.2.3 Experience of the diagnostic process

What is the experience of making diagnoses like?

Although most professionals accepted it as an inevitable part of the job, there was a consensus in relation to this question: Professionals agreed that the experience of giving a diagnosis to families was emotionally challenging and very variable. For many families the diagnostic disclosure is “something that they will remember for the rest of their lives” and often is “a huge blow.” Several participants had experienced families in tears at the time of diagnosis. In other cases diagnostic disclosures are met with happiness and relief from parents, if they feel that, upon receiving the diagnosis, “someone has finally acknowledged what they already knew for years.” Even when parents are expecting it, however, sometimes “the rubber stamp is different” and there is a lot of sadness. No matter what the parents’ reaction though, “it’s not just a yes or no – it’s about coming up with an understanding of the child that helps something move on,” and therefore “a huge responsibility.”

To what extent do these issues affect the diagnostic process and diagnostic decisions?

Because the experience of giving the diagnosis can be anxiety provoking and emotional for health professionals, many in the group stated the benefits of being supported by colleagues, both in reaching the diagnostic decision, and during the diagnostic disclosure interview. Participants commented that the most important thing is that “it’s never done on your own,” in order that these issues do not affect the diagnostic decision. For one service, one of the professionals present would already be known to the parents—having attended school or home visits, thereby forming a relationship with the families, but this is not always possible given limited resources.

Moreover, professionals felt much better about giving a diagnosis if they could offer some level of immediate post-diagnostic support. One team had sufficient resources to follow up the diagnosis 48 hours later with a phone call and this was viewed as especially beneficial. However, for other services this level of post-diagnostic support was not possible due to limited resources. And it was this that was described as the most challenging aspect of the job: It’s easy to say “your son has autism,” but much harder to say that there’s nothing there to support him or the family. As one participant said, “The worst is, actually, [that] you sometimes feel as if you’re sending people out into an abyss.”

This question also raised an important concern for members in terms of the amount of time available for each diagnosis. Participants stated that, if done in a caring way, the whole diagnostic and assessment process was very time consuming and the total amount of time professionals have to spend on the diagnostic process was often not taken into account by higher levels of the organisation. Activities not taken into account include “properly and carefully taking parents from the start of the process through to the end,” thinking through the implications of the diagnosis and assessment for intervention, and writing and sending detailed reports—in short, supporting parents during the diagnostic process and “[doing] a proper hand-over” to post-diagnostic services. These activities were described as “add-on bits” that were not taken into account “at the level above” and that were not properly resourced.

How could the experience be improved?

Echoing another participant’s comment above, one participant questioned the idea that a quick diagnosis is good for families. “I think it should be a process – almost by the time they get to it saying ‘Oh come on tell me, I already know.’ That’s how I would like them to be.” She said that to diagnose quickly isn’t necessarily the most sensible thing, “and maybe we need to have more of a dialogue with parents about the nature of the diagnostic process and why we take time to do it in a certain way.” This sentiment was met with agreement by other members of the focus group.

4. Perceived value of diagnostic instruments

How do you use diagnostic instruments?

The ADI and ADOS were the most commonly employed diagnostic tools, although a child psychologist reported that in some cases interview schedules, like the ADI and 3di, are more likely to be used instead of the ADOS. Participants varied in terms of:

1. In what proportion of cases they used diagnostic tools;
2. Where in the assessment cycle tools were used;
3. The manner in which tools were used.

1. One participant reported that, in her team, tools would not be used if the child was well known to the service, if they are known to meet the DSM criteria, or “if it is obvious they are classically autistic when they come in to the room.” In contrast, another participant reported using the ADOS and 3di in all cases.

2. One participant stated his team always uses both the ADOS and the ADI, and that where the results of these two assessments disagree a school visit would be conducted. Representatives of two different teams reported undertaking a developmental history and school visit in the first instance and only then, if there was still uncertainty, using an ADOS.

3. Several participants reported taking items from diagnostic tools and blending them into their own unique assessment, whereas others reported using the tools exactly as described in the handbooks and using the scoring system to the letter.

What is the value of the training associated with using diagnostic instruments?

Whilst there was some discussion concerning the importance of training in the use of diagnostic instruments, there was also some controversy concerning the status of the actual evidence base for the integrity of these instruments. Where value was given to having the training in ADOS and ADI, this was to remind professionals of the rigour to which instruments should be used and the ongoing support offered by the trainers. It was also reported that there had been some problems when staff members had not been trained in the use of the instruments.

However, there was clear consensus about not over-emphasising the importance of formal instruments and tools in making a diagnostic assessment. Rather, the participants stressed, (a) the role of their pre-existing expertise and psychological knowledge (b) their experience, and importantly (c) the role of clinical judgement. The group reported that instrument trainers were right to stress the importance of making a professional clinical judgement and that it's not just the “numbers on the page”.

What is the value of using diagnostic instruments in practice?

Standardisation, objectivity and robustness were viewed as critically important factors in terms of using diagnostic instruments in practice. A structured tool helps parents understand what has been done in the session and the use of a standardised tool allows for inter-rater agreement between professionals from different disciplines. Whilst clinical judgement is strongly valued by members of the focus group, having the instrument for use also means that bias can be minimised and offset.

What are the barriers to using these instruments?

Having the confidence to start using the tools, the physical space to undertake the assessment and the financial resources to purchase the equipment were seen as significant barriers to use of the instruments. Travelling across the region to undertake diagnostic assessments was also seen as a barrier for one participant from the north west of Wales.

Participants stated that training can be very time consuming and expensive; it usually takes place in Cambridge or the South East of England, and it is limited in its availability. It also requires maintenance and succession planning in order for all members of the team to be successfully engaged in the process.

Some members of the group felt that the length of time needed to implement the tests can be somewhat prohibitive, although one participant said that she felt using diagnostic tools increases the (time-) efficiency of information gathering.

Importantly, it was further noted that professionals should be aware of the rights of children and their families to have the tests performed in their first language e.g. Welsh, Bengali, Somali, but that translation could also be both time consuming and expensive.

What other training or mentoring would you benefit from and/or what would you have benefitted from in the past?

A number of participants viewed supervision in the use of certain instruments (e.g. 3DI) particularly valuable, especially with regard to those cases involving complex and borderline cases. Participants further reported that any training related to autism is useful, not just that restricted to the use of the tools or instruments. Echoing an earlier point, one member emphasised the primary importance of “a sound, broad knowledge of autism.” And that “in the end, whilst the instruments help structure thinking...it comes down to your (professional) judgement.” In response to this question there was also consensus underscoring the importance of accumulated experience of field observations of children, in the development of this level of expertise, skill and practitioner knowledge.

2.2.5 Provision of post-diagnostic support

How does referral for post-diagnostic support work in everyday practice?

There seemed to be different definitions of post-diagnostic support implicit in the group's responses, and each of these will be dealt with separately below:

1. Helping parents to come to terms with the diagnosis (e.g. identifying their difficulties, answering their questions about the diagnosis, and providing brief post-diagnostic counselling).
2. (a) Pointing parents towards other services that provide support beyond diagnosis and in the direction of support groups.

(b) Referring children for interventions to “treat” autism.

In terms of helping parents to come to terms with the diagnosis, responses to the previous question indicated that clinicians feel they do not have time to do this adequately.

In terms of *support*, one participant mentioned the Help! programme provided by the NAS—seminars which offer support for parents and carers of school-age children who have a recent

diagnosis of an autism spectrum disorder (ASD), but this was mentioned only in relation to mid-Wales.

In terms of *intervention*, participants commented on the variability of intervention available even between small geographical areas. Intervention will not be discussed further here because it is outside the remit of this report.

Analysis of the responses suggests that the line between 2a (*support*) and 2b (*intervention*) is somewhat blurred as: (a) intervention was mentioned in this section on post-diagnostic support but it was not mentioned in participants' description of post-diagnostic support when they were later asked explicitly to define it, (b) some services aim to provide support to parents AND treatment for the child; for example, the Early Bird programme was mentioned by participants in this part of the focus group session, and this three-month programme aims to support parents in the period between diagnosis and school placement *and* to provide them with techniques that will help them facilitate their child's development (source: NAS website). The Early Bird programme is not available throughout Wales, however, and a particular shortage of post-diagnostic support and intervention was identified for children diagnosed during the preschool years. More information about what post-diagnostic support is available in Wales is given in Section 3.3.4.

2.2.6 Multidisciplinary working

This topic was introduced by the facilitator who referred to The Strategic Action Plan and National Autism Plan for Children, both of which recommend that, in the majority of cases, diagnosis should be a multi-disciplinary process.

To what extent is diagnosis already a multidisciplinary process?

There was some controversy around what the term multidisciplinary actually meant in practice and it was described as a "bandied about term." In terms of definitions, one participant commented, to general agreement, that: "It can be a group of people where one takes the lead and makes all the decisions or it can be a group of people who really appreciate each others' skills and make things jointly." The implication was that the latter was considered by the group to be "true" multidisciplinary working but that many people use the term "multidisciplinary" to mean the former.

One member reported that in their tertiary team there was multidisciplinary working, but not at the secondary level where the referral often came from the paediatrician who would most likely work alone, although they could request a report from a SaLT. Our other enquiries suggest that, in other cases, tertiary level assessments might be done by a consultant working on their own.

One area of multidisciplinary working that professionals in the group recognised as problematic was the gap in social services provision. There was agreement about the unmet need for engagement with social services and the value of having them on board within a multidisciplinary team. To one member the stigma or concern of parents to the involvement of social services was seen as the major barrier. The group viewed social services as the main agency missing from multidisciplinary ASD teams, although Sections 3.3.1 and 3.3.4 indicate that other disciplines are often missing.

Is multidisciplinary team working something we should be aiming for in all cases?

The notion of the multidisciplinary team was positively viewed as a universal aim and appropriate in all cases. There was full agreement to the idea that the multidisciplinary team was the most effective vehicle for diagnosis and the diagnostic process. Indeed, to general agreement, a

psychiatrist reported that when there are problems with a diagnosis or discrepancies you usually find that the diagnosis has been made by a single professional working alone.

Advocating multidisciplinary team-working, an educational psychologist suggested that with a number of different perspectives you get a profile of the child and their needs as well as their diagnostic situation. However, a hidden cost for the multidisciplinary assessment is that this can promote disagreement within a team as there are too many diverse views and accompanying group dynamics which may hamper the process.

How can we achieve multidisciplinary working and what are the main challenges in bringing this about?

In discussion, members reported that there need to be four main elements in place:

1. **Official commissioning** of an ASD team, i.e., each contributor having official permission to spend their time on this, with commissioners in Health and those in Education willing to work together. Many regional services are not officially commissioned as such; rather, professionals have come together on the basis of a shared vision and a commitment.
2. **Well-specified procedures** for the practical arrangements outlining who is responsible for what. It was suggested that there should be a flow chart or some system in order that team members “know what is happening,” since participants’ experience of the process is that it can be quite ad hoc in terms of report writing and administration.
3. The presence of an **administrative coordinator** could facilitate these types of processes, and prevent team members’ relatively expensive time being used on administrative tasks.
4. **Trust and respect** among professionals from different agencies working together in a multidisciplinary context, so that all team members “really appreciate each others’ skills and make decisions jointly.” Participants agreed that fostering a culture of openness and communication was especially valuable, although it was recognised that this depends on having the time available to do so.

2.2.7 Consistency of practice and structures

The facilitator introduced this topic to the group by stating that an important theme in the Strategic Action Plan is that there should be consistency of practice and structures for diagnosis, in terms of:

1. A single diagnostic model
2. Consistency of diagnostic methodology

In order to explore this topic and to elicit the group’s responses the following topic related questions were formulated:

What does “consistency” mean in this context?

What is the value of consistency and what are the disadvantages?

What are the main challenges in bringing about consistency?

What does “consistency” mean in this context?

There was variation in the way that participants interpreted the concept of “consistency.” Several possibilities were identified – that it means consistency in terms of:

1. The multidisciplinary mode of working being the norm.
2. Always using a selection of diagnostic tools.
3. The terms used for the disorders being diagnosed (e.g., autistic disorder as separate from ASD vs. ASD encompassing autistic disorder)
4. Using the same method for diagnosing each child.
5. “The basic principles of assessment”

What is the value of consistency and what are the disadvantages?

There was general consensus that consistency should be an aim in principle, to avoid a “postcode lottery” and so that, if a family relocates, the health professionals in their new area can “trust” the diagnosis done elsewhere and will be able to see how it was done.

The participants expressed enthusiasm for consistency in terms of point 1 (above), stating that the multidisciplinary mode of working should be the norm, and adding that the roles should be maintained in multidisciplinary teams so that if staff leave they are replaced—maintaining the integrity and role structure of the team.

There was also general agreement that consistency in terms of point 3 is something to be aimed for, i.e., that the terminology for the disorder should be consistent throughout Wales.

The participants had reservations about aiming for consistency in terms of point 4, i.e., using the same method for diagnosing each child, for several reasons. One participant gave an example where a child coming into a diagnostic clinic already has “a fantastic cognitive assessment done by someone previously,” and she said that another cognitive assessment would not be necessary in this case, even if the previous assessor had used different methods: “That’s a waste of resources. You need to use what you’ve already got about the child – you need that flexibility.” Moreover, the group discussed how the actual diagnostic methodologies employed depends on a child’s strengths and weaknesses. One participant stated that, “To say every child must go through a process where they get x, y, and z is pointless. Clinical judgement must be allowed to reign.” Another participant pointed out that at present we simply do not have the evidence or knowledge about what instrument is the best or better than others so that professionals, at least, cannot be prescriptive about who should use what.

Despite this, it was reiterated that inconsistency in methods of diagnosis means that, “There is definitely a postcode lottery without a shadow of a doubt and we need to get rid of that and have some kind of black and white [protocol] for consistency.” Participants commented that at present inconsistencies are apparent even within health trusts; especially given the different configurations of services and personnel on the ground. However, what guidelines for consistency would look like was very difficult to establish, considering recommendations would have to be broad enough to allow room for flexibility and clinical judgement, but not so broad as to be meaningless. The ideal was described as a robust “portable framework” that could “travel” – i.e. parents could travel anywhere and expect to get the same diagnosis.

However, it was also appreciated that there may be key differences in processes: on the one hand there was a view that there should be minimum criteria or quality standards, but this was also met with: (i) a recognition of variation in ASD,—that autism was not “black and white” (one participant reported that in her region “we actually distinguish between ASD and autistic disorder”) and can be presented with a co-morbid symptom pattern and (ii), that in terms of services and processes in

different regional areas there are very different histories of practice, service configurations, institutional structures and roles, professional's preferences for particular diagnostic tools and their personalities.

Furthermore, in terms of setting basic criteria or principles (e.g., developmental history, structured observation of the child) there was a concern that some services may subsequently only try to reach a minimum standard and no other. However, one member also stated that if there were basic principles and standards in place they could lobby the commissioners in their region in order to ensure that they had an effective diagnostic team and service (where presumably they may lack those resources currently). Importantly, a participant suggested that the group should be cautious in its thinking about consistency of principles, as the focus group was not really representative of health professionals across Wales and that there may be real inconsistencies across certain Welsh regions and that in some areas "there's no appetite" to make consistency happen.

An educational psychologist suggested that professionals do need external guidance and self-monitoring into how to work effectively and "up-to-date" in this area and that having further discussions aimed at clarity and transparency on these matters would be very useful. In particular, participants clearly welcomed the opportunity to freely discuss and reflect on the focus group issues, especially relating to diagnostic practice, diagnosis and the wider ASD strategy, in a way that was not inspectorial or that made them feel they were being personally evaluated.

What are the main challenges in bringing about consistency?

In response to this question there was some discussion about the relation between policy making and practice/practitioners. A paediatrician reported that it was very difficult to get individuals to commit to act on the policy and adhere to the standards that a government could set and remain accountable to meet those standards. This member also pointed out that professionals can become comfortable and defensive about their existing ways of working, especially as they tend to be very stretched and with limited resources. Effecting change on a personal level may be very difficult.

However, this view was balanced by the fact that it was considered very positive by the group that, uniquely, there was an action plan in Wales and that the Welsh Assembly Government was attempting to move forward with the ASD strategy, facilitating dialogue, research and evaluation.

3 Questionnaire Study

3.1 Development of the questionnaire

The questionnaire was designed to provide information relating to all parts of Objective 1, on:

- (a) how and by whom services are delivered
- (b) the methodologies used in the process of diagnosing children
- (c) the provision and funding of specialist services

We also asked an open-ended question relating to what issues respondents are “currently facing in [their] ASD-related work” to help to identify where strengths and weaknesses lie (Objective 2).

Question content was guided by the objectives above, and the design of questions was also guided by the focus group discussion. For example, the focus group indicated that some clinicians might diagnose children without the use of standardised diagnostic tools, especially since the ASD Strategic Action Plan emphasises the importance of assessment of needs beyond specific diagnostic symptoms. The focus group also emphasised clinical judgement in relation to the use and training of diagnostic tools. We therefore we decided to provide more open questions about the range of methods used, asking about training on diagnostic tools only for those who stated that they chose to use them. The questionnaire can be found in Appendix B. The questionnaire was sent in English and was available in Welsh on request. The question order was selected to make the questionnaire user-friendly, including deciding to include the open-ended question at the beginning. However the answers to each question were designed to stand alone and the presentation of results below does not reflect the order of the questions.

3.2 Participants and procedure

The questionnaire was sent to everyone on the contact list (see Section 1.5 on "Preliminary data searching" for details of contact list). As described earlier, our aim was for this contact list to contain the names and email addresses of all of the clinical psychologists, paediatricians and psychiatrists involved in ASD diagnosis in children in Wales. In terms of speech and language therapists, our aim was to obtain the names and email addresses of therapists who were part of multidisciplinary diagnostic teams; however we were aware that in some areas speech and language assessments could be commissioned by any speech and language therapist working with children. Therefore we asked one representative from each health board to arrange for the questionnaire to be forwarded to all the other SaLTs. Similarly, we assumed there to be more educational psychologists so we contacted or attempted to contact an educational psychologist in each of the 22 local authorities to arrange for the questionnaire to be forwarded to everyone who might be involved in the assessment of children with suspected ASD. The contact list contained 43 other professionals including occupational therapists, specialist nurses and others. Questionnaires were sent by email during the week beginning 9th August with a deadline for return of two weeks later. Reminders were sent after two weeks. Given the low response rate at this stage, this process was repeated until a final deadline of 21st September.

3.3 Results

The number of questionnaires returned is shown by professional group in Table 2. Because we had a complete or near-complete list of psychologists, paediatricians and psychiatrists, the response rate was calculated for these groups, and equals 57%. Responses were obtained from educational psychologists from 15 of the 22 local authorities. The number of questionnaires returned from each health board is shown in Table 3.

Table 2: The number of responses from each professional group

Professional group	Number of responses
Clinical psychologists	24
Educational psychologists	26
Paediatricians	23
Psychiatrists	19
Speech and language therapists	15
Other	11
Total	118

Table 3: The number of responses from each local health board

Local Health Board	Number of responses
Abertawe Bro Morgannwg	8
Aneurin Bevan	18
Betsi Cadwaladr	32
Cardiff & Vale	14
Cwm Taf	5
Hywel Dda	9
Powys	5
Unknown	1
Total	92

Notes.

Educational psychologists are not included in this table because they do not represent health boards.

^a One questionnaire was returned by post without a name, so could not be traced to a health board.

Surveys of healthcare professionals are usually characterised by low response rates (VanGeest, Johnson, & Welch, 2007). Research conducted between 2000 and 2005 indicates that email questionnaires may yield lower response rates than postal questionnaires (VanGeest et al., 2007). However a randomised controlled trial of healthcare professionals' responses to a survey distributed by email or regular post found that email responders tended to provide more informative responses where typing/writing was required (Seguin, MacDonald, Godwin, & McCall, 2004). The current response rate of around 57% is comparable to that of Seguin et al.'s postal condition, which

achieved a response rate of 53%. It is also worth noting that the response rate may have been higher if it had been possible to send the questionnaire outside of the holiday period.

Results are presented in line with the objectives of the study.

3.3.1 How and by whom diagnostic services are delivered

To investigate how professionals work in relation to each other, participants were asked the following question.

Please indicate for what proportion of cases the following statements apply to you (0% - 100%).

Percentages should add up to 100



- % A I diagnose children on the basis of my *own* observations, assessments and history-taking.
- % B I diagnose children, *sometimes* having consulted members of other professional groups (e.g., a speech and language therapist, an educational psychologist).
- % C I diagnose children, *usually* having consulted members of other professional groups (e.g., a speech and language therapist, an educational psychologist).
- % D I am part of a multidisciplinary group and I make a diagnosis after I have consulted other team members.
- % E I lead or am part of a multidisciplinary group and a diagnosis is made after all team members have met and discussed the diagnostic decision.
- % F I am consulted during the diagnosis and assessment process.
- % G Other (please describe:)"

The results were analysed to gain a sense of the extent to which the diagnostic process is multidisciplinary. Of those who indicated that Statement F did not describe their sole mode of working, 20% said they sometimes make solo diagnoses, but none reported that this was their usual method of working. Therefore multidisciplinary working was the main mode of working for 80% of respondents. Participants of the focus group session indicated that Statement E (above) reflects the sort of working that they consider “truly” multidisciplinary. Questionnaire respondents indicated that multidisciplinary working as described in Statement E was happening in an average of 56% of cases. Questionnaire respondents were also asked:

In what percentage of cases do you think multidisciplinary working as described in Statement E (above) is appropriate? Please estimate: %

The results indicated that on average respondents thought multidisciplinary working is desirable in about 92% of cases, although there was some variation, with 9% of respondents saying they thought it desirable in 50% of cases or fewer.

Therefore the questionnaire indicated that 56% of cases are dealt with in a “truly” multidisciplinary way, whereas respondents feel this mode of working is appropriate in 92% of cases. Given the 50% response rate, though, these figures should be treated as approximate.

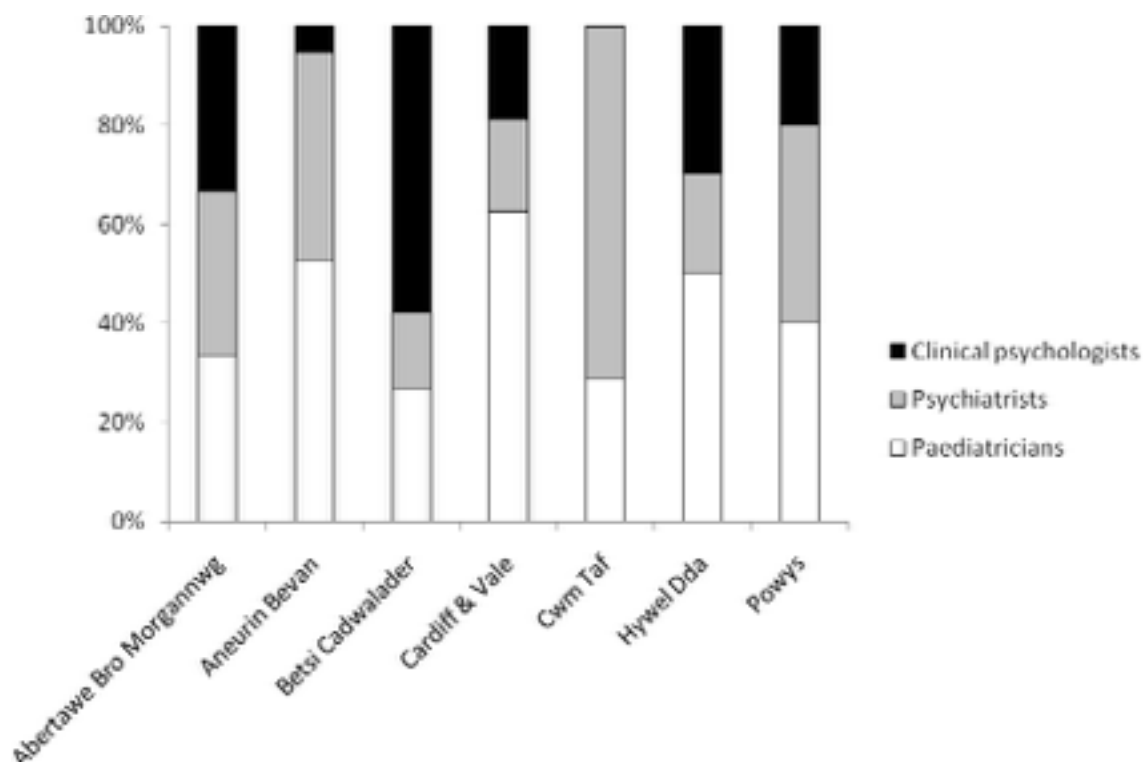
As described earlier, we endeavoured to find at least the names of all the paediatricians, psychiatrists and clinical psychologists involved in the diagnosis and assessment of children with

suspected ASD throughout Wales. The number of professionals in each category is shown by health board in Table 4, and depicted graphically in Figure 1.

Table 4: Number of paediatricians, psychiatrists, and clinical psychologists found in the preliminary data searching phase of the project, by health board

Local Health Board	Number of:			Total
	Paediatricians	Psychiatrists	Clinical psychologists	
Abertawe Bro Morgannwg	3	3	3	9
Aneurin Bevan	10	8	1	19
Betsi Cadwaladr	12	7	26	45
Cardiff & Vale	10	3	3	16
Cwm Taf	2	5	0	7
Hywel Dda	5	2	3	10
Powys	2	2	1	5

Figure 1: Comparison of the number of paediatricians, psychiatrists, and clinical psychologists across health boards



Note. We were informed that ABM health board does not have CAMHS and that psychiatrists working in the area covered by ABM are actually employed by Cwm Taf. These psychiatrists are shown under ABM in this figure.

Figure 1 indicates that clinical psychologists predominate in ASD diagnosis in Betsi Cadwaladr. In contrast, paediatricians seem to be more involved in Cardiff and Vale, and it appears that psychiatrists are often involved in Cwm Taf. As stated by a focus group member, “What is where in Health is a maelstrom of history and enthusiasms of individual people and in some places psychiatry has run with it, and in some cases a paediatrician has run with it – it’s personality led, and it’s history led.”

As we did not have a complete list of speech and language therapists or educational psychologists, we relied on questionnaire data to estimate the proportion of cases in which they are involved. Participants were asked: *In what percentage of cases do children’s diagnosis and assessment have a contribution from [each of the professions shown in Table 5].*

Results (Table 5) indicate that speech and language therapists are the most commonly-contributing professional group. However, the range was 0 to 100, so some professionals reported that none of the children they see are assessed by a speech and language therapist. Nearly 1 in 5 respondents said that an assessment by a speech and language therapist is not routinely accessed (i.e., that it is accessed in between 0 and 20% of cases). In another part of the questionnaire (see Section 3.3.4) many participants commented on the importance of reports by a speech and language therapists.

Educational psychologists were reported to contribute to diagnosis and assessment in a mean of 57% of cases, with the reported figure again varying from 0 to 100 (Table 5). The variation in the amount of input by educational psychologists could in part reflect differences in the age groups that different professionals are seeing, e.g., it might be that EPs most often see school aged children. However, many respondents mentioned lack of educational psychology input as a problem when asked an open-ended question about the service they provide (see Section 3.3.4).

The contribution of the other sorts of professional is similarly variable, with the frequency of input ranging from 0% of cases to 100% of cases. Although this could be described as natural variation, in another part of the questionnaire many respondents expressed frustration at not being able to access the expertise of particular professional groups. This is described in Section 3.3.4 below.

Table 5: The proportion of cases in which there is a contribution by each of the professional groups

Professional group	Mean %	Minimum %	Maximum %
Speech and language therapist	75	0	100
Educational psychologist	57	0	100
Paediatrician	64	0	100
Psychiatrist	58	0	100
Clinical psychologist	50	0	100

In sum, there is an appetite for multidisciplinary working that is not being satisfied at the moment. The question asking about the proportion of children being seen by each of the professional groups revealed a variable picture, which was in part due to variation in the way that services are organised, but which was partly caused by the lack of availability of some professional groups, according to the qualitative results (see Section 3.3.4). It is perhaps noteworthy that the contact list contained professional groups other than the five listed so far, including specialist learning disabilities and CAMHS nurses and occupational therapists.

3.3.2 Methodologies used in the process of diagnosing children

Elements of assessment used

Participants were asked, "In what percentage of cases do children's diagnosis and assessment include the following elements (please estimate):

- (a) **Observation** of child
- (b) **History-taking**
- (c) Assessment of **structural** language skills
- (d) Assessment of **pragmatic** language skills
- (e) Assessment of **nonverbal cognitive ability**
- (f) **School/home visit**

Results (Table 6) indicates that clinical observation and history-taking take place in the vast majority of cases. Assessments of language and nonverbal ability take place less often, but still in most cases. Again, these results are characterised by a large degree of variation between individuals, with ranges of 0 to 100 for language and nonverbal assessments.

Table 6: Percentage of cases in which each element of assessment is used

Element of assessment	% of cases in which this element is used		
	Mean	Minimum	Maximum
Observation	97	50	100
History-taking	98	50	100
Structural language assessment	63	0	100
Pragmatic language assessment	67	0	100
Nonverbal cognitive assessment	62	0	100
School/home visit	74	0	100

Participants were also asked the percentage of cases in which assessments are conducted using standardised tools. In the case of clinical *observation*, these might be the ADOS; in the case of *history-taking* these might be the ADI or DISCO; in the case of *language and nonverbal abilities*, these might be the CELF, the CCC, and the WISC. The results are shown in Table 7.

Table 7: Percentage of cases in which each element of assessment is used in the form of a standardised assessment

	% of cases in which this element is used in the form of a standardised assessment		
	Mean	Minimum	Maximum
Observation	63	0	100
History-taking	64	0	100
Structural language assessment	41	0	100
Pragmatic language assessment	38	0	100
Nonverbal cognitive assessment	50	0	100

School/home visit	-	-	-
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Comparing Tables 6 and 7 reveals that all elements were in standardised form about two-thirds of the time, but again the range was large, with some respondents reporting that they never access standardised assessments in one or more areas, and others reporting that they always do.

Use of diagnostic instruments

Section 2 of the questionnaire asked about diagnostic instruments. Analysis of the different types of instruments used showed 48% of respondents used the ADOS for at least some cases. The figures for the ADI, 3di, and DISCO were 21%, 25%, and 7% respectively. 4% of participants reported using the DAISI, and 4% of participants reported using the CARS. Other “diagnostic instruments” were reported on (Appendix C), but not all of these would be considered diagnostic instruments by all, and each of these was added by only one person. Therefore they are not reported further here. All the data presented hereafter relate to these four instruments, ADOS, the ADI, the DISCO, or the 3di since they differ from other instruments in that they there are training courses devoted to training professionals in their use.

65 of the 118 participants (55%) reported using at least one of the four main instruments (the ADOS, the ADI, the DISCO, or the 3di) and 54/65 had also attended training. Further analysis of those who use the four main diagnostic instruments also explored the way that they use these instruments in practice and the extent of training completed (Table 8).

Table 8: The manner in which diagnostic instruments are used, and the extent of training completed amongst professionals who use them

	ADOS (n = 55)	ADI (n = 25)	DISCO (n = 10)	3di (n = 26)
% who endorsed the statement, “I usually use this tool <i>in its entirety</i> and I usually <i>use the scoring system</i> to complement my clinical judgement” (n in parentheses)	82 (45)	76 (19)	40 (4)	54 (14)
% who have attended a training course in the use of this instrument (n in parentheses)	65 (36)	60 (15)	70 (7)	68 (18)
% who submitted a sample of their use of the instrument and met required standards for agreement, as determined by instrument authors (n in parentheses)	13 (7)	28 (7)	60 (6)	18 (5)

Note.

ns in top row indicate the number of participants who use these instruments.

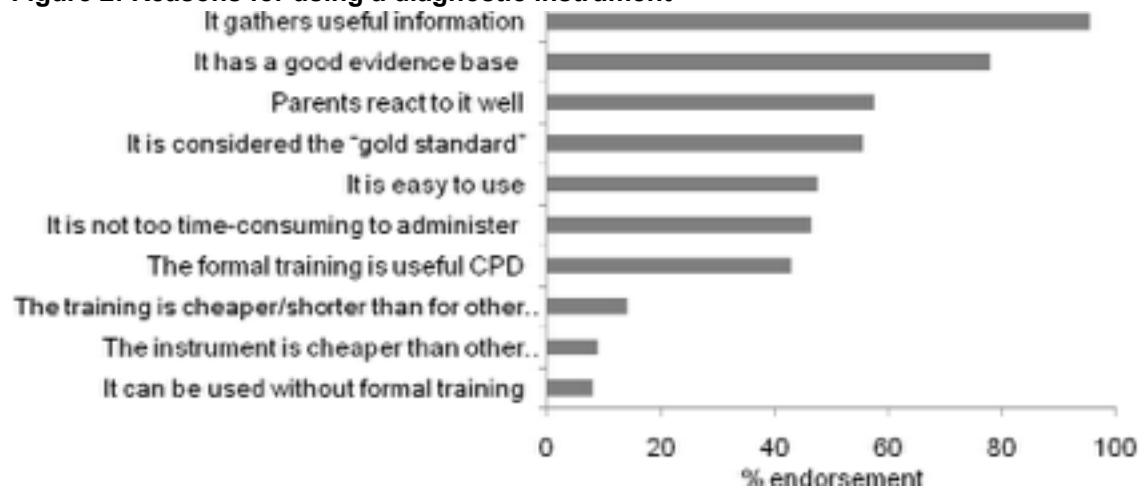
In summary, taking the 118 questionnaire respondents as a whole, results showed that around half (54) had received training in the ADOS, ADI, 3di, or DISCO and a larger proportion (65) had used or were currently using one or more of these tools. Very few of those who attended a training course had capitalised on the opportunity to complete this training to a standard whereby they might be able to train others in their team. Because the sub-sample answering questions about

diagnostic tools were only those who had used them, there might have been further clinicians who were trained on one or more tool but not yet using it.

Perceived value of diagnostic instruments

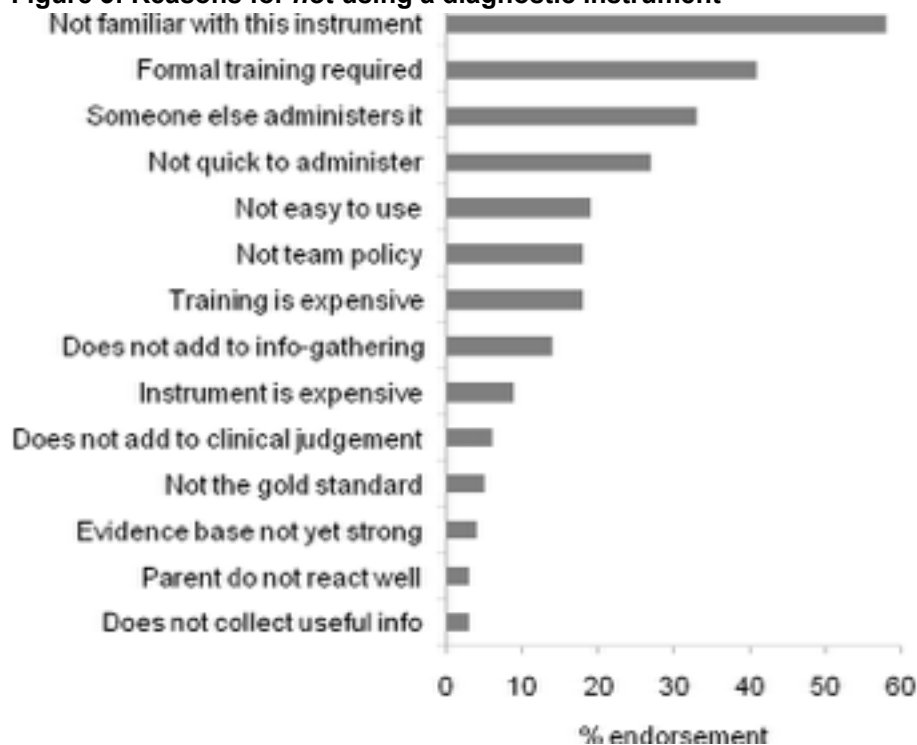
In order to identify clinicians' criteria for selecting one particular diagnostic instrument over others, participants were asked, "Which of the following *were* factors in the decision to *start* using the instrument?" and were invited to tick any of the suggestions provided (see Appendix B) or alternatively specify other reasons. Participants were also asked, "Which of the following *are* factors in your decision to use the instrument *now*?" and, again, were invited to tick any of the suggestions provided (see Appendix B), or specify other reasons. As the answers to these two questions did not differ, they have been collapsed into a single figure (Figure 2). The 65 participants who reported using at least one of the four tools above, completed the questionnaire to indicate their reason(s) for choosing this instrument.

Figure 2: Reasons for using a diagnostic instrument



Participants were asked, "For the instruments you do not use, please indicate why you do not use them." They were invited to tick any of the suggestions provided (see Appendix B) or specify other reasons. Results are shown in Figure 3.

Figure 3: Reasons for *not* using a diagnostic instrument



3.3.3 Provision and funding of specialist services

Specialist services for diagnosing complex cases are running in Wales. However there is no comprehensive map of these services and how they operate. The lack of top down information made it difficult to obtain a clear picture of the provision of specialist services. We started with the specialist services listed in Lowe's (2002) report. This information was used to try to locate clinicians currently working in specialist services so they could receive a questionnaire. As part of the questionnaire, all participants were asked:

<i>Do you work for a specialist autism service?</i>	Yes	No
<i>If yes, What is its name?</i>		
<i>Is it classed as a tertiary service?</i>	Yes	No
<i>Is it funded as such?</i>	Yes	No

The results are shown in Table 9. Please note that although we aimed to identify the clinical lead of each team, we were unable to confirm this in some cases. Therefore we have listed the key figures in each team that we know of, and apologise for any omissions.

The table indicates that most of the specialist services identified in the current report were in operation in 2002, with the exception of the Social Communication Assessment Teams in Powys. One service mentioned in Lowe's (2002) report is the Children's Intensive Support Service (CISS), based in Cardiff but employed by ABM. Questionnaire responses and further enquiries conducted as part of the current evaluation indicate this is a tertiary, interdisciplinary team that serves children with severe learning disability and challenging behaviour. A significant majority of cases have ASD

but the team holds no formal responsibility for diagnosing ASD, and questionnaire results indicate that in about 85% of cases the diagnosis has already been made before a child is referred to this team. Therefore the CISS is not listed as a specialist ASD diagnostic service in the current report.

Several specialist services identified in the Lowe report were not referred to amongst the questionnaire responses:

- one in Ogwr led by a Dr Kim Billington (we could find no trace of this service or Dr Billington);
- one in Ceredigion led by a Dr Upadhyay (we did not find Dr Upadhyay but professionals working in Ceredigion indicated that they do *not* work for a specialist autism service)
- one in Carmarthenshire led by a Dr Warren (we did not find Dr Warren but professionals working in Carmarthenshire responded that they do *not* work for a specialist autism service)
- one in Bangor led by Dr Wimpory (we found that specialist children's services for Gwynedd and also child development multidisciplinary services for Anglesey are led on ASD by Dr Wimpory, and they include clinical psychologists particularly well trained in ASD assessment, but this is carried out within a generic child development service rather than an ASD-specific team).
- one in Merthyr Tydfil led by Dr Rangarajan (Dr Rangarajan indicated that he does not work for a specialist autism service).

Table 9 indicates that most if not all health boards have a specialist service but that, as far as respondents were aware, these are not funded as tertiary services.

Table 9: Specialist children's ASD diagnostic teams in Wales

Health Board	Team	Key figures identified in current study	Mentioned in Lowe report (2002)?	TERTIARY ?	FUNDED ?
ABM	Neath Port Talbot Early Years Communication and Social Behaviour assessment team	Dr Tamsin Josty	YES	No response	NO
Aneurin Bevan	Gwent Tertiary Services for ASD	Dr Sundari, Dr McKigney, Dr Kanaris	YES	YES	Mixed responses
BCU	Denbighshire Autism Diagnostic Team for children under 8 yrs of age and children with LDs	Dr Bera	YES	YES	NO

	Specialist service for early years and school age children in Flintshire and Wrexham (four sub-teams)	Dr Alan Dowey	Wrexham Early Years: YES Other sub-teams: NO	YES	NO
Cwm Taf	None reported in the current study, but Lowe report states that Dr Latif headed up a specialist team in 2002.		YES	No response	No response
Cardiff & Vale	Cardiff and Vale University HB Social Communication Disorder Team	Dr Elspeth Webb	YES	YES	NO
Hywel Dda	Pembrokeshire Autism Spectrum Assessment Team	Dr Vipulendran/ Dr Trudie Brew	YES	NO	NO
Powys	North Powys Social Communication Assessment Team (SCAT)	Dr Helen Hayes/Dr Barbara Rogers	NO	NO	NO
	South Powys SCAT	Dr Chris Vulliamy	NO	No response	No response

In Wales there is a tradition of bringing in experienced clinicians from outside the country, to carry out diagnoses of complex, difficult to diagnose cases. Therefore participants were asked:

*In the last five years, have you or your team referred any cases of suspected ASD to any clinicians based **outside** Wales?*

Yes No Don't know

If yes, please give details (the approximate date, reason, etc.).

Professionals working in the following Health Boards stated that they have referred complex cases to clinicians based outside Wales: Cardiff & Vale, Cwm Taf, Abertawe Bro Morgannwg, and Hywel Dda. Additional enquiries indicated that at least one experienced clinician from England provides a tertiary service in Wales (Ton Teg), approximately once every two months. Usually this is to see a complex case where there is a query over autism and perhaps the clinicians think autism but education or social services think not. The original agreement was that she would support and advise the team but very often the clinician ends up doing the diagnosis. The Health Board concerned pay for the clinician's sessions directly by paying the clinician's own Health Board. This clinician sometimes gets other referrals from other parts of Wales but refers back through Ton Teg. We gained evidence that at least one other clinician is 'bought in' from outside Wales. In this case the clinician provides expert evidence for the Court Services and funding comes through the court concerned.

Professionals working in two other Health Boards, Betsi Cadwaladr and Powys, referred cases to clinicians based outside Wales where parents requested a second opinion.

3.3.4 Effectiveness of diagnostic services

To fulfil Objective 2, professionals were asked for their views on service effectiveness and areas for improvement (part (a) below). This was an open-ended question but participants were given examples of issues they could tell us about; these examples were taken from the focus group discussion. We also asked for information on two potential areas for improvement identified during the focus group discussion: post-diagnostic support and the language medium of assessments (parts (b) and (c) below). These two issues were asked about separately from the other issues because we were asking for *information* relating to these two topics, as opposed to opinions. Finally, participants were asked about the relative importance of various factors in influencing their diagnostic practice (part (d) below).

Professionals' views on service effectiveness and areas for improvement

Participants were asked an open-ended question to elicit views about some of the themes emerging from the focus group discussion:

What issues are you currently facing in your ASD-related work, and/or, what would make your contribution to the diagnosis and assessment of children with ASD easier/more effective? Examples include: Arrangements for multidisciplinary working, Amount of time available per case, Amount of administrative support, CAMHS Annual Operating Frame targets.

The following synthesis reports the views of the 108 participants who answered this question.

Participants indicated the major issues as being lack of time, staff, and resources, and, in particular, the lack of ring-fenced time and resources for ASD, and the fact that many services are not commissioned. Pressure of waiting list targets was mentioned frequently. Equally, respondents were concerned about the fact that waiting lists are long which causes stress to families. The pressure of meeting demand with limited resources was linked to an increasing number of referrals coming through to diagnostic services.

Where respondents specified the time/resource issues in more detail, time per case was cited overwhelmingly as the major issue: the assessment process takes longer than staff can give to each case. The questionnaire participants concurred with focus group participants in indicating that having more administrative staff would ease this problem, considering that a large proportion of their time is spent on administrative tasks. Aspects of "best practice" viewed as particularly time consuming included multidisciplinary working and observing the child in more than one setting. Respondents also expressed a need for more time for developing procedures and care pathways, for training (in particular, training in the use of diagnostic instruments), for sharing information with colleagues in own and other teams, and for peer review and building expertise.

A lack of expertise within the team was cited as a problem by a minority of respondents, and providing the means for professional development would be a good investment of resources. Participants indicated that ways of doing this would include access to a resource base of autism-specific materials and the most up-to-date research.

The results described above indicate that multidisciplinary working can be time-consuming, especially when there is no administrative support. However, many respondents explicitly indicated that multidisciplinary working would improve the service they provide.

As such, barriers to multidisciplinary working were another major theme in terms of issues that health and education professionals are facing. One major barrier is it is difficult to co-ordinate the meeting of members of a multidisciplinary team, so that sharing with other disciplines has to be by correspondence, phone and emails which limits broader discussion. As well as the practical arrangements of multidisciplinary working, respondents wrote about the lack of “consistency of approach,” particularly between paediatrics and CAMHS, and the lack of organisational structures and protocols that span across disciplines. In respondents’ own words, issues included the “lack of clarity regarding the roles and responsibilities of services,” and that “arrangements for multidisciplinary working are not consistent across teams.” One participant commented that “the different systems operating in the Local Health Board make it very complicated to contribute appropriately, as it is all a matter of knowing the system and the professionals involved for each child.” Changes that would improve the diagnostic service included the “development of multi-agency ASD referral pathway to ensure adequate information accompanies the referral and the referrals are appropriate” and there appear to be several pathways in development at the moment.

Post-diagnostic support

Participants were also asked specifically about post-diagnostic support as this was identified as an issue affecting diagnostic services by the focus group. Participants were asked:

Is post-diagnostic support given after the disclosure interview?

(Please include all post-diagnostic support given after the interview, whether or not your service is the provider.)

Yes No

If yes, please describe (e.g., who provides it, whether it's parent- or child-focused, how long/frequent are the sessions, and what proportion of cases receive it):

87% of respondents indicated that post-diagnostic support is available to the children in their caseload. Participants specified support provided by a variety of agencies, including Health, Education, and the voluntary sector (notably the National Autistic Society). Participants appeared to interpret the term post-diagnostic support in varying ways—some participants reported on how they explain the diagnosis and its implications, whereas others reported on educational placements and interventions such as social skills training for children with a diagnosis of autism. The results of this question are therefore difficult to interpret. However, problems with post-diagnostic support was one of the problems mentioned most frequently in response to Question 2. Some participants reported a total lack of support and other services post-diagnosis, whereas others said there were long waiting lists and an unco-ordinated approach. Again, differences in the way terms such as “post-assessment work” and “follow-on support” were being used makes responses hard to interpret.

Language medium of assessments

In relation to language, the ASD Strategic Action Plan makes specific recommendations to identify demand for services in the medium of Welsh and identify gaps in provision and training. Although this was not specified as part of the objectives for this project, we asked professionals for some estimates regarding the scale of “the problem” (see Appendix B, Section 4).

After averaging responses, the results indicate that in 12% of cases the family's first language is Welsh. In 5% of cases the child is assessed in Welsh (indicating a shortfall of 7%), and in 6% of cases the history is taken in Welsh (a shortfall of 6%).

In an average of 4% of cases the family's first language is neither Welsh nor English (e.g., Punjabi). In 2% of cases an interpreter is used (shortfall of 2%).

Therefore in around 8% of cases, the child's/family's right to access a service in their first language is not met.

Naturally, the magnitude of this problem varies around Wales. Fifteen respondents (15% of those who answered this question) indicated that at least 50% of the families they see have Welsh as a first language. After averaging *these* responses, the results indicate that in 63% of cases the family's first language is Welsh (range 50-90%). These respondents indicated that the child is assessed in Welsh in an average of 31% of cases (range 0-80%), indicating an average shortfall of 32% in these areas. The average proportion of families having their child's history taken in Welsh in these areas is 35% (range 0-80%), indicating an average shortfall of 28% in these areas.

Please note that participants were asked to estimate figures rather than conduct an audit, so these figures are only approximate.

Factors influencing diagnostic practice

To understand the process of diagnostic practice from the clinician's point of view the following question was asked:

How important are the following factors in influencing the way you carry out your practice?

Please rate each factor from 1 (unimportant) to 7 (extremely important).

1 2 3 4 5 6 7

Your own clinical experience

Training courses you have attended

Mentoring you have received

Recent research

Your understanding of typical child development

Health Board policy

The ASD Strategic Action Plan for Wales

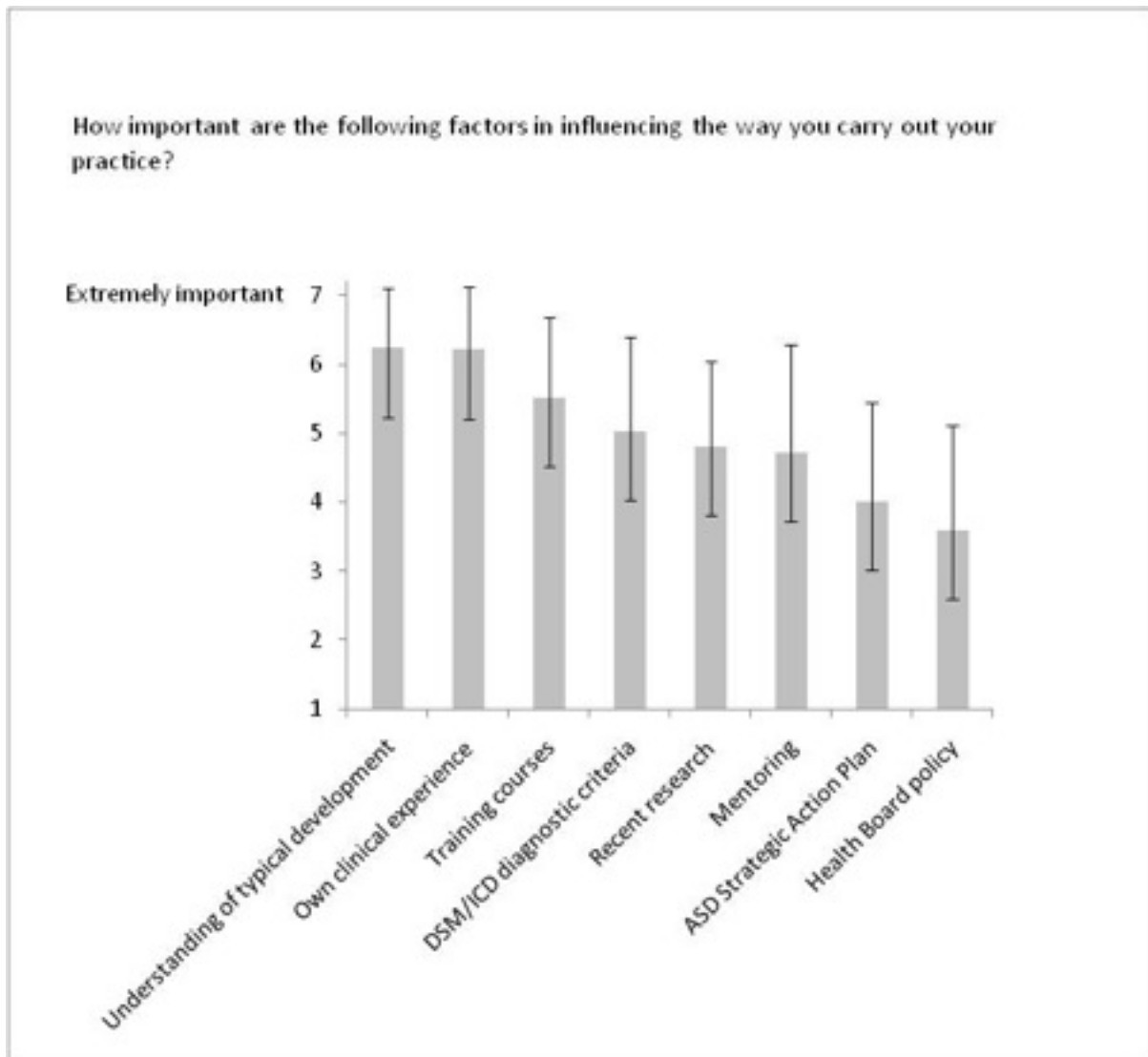
DSM / ICD diagnostic criteria

Other (please state:)

Participants were invited to add other factors but no one factor was added by more than 1 in 10 participants. Therefore the results are presented for just the factors that were shown in the questionnaire.

Results (Figure 4) indicate that Understanding of typical child development and one's own clinical experience were rated as most important. The ASD Strategic Action Plan and Health Board policy were identified as least important, though still "somewhat important." Training courses were identified as valuable, as was knowledge of recent research.

Figure 4: Factors influencing practice



Notes.

Bars (grey blocks) indicate mean rating of importance.

Error bars (black lines) indicate ± 1 standard deviation, i.e., 67% of the responses lie within the black bars.

4 Summary and Discussion

The objectives of the evaluation study were to:

1. Obtain information on (a) how and by whom diagnostic services are delivered (b) the methods used in the diagnosis process and (c) how specialist services are delivered and funded
2. Obtain clinicians' views about the effectiveness of current diagnostic services, including their evaluation of strengths, weaknesses and potential for improvements.

In this section, we summarise the results from both focus group and questionnaire studies according to these objectives and discuss their implications.

4.1 Objective 1

The original plan was to obtain a list of professionals and detailed information about how diagnostic services were delivered in each region. The goal in mind was to compile a map of the structure and organisation of diagnostic services across the regions within Wales. However any 'top-down method' that we used to access records through heads of services did not yield the information needed. Therefore the study relied solely on information gained through 'bottom-up' sources. That is, first we asked contacts within clinical services to pass on the names of other professionals involved in the diagnosis of children. Then we included these individuals in the study, asking them individually to address the question of how and by whom diagnostic services are delivered. Some of this information would have been more effectively produced from more central sources, had we been able to find them. Although this approach still enabled us to meet Objective 1, there were limitations on the information extracted. For example, the results of the focus group made it clear that diagnostic 'teams' and the work that they carried out, varied enormously between regions and even within health board areas. Yet, without advance knowledge about service organisation, it was a challenge to formulate a set of questionnaire questions that would apply to all respondents equally. Also, because there was a need to collect questionnaire responses anonymously, we could not identify names and link them to other team members in their group, when compiling results. These aspects, combined with the fact that the questionnaire responses belonged to a sample of the total list, meant that we could not obtain a full and detailed picture of the structure and organisation of services throughout Wales, and the results are limited in terms of their potential to make geographical comparisons. Nevertheless, an acceptable sample of individuals responded to the questionnaire. These participants and the focus group participants were able to report on the service that they worked within themselves, in terms of how professionals work in relation to each other, and the results of this enquiry is reported below.

It is important to note that poor access to central information about services represents important data for the study. The organisation of services at higher levels appears to be equally as variable as is the team organisation at lower levels. This was confirmed in a meeting with the lead of CAMHS strategy in WAG, who explained that there is great variety of organisational structures dealing with children's diagnosis across (and even within) regions. This confusing array of different systems and lack of coordination is reflected in clinicians' comments seen at an individual level within the study. Clinicians pointed to lack of official commissioning and lack of guidelines, procedures and resources as major areas of challenge and commented on the lack of understanding by those at higher levels of the requirements of assessment and diagnosis. We discuss this in the evaluation section below.

4.1.1 How and by whom diagnostic services are delivered

As mentioned earlier, multidisciplinary team-working is recommended as best practice for the diagnosis of children with autism, according to The National Plan for Children with Autism and the Welsh Assembly Government's Strategic Action Plan. This means that a team might comprise any combination of the following professionals; psychiatrist, paediatrician, clinical psychologist, educational psychologist, social worker, speech and language therapist, and others including specialist nurses and occupational therapists.

For the focus group study, we collected initial data about multidisciplinary team working and about the configuration of professionals involved in the diagnosis process. We used this information to guide questions in the questionnaire study to gain more specific information about the use of multidisciplinary teams in practice and the balance of different professionals involved.

Members of the focus group had experience of different types of diagnostic team. This range included a dedicated multidisciplinary team through to a less connected group including more independent professionals brought together for case meetings. The focus group acknowledged that the term "multidisciplinary" can be used in different ways, although they agreed that true multidisciplinary team work should involve engaging in truly joint work and decision making. Multidisciplinary working of this kind was seen in the majority of diagnoses (56%) according to the questionnaire study. Exceptions were also reported and multidisciplinary working was not considered desirable in all cases. However it was in fact was the main mode of working. Nevertheless there was a discrepancy between what was thought to be desirable and actual practice as respondents thought that true multidisciplinary working was appropriate in 92% of cases even though they achieved it in only 56% cases.

The questionnaire study confirmed that teams comprised different combinations of professionals. A questionnaire analysis of the contribution made by different professionals (psychiatrists, paediatricians, clinical psychologists, educational psychologists and speech and language therapists) revealed that the professional group that contributed to the highest percentage of cases of diagnosis and assessment, were speech and language therapists (75%). Professional groups that were noted as often lacking in teams were social workers (focus group) and educational psychologists (questionnaire), though some teams were well served by educational psychologists. Types of professionals varied with geographical region. When comparing the three professional groups of psychiatrists, paediatricians and clinical psychologists, the questionnaire study showed that clinical psychologists providing the predominant contribution in Betsi Cadwaladr, while paediatricians in Cardiff and Vale and psychiatrists did so in Cym Taf. This variation is likely to reflect historical precedence and to have implications for other differences in working practices given differences in training and background.

Questions were also asked about the process before and after the actual diagnosis. This is not the main focus of this report, but a summary of the results is provided in the results section.

4.1.2 Methodologies that are used in the diagnosis process

The delivery of diagnostic services relies on effective methods. Traditional methods include recording the child's developmental history by means of an interview with the parent, and the carrying out of an observation with the child. A number of diagnostic tools have been developed in recent years to guide this process of interview and observation. The use of standardised assessments including specific diagnostic tools is recommended in the care pathway outlined by the ASD Strategic Action Plan.

The focus group acknowledged the value of diagnostic tools to provide standardisation of the diagnosis process and reduce bias. The view was that formal tools should always be supplemented by clinical experience with clinical judgement having a key role. Discussion also revealed that diagnostic tools are not always used in straightforward cases; for example if the child is already known to meet diagnostic criteria. In addition when tools are used, some clinicians used them exactly as intended, others blended different items together while others may draw on additional information. There was consensus in the focus group discussion about the clinicians' need for experience of observations of children and development of expertise, knowledge and concepts through training.

The information from the focus group guided the design of questions in the questionnaire so that these questions specifically asked about the proportion of cases in which diagnostic tools were used, when and how they were used. Results of the questionnaire showed that history taking and observation and also, language and nonverbal assessments in a standardised form. for about two thirds of cases but some respondents never used standardised assessment. With respect to standardised diagnostic tools in particular, just over half of the respondents used at least one of the following well known tools; ADOS, ADI, DISCO, ADI-R or 3di. Their reason for choosing these instruments supports the focus group's earlier report that these tools provide good standardisation and objectivity. Questionnaire responses also confirmed that the tools gathered useful evidence, were evidence-based methods and that parents reacted well to them. Clinicians' most frequent reason for not choosing a tool was linked to lack of familiarity. Tools were not generally chosen simply because of ease of use and were often reported to be time consuming as well as expensive, although requirement for expensive training and time to use a tool were listed as barriers. In sum, while clinicians recognise the value of clinical tools, especially with respect to the concepts of ASD that the tools represent and the objectivity in their use, the tools are not being used in a consistent way in practice and clinical judgement is considered to be more important.

4.1.3 Provision and funding of specialist services

As mentioned above, it was not possible to identify or map the specialist services in Wales through 'top down' means. The questionnaire sent to 118 clinicians indicated that most if not all health boards have a specialist service but that, as far as respondents were aware these are not funded as tertiary services. The services are not receiving the appropriate funding for tertiary services and are therefore under resourced, contributing to the strains and difficulties reported throughout this report.

A number of health boards also reported referring complex cases to clinicians outside Wales in the last five years. Four of the seven health boards did so (Cardiff & Vale, Cwm Taf, Abertawe Bro Morgannwg, and Hywel Dda) while professionals working in two other Health Boards, Betsi Cadwaladr and Powys, referred cases to clinicians based outside Wales where parents requested a second opinion. In addition, we identified two senior clinicians from London who have made visits to Wales to give opinion on diagnosis and discussed their role in a separate meeting. One of these clinicians has been called to give an opinion in the case of court cases and the court makes the arrangement. The other senior clinician from London visits every two months to see complex cases, often when there is a dispute about diagnosis between the clinical services and education or social services which may be financing the outcome. This clinician is available to support and advise the team but sometimes the practicalities mean that this clinician actually carries out the diagnosis in the absence of the team (standardised assessments have already been done). The Health Board pay for these sessions directly by paying South London Health Board. The same clinician sometimes receives referrals from other parts of Wales but refers back to the lead Health Board.

4.2 Objective 2: Clinicians' views about the effectiveness of current diagnostic services, including their evaluation of strengths, weaknesses and potential for improvements

In both the focus group and the questionnaire study, clinicians were asked to give their views about potential improvements to current diagnostic practices. The focus group discussion in particular focused on clinicians' evaluation of strengths and weaknesses of practice and structures in relation to the goals of ASD Strategic Action Plan for multidisciplinary working and for consistency of practice.

The strengths of current diagnostic services according to focus group participants were the existence of a unique ASD Strategic Action Plan, opportunities for facilitating dialogue, expanding research and evaluation focus. Also the group pointed to the desire for multidisciplinary working and for the aim of consistency if a good protocol is put in place. Weaknesses include lack of consistency of services (post code lottery), lack of official commissioning of services, lack of understanding by senior management of time and resources needed for diagnosis services, lack of clarity over the procedures for multidisciplinary team working and lack of administrative support. For questionnaire respondents, weaknesses include lack of ring-fenced resources for ASD, lack of commissioning and waiting lists, time per case created by the demands of multidisciplinary working.

Both the focus group and questionnaire respondents highlighted the dilemma they face of needing to maintain individual clinical judgement and autonomy in their practice, especially given the complexity of needs seen in children with autism spectrum, while at the same time recognising the need for consistent, official diagnostic procedures to be set in place within clear organisational structures. They also pointed out the challenge of bringing about changes in consistency of practice when great variation exists and when resources are stretched. Despite this dilemma, in both parts of the study, participants highlighted the need to achieve clarity over roles and responsibilities, guidelines for consistency in structures and protocols, and a service framework that can transfer across regions so that families can be assured of the same type of procedures and support across Wales.

Participants' proposals for improvements include changes that will optimise clinical staff expertise and resources, with clinicians themselves taking an active role in the design and implementation of more consistent procedures and practices. Members of the focus group proposed that external guidance and self monitoring was needed in order to help clinicians to update their understanding and discussion needed between clinicians about issues of clarity and transparency, for example to achieve consensus about optimal multidisciplinary organisation and process. Questionnaire responses also identified a need for building expertise and providing the means for professional development. Questionnaire responses included suggestions for information sharing with colleagues, peer review, access to a resource base (materials and up to date research) time for developing procedures and care pathways and time for training in the use of diagnostic instruments.

There are some clinicians currently involved in ASD diagnostic services however, who may not welcome increased time and commitment to ASD diagnostic services. With this in mind it may also be important to set up mechanisms that streamline diagnostic processes, with the potential for separating the more complex cases and reducing redundancy in the diagnostic process. Complex cases might form a 'separate tier', equivalent to the cases currently diagnosed by clinicians outside Wales previously, and help to build specialist or tertiary diagnostic services into a specialist body of expertise that is developed in Wales.

Participants' proposals for improvements also included the need to make structural and organisational changes. Focus group participants highlighted the need for official commissioning, the development of a framework of official procedures, and guidelines over multidisciplinary team-working. Questionnaire participants also recommended ring-fenced resources, commissioning, and

clarification of systems. Organisational and operational changes are crucial in order to enable staff to benefit from the expertise building and/or specialisation and streamlining of practice proposals above. Although participants did not suggest specific mechanisms for how to bring about changes in organisational systems, it seems likely that changes are needed at different levels of the management structure. At the higher level, negotiation with service commissioners and managers is needed. At the lower level, streamlined procedures for practice are needed and improved information access is needed to ensure that adequate information accompanies referrals.

During the current project we initially attempted to obtain details of the organisation of services from the ASD regional support officers but it was not possible to identify (a) who were the directors of services in all different regions of Wales and (b) the configuration of different diagnosing teams across Wales (even within the same Health Board). It is clear that the configuration of services is very different in different regions of Wales. Information about service organisation in each region is neither consistent nor transparent. The lack of consistency of organizational structure and processes means that families moving to different areas in Wales cannot be sure of continuity in services. The lack of information about different organizational systems also means that it is also difficult to connect across the different information on cases coming for diagnosis through the different services involved (e.g. CAMHS, Child Health)

4.3 Other perspectives

Although the focus of this study was to gather information on methods and systems of service delivery and obtain clinicians views, future follow-up work should be expanded to include the service user perspective. As a preparation for this we consulted with a parent representative through a health board stakeholders' meeting where at least 6 counties were represented. The parent representative proposed that future examination of parents' perspectives of children's diagnostic services in Wales would need to consider the following points:

1. Waiting times.
2. Length of diagnostic process (how many sessions etc)
3. Literature definitely about what the diagnosis means, eg Autism, Asperger Syndrome etc
4. Written advice on post diagnosis at the time of diagnosis: eg re Support Groups; Benefits such as DVLA; access to services; SNAP (an organisation helps parents of special needs children through statementing etc)
5. Parents should be told beforehand that they will be meeting on a professional or a multidisciplinary group. ASD clients can find it hard to have to meet and connect with more than one person.
6. Explanations about the diagnostic process given to parents
7. Child care available during the diagnostic process
8. Access to counselling for the parents who may have psychological distress as a result of the diagnosis.
9. Information for parents on what to expect later in their ASD child's life re mental health issues.

All these are valid points that need to be taken into account in designing new procedures and practices. Added to these points we would include the need to ensure that families whose first language is Welsh have the opportunity to access and assessment and information in Welsh.

4.4 Conclusion

In conclusion, information on the current delivery of children's diagnostic services shows that multidisciplinary team working is the main mode of working, though its form can vary and the composition of clinicians within the team is variable across regions. However multidisciplinary team working is not carried out in the most optimal way according to the clinicians participating in the study. Clinicians consistently use clinical observation and history taking methods in the vast majority of cases and about half of the clinicians support these methods with standardised diagnostic tools such as the ADOS. Finally, investigation into the provision of specialist services indicates that specialist services can be identified in almost all the health boards but these services are not being funded as tertiary services. There is still evidence diagnostic consultancy is bought in from outside Wales for complex, difficult to diagnose cases by at least one health board.

The view of clinicians reveals recognition of the advantages of both multidisciplinary working and consistency of practice, balanced against the challenge of severe time and resource restrictions and need for autonomy in clinical judgement. Clinicians suggest that improvements can be made by building clinical expertise and resources, streamlining diagnostic processes and improving structural and organisational systems. Recommendations are made below for initial mechanisms that could be put in place in the coming year to assist such changes.

5 Recommendations

5.1 Recommendation 1: Developing a network of expertise and mentoring

It is recommended that a *network of expertise and mentoring* be developed that will support multi-agency clinics at a regional level and make links with adult diagnostic services. The goal is to enlarge the community of expertise with Wales, to enhance training and skill in diagnostic work for complex cases and to support the optimal delivery of multidisciplinary team working practice.

The newly established Adult ASD Clinical network that has been recommended within the recent *Adult Task and Finish Report* should benefit from this network as some clinicians work with both children and adults. A coordinated specialist network will also reduce the costs of bringing in experts from outside Wales to focus on individual case aiming to ensure that expertise is increased and maintained within Wales. The coordinated network would draw on the expertise of mentors. Mentors would include key local experts and international experts. The difference from the model of bringing in experts to consult on the diagnosis of individual cases is that this scheme is more sustainable. Clinicians from across Wales would gain expertise and work through issues related to interdisciplinary team working by means of a coordinated system. This allows expertise to be passed on, leading to a improved community of practice.

There are a number of areas in which the building of expertise could be targeted.

1. Advice for specific cases that are pressing and urgent and difficult to diagnose.
2. Increase in understanding about the concepts that clinicians are working with and how to deal with particular types of cases in relation to these concepts.
3. Greater skill in using clinical tools for diagnosis.

The framework for the network would be based on a pre-existing web based infrastructure set up on the AWARES web-site (www.awares.org/conferences). Adaptations can be made to the website for a dedicated network space that supports different activities. Although the website would provide the basic framework for this initiative, activities will be both off-line and on-line (face to face and interactive). A key component of the network would be mentoring, support and discussion from the level of conceptual issues and diagnostic tools through to support and advice on individual cases.

The network would work at two different levels. At the regional and national level level, the network would be used as a *forum*. International experts would guest and contribute to forum discussions (for example the authors of diagnostic tools such as ADOS, ADI-R, DISCO, 3di, invited to advise on their use. A themed forum discussion can also be held to discuss particular types of cases (e.g. regression, PDA, PDD-NOS, diagnosis in infancy) and these forum discussions could be opened up to include an international audience.

The network would also extend a set of *consultancy clinics*. A subset of the international experts contributing to the forum above (one per region), would form a mentoring pair with experts from within Wales to support these consultancy clinics. The purpose of the consultancy clinics would be to provide guidance and training for diagnosis. The clinic will meet on one day each month and the day would include assessment of individual children. Training can be delivered remotely through video conferencing following the model used elsewhere in Wales (e.g. medical training between Bangor and Cardiff). The web system Cisco Webex allows communication and presentations between different groups to be confidential (it is fully encrypted and password controlled) and allows a record to be taken for archive. Additional follow up discussion is possible at local levels via confidential telephone, skype or small face-to-face group meetings. At this stage we propose one cross-agency consultancy clinic within each region as defined by the ASD Strategic Plan (north, south, mid and west wales) and run for one year only on a pilot basis. Invitations will also be extended to Educational Psychologists.

The aim is that activities can be coordinated to link together through the web-based network, offering opportunities to enhance consistency in practice. For example the issue of multidisciplinary working will arise during a consultancy clinic and also form the focus of a national forum topic.

A further recommendation is that steps should be taken to increase opportunities for training clinicians to become trainers of diagnostic tools

We also recommend translation of diagnostic tools into Welsh. We recommend that a grant application is made to Welsh Language Board for this purpose.

5.2 Recommendation 2: Changes to organisational systems

While the recommendations above relate to clinical staff expertise and resources, barriers to good practice cannot be removed without also including improvements to organisational systems. The second recommendation proposed changes to organisational systems in order to achieve the following outcomes: a) clearer mapping of service organisation, b) identification of referral pathways, and tracking of individual services c) a service delivery framework with operating guidelines and procedures. By increasing transparency and consistency this should have implications for efficiency and for forward planning of services. The goal is for a framework of practice, the content and consistency of which is negotiated between clinicians, NHS and Welsh Assembly Government.

There are several elements to this recommendation. First, it should involve *mapping of organisational structures* across the health boards. We were obliged to carry out this 5 month project in the absence of a mapping of services. However, we recommend firstly that a concerted mapping exercise is undertaken. We recommend that this particular exercise is carried out locally by those who have management responsibilities for diagnosis in each health board and coordinated by the Welsh Assembly Government. The outcome should be a diagrammatic structure for each health board identifying those responsible for children's ASD diagnostic services and also the organisation of clinicians into units or teams. Second, it should include the opportunity for *commissioning of services* by ensuring coordination of commissioners in Health and in Education, with the goal of establishing ringfenced time and resources for ASD diagnostic services. It should also include the careful *development of guidelines and procedures* where applicable.

We recommend dedicated management/organisational consultancy from the Welsh Assembly Government to ensure that these goals are on the agenda and are implemented.

Another element of this recommendation involves the development of an *infrastructure* that will streamline access to information and help to reduce redundancy in information gathering (for example, repetition of developmental history information by different professionals). The goal is to ultimately to reduce some of the administrative burden related to coordination of information. Information mapping is needed at an individual case level to examine the kinds of data that are collected across different systems (e.g. Child Health and CAMHS) and to review the suitability of these data to be integrated and adapted. The work will involve systematic examination of data collected by the NHS and its value for inclusion in a database that can be used by clinicians. The potential for linking across databases (e.g. NHS database and research registers) and for gaining combined consent that would link with data from gene bank, neuroimaging, neonatal screening and brain bank will also be examined. We recommend that this piece of work is carried out within one Health Board (BCU) to provide the initial model, building on the initial development in building a pilot database. This work can be carried out by a Research Officer working with the supervision of Consultant Clinical Psychologist and Researcher with NHS contract/access.

We recommend that this work is carried out in collaboration with CRC Network LDAN as the development of databases is part of the ongoing work of this network.

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Appendices

Appendix A

Information given to focus group participants in advance of the discussion

Evaluation of Children's ASD Diagnostic Services Background Information

This project was commissioned by the Welsh Assembly Government in 2009 to fulfil some of the recommendations of the ASD Strategic Action Plan. Its aims are to gain an understanding of the scope and nature of children's ASD diagnostic and tertiary services in Wales, specifically:

- How they are delivered
- By whom they are delivered
- The methodologies used
- How specialist services are funded

It is not an audit, but, rather, an exercise to give an overview of services and gather some information on clinicians' priorities for policy developments in this area. The project team comprises:

Prof Sue Leekam	Principal Investigator and Director of the Wales Autism Research Centre (WARC), Cardiff University
Dr Jane Lidstone	Full-time Research Associate, WARC
Dr Dawn Wimpory	Clinical Consultant, Betsi Cadwaladr UHB
Dr Chris Ramsden	Evaluation Consultant

The focus group is the first data-gathering stage of the project. This will provide insights in its own right, and it will inform the development of a questionnaire, to be sent to all clinicians involved in the diagnosis of ASD in children in Wales.

The session facilitator will be Chris Ramsden, an evaluation expert and action researcher; Jane Lidstone will be taking notes. So that no important points are missed, we will also be audio-recording the session. However we would like to stress that focus group members are not there to represent their team or health authority; rather, clinicians generally. As such your participation will be anonymous; in the final report, no comments or themes will be linked to names nor to geographical areas, and membership of this focus group will not be disclosed. Although there will be an audio-recording, we will use aliases to preserve anonymity and the recording will be destroyed after two weeks.

After lunch at 1pm, we will start at 2pm by exploring the diagnostic process. Examples of questions:

What is the experience of making diagnoses like?

How do you use diagnostic instruments? What are their advantages and disadvantages?

How does the assessment of need for services relate to the diagnostic process?

How does referral for post-diagnostic support work in everyday practice?

At 3.15 we will have a break, and, when we resume, we will talk about some of the recommendations of the Strategic Action Plan (you don't need to read this before the focus group); in particular, recommendations for multi-disciplinary assessment and consistency of practice.

Finally, we would like to talk about possible plans for gathering information by questionnaire from all clinicians diagnosing ASD in children in Wales. An ideal situation would be to ask each diagnostic team a series of questions such as *How is the team funded? Is there a lead agency? How do different professionals contribute to the diagnostic decision?* We would appreciate your feedback on whether or not you think this would be possible, or if we will instead have to ask all questions on an individual level.

The session will end at 4.30.

To be able to use the focus group time effectively, it would be helpful to have a little information from you in advance. We would be grateful if you could complete this short questionnaire. Please return to Jane Lidstone at [email address] by Thursday 15th July. Many thanks.

Pre-focus group Questionnaire

Name:

Position (e.g., consultant psychiatrist):

Please choose an alias you would like (e.g., Sam) and write it here:

One of the topics for discussion will be the most important external factors that influence the diagnostic process. To help us to decide which to talk about, please rank the following by importance, 1 to 6 (1 being the most important):

Rank	Factor
	Opinions of parents and school
	Policy
	Targets / performance indicators
	Resources (time, money) in comparison to demand for services
	Child's need for services
	Other (please specify)

For some discussion topics, it would be useful to have a little background information on your work and its context. We would appreciate it if you could answer the following questions.

Which service and/or team are you paid to work for?

Are there any formal or informal arrangements for team-working (multidisciplinary or otherwise)?

Is it a specialist/tertiary service you work for?

Is it funded as such?

We would like to spend a small proportion of the allotted time exploring the use and usefulness of diagnostic instruments such as the ADOS, ADI, DISCO, and 3di. Please briefly describe:

- (a) what instruments you use, if any*
- (b) to what extent you use each one, and,*
- (c) any form of training (formal or informal) you have had with them.*

Many thanks

Appendix B

The questionnaire

Evaluation of Children's ASD Diagnostic Services

Questionnaire

Thank you for completing this questionnaire. We understand there are many demands on your time and very much appreciate you taking the time to tell us about the way ASD diagnostic services work in Wales. We will collate this information and report to the Welsh Assembly Government in October 2010, and we envisage this information being used to gain an understanding of the services currently available and the policy developments that could facilitate their work.

If you have any questions, you are very welcome to contact Jane Lidstone on [telephone number], or at [email address].

Please use the **grey boxes** for your answers.

If returning by post, please include your name so that we know not to send you any more reminders. Only Jane Lidstone will have access to individual respondents' answers:

No names will be used in the final report.

We would be grateful if you could return your completed questionnaire to Jane Lidstone by **[varying dates]**. Thank you.

Section 1

- 1. Your profession:**
- Clinical Psychologist
 - Educational Psychologist
 - Occupational Therapist
 - Paediatrician
 - Psychiatrist
 - Specialist Nurse
 - Speech and Language Therapist
 - Other (please specify:)

2. What issues are you currently facing in your ASD-related work, and/or, what would make your contribution to the diagnosis and assessment of children with ASD easier/more effective?

Examples include *Arrangements for multidisciplinary working, Amount of time available per case, Amount of administrative support, CAMHS Annual Operating Frame targets.*

Please describe here:

3. How important are the following factors in influencing the way you carry out your practice?

Please rate each factor from 1 (unimportant) to 7 (extremely important).

1 2 3 4 5 6 7

Your own clinical experience

Training courses you have attended

Mentoring you have received

Recent research

Your understanding of typical child development

Health Board policy

The ASD Strategic Action Plan for Wales

DSM / ICD diagnostic criteria

Other (please state:)

If you are familiar with any diagnostic instruments (e.g. the ADOS, ADI, DISCO, 3di, DAISI), please continue to Section 2 (next page).

OTHERWISE, PLEASE SKIP TO SECTION 4 (page 9).

Section 2 Diagnostic instruments

We would like to find out a bit about professionals' rationale for using diagnostic instruments and the perceived strengths and weaknesses of the instruments.

If you ever use any diagnostic instruments (e.g., the ADOS, ADI, DISCO, 3di, DAISI), please continue with this section.

IF YOU DO NOT USE ANY DIAGNOSTIC INSTRUMENTS, PLEASE SKIP TO SECTION 3 (page 8).

	ADOS	ADI	DISCO	3di	Other (e.g., DAISI) Please specify:

<p>1. In what percentage of cases do you use this instrument (please estimate, from 0 to 100%)?</p>	<p>■ %</p>	<p>■ %</p>	<p>■ %</p>	<p>■ %</p>	<p>■ %</p>
<p>2. If you use this instrument, or have ever used it, why did you <u>start</u> to use it? Please tick all that apply</p> <p>Individual choice </p> <p>Choice of team </p> <p>Choice of health board/local authority </p> <p>Other (Please specify) </p> <p>Don't use </p>					

Please continue to Question 3 (next page).

	ADOS	ADI	DISCO	3di	Other (e.g., DAISI) Please specify:
<p>3. Which of the following <u>were</u> factors in the decision to <u>start</u> using the instrument?</p> <p><i>Please tick all that apply</i></p> <p>It is easy to use</p> <p>It is not too time-consuming to administer</p> <p>The instrument is cheaper than other diagnostic tools</p> <p>It gathers useful information</p> <p>It has a good evidence base</p> <p>It can be used without formal training</p> <p>The formal training is useful CPD</p> <p>The training is cheaper/shorter than that for other diagnostic tools</p> <p>It is considered the “gold standard”</p> <p>Parents react to it well</p> <p>Other (please specify)</p> <p>Don't know</p> <p>N/A</p>					

Please continue to Question 4 (next page).

	ADOS	ADI	DISCO	3di	Other (e.g., DAISI) Please specify:
<p>4. Which of the following <u>are</u> factors in your decision to use the instrument <u>now</u>?</p> <p><i>Please tick all that apply</i></p> <p>It is easy to use</p> <p>It is not too time-consuming to administer</p> <p>It gathers useful information</p> <p>It has a good evidence base</p> <p>It is considered the “gold standard”</p> <p>Parents react to it well</p> <p>.....</p> <p>Team/health board policy</p> <p>Other (please specify)</p> <p>N/ A.....</p>					

Please continue to Question 5 (next page).

	ADOS	ADI	DISCO	3di	Other (e.g., DAISI) Please specify:
<p>5. Which statement best describes how you use the tool (when you do use it)?</p> <p><i>For each instrument, please endorse only one statement</i></p> <p>I usually use parts of this tool, to aid information-gathering</p> <p>I usually use this tool in its entirety, to aid information-gathering</p> <p>.....</p> <p>I usually use this tool in its entirety and I sometimes use the scoring system to complement my clinical judgement</p> <p>I usually use this tool in its entirety and I usually use the scoring system to complement my clinical judgement</p> <p>Other (please state)</p> <p>.....</p> <p>..</p>					

Please continue to Question 6 (next page).

	ADOS	ADI	DISCO	3di	Other (e.g., DAISI) Please specify:
<p>6. Please indicate your level of training in each instrument</p> <p><i>Please tick all that apply</i></p>	<p>None Informal 5-day course DVD-based training Met 80% criteria on post-course submission</p> <p>Other (please state:)</p>	<p>None Informal 3-day course DVD-based training Met 80% criteria on post-course submission</p> <p>Other (please state:)</p>	<p>None Informal Course part1 Course part2 Met passing out criteria</p> <p>Refresher course</p> <p>Other (please state:)</p>	<p>None Informal 2-day course</p> <p>Submitted sample clinical use for course trainers' assessment</p> <p>Other (please state:)</p>	<p>Clinic- or university-based training session</p> <p>Supervised use</p> <p>Self-taught through reading journal article</p> <p>Self-taught through observing colleague</p> <p>Other (please state:)</p>

Thank you for completing Section 2. Please continue to Section 3 (next page).

Section 3 For the instruments you do not use, please indicate why you do not use them.

	ADOS	ADI	DISCO	3di	Other (e.g., DAISI) Please specify:
<p>I am not familiar with this instrument</p> <p>The instrument is too expensive</p> <p>It can not be used without formal training</p> <p>The training is too long/expensive</p> <p>It is not very easy to use</p> <p>It is not very quick to administer</p> <p>It does not gather very useful information.....</p> <p>Parents don't respond to it very well</p> <p>It does not add anything to my information-gathering</p> <p>It does not add anything to my clinical judgement</p> <p>Its evidence base is not yet strong enough.....</p> <p>This instrument is not the "gold standard"</p> <p>Someone else in the team administers it.....</p> <p>It is not team/health board policy to use this instrument</p> <p>Other (please specify)</p> <p>N/ A.....</p> <p>.....</p>					

Thank you for completing Section 3. Please continue to Section 4 (next page).

5. In what percentage of cases do children's diagnosis and assessment include the following elements:

- | | |
|--|------------|
| (a) (i) An ADOS | % |
| (ii) Another standardised observation instrument | % PLEASE |
| (b) A standardised history-taking instrument | % ESTIMATE |
| (c) A standardised assessment of structural language | % |
| (d) A standardised assessment of pragmatic language | % |
| (e) A standardised assessment of nonverbal cognitive ability | % |

6. This question is about children and families whose first language is not English.

- | | |
|---------|---|
| (a) (i) | In what percentage of cases is the child's/family's first language Welsh ? |
| | Please estimate: % |
| (ii) | In what percentage <i>of these cases</i> is the child assessed in Welsh? |
| | Please estimate: % |
| (iii) | In what percentage <i>of these cases</i> is the history taken in Welsh? |
| | Please estimate: % |
| (b) (i) | In what % of cases is the child's/family's first language neither Welsh nor English (e.g., Punjabi)? |
| | Please estimate: % |
| (ii) | In what percentage <i>of these cases</i> is an interpreter used? |
| | Please estimate: % |

7. Is **post-diagnostic support** given after the disclosure interview?

(Please include all post-diagnostic support given after the interview, whether or not your service is the provider.)

Yes No

If yes, please describe (e.g., who provides it, whether it's parent- or child-focussed, how long/frequent are the sessions, and what proportion of cases receive it):

8. In the last five years, have you or your team referred any cases of suspected ASD to any clinicians based in a health board in Wales other than your own?

Yes No Don't know

If yes, please give details (the approximate date, reason, etc.):

9. In the last five years, have you or your team referred any cases of suspected ASD to any clinicians based **outside** Wales?

Yes No Don't know

If yes, please give details (the approximate date, reason, etc.):

10. Do you work for a specialist autism service? Yes No

If yes, What is its name?

Is it classed as a tertiary service? Yes No

Is it funded as such? Yes No

Many thanks for completing this questionnaire. We hope the results will be of benefit to you in the fullness of time.

Whilst WAG may require us to keep the results confidential initially, we would like to provide you with a summary of our anonymous respondents' feedback in the hope that this could inform your practice/ training plans etc. If you would like to receive such a summary please tick here:

If you would like to make any further comments, please do so here:

Please return the questionnaire to Jane Lidstone by email or post:

[Email address]

[Postal address]

Appendix C

Assessments included in the diagnostic instruments section by respondents

- Autism-specific diagnostic instruments and screening instruments (DAISI, CARS, Gilliam Asperger Disorder Scale, Gilliam Autism Rating Scale, Autism Screening Questionnaire, Social Communication Questionnaire, Asperger Syndrome Diagnostic Scale).
- Assessments of theory of mind and pragmatic language ability (“Sally Ann Task”, Happé’s “Strange Stories”, “NEPSY-II” Affect Recognition & Theory of Mind, “Understanding Ambiguity”, Children’s Communication Checklist-2)
- Other language assessments (“SaLT assessment”)
- Assessments of nonverbal cognitive ability (Wechsler Intelligence Scale for Children, British Ability Scales)
- Non-autism-specific instruments (Strengths and Difficulties Questionnaire, Social and Developmental Disorders Clinical Interview, Psychoeducational Profile Revised)
- Other tools and diagnostic criteria (a “local tool,” a “detailed autism specific developmental history,” a “modified ADI,” a “play-based assessment,” Gillberg diagnostic criteria, and the NIASA proforma).