

No exclusions – developing an autism diagnostic service for adults irrespective of intellectual ability

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Abstract

Purpose – Autism is a spectrum condition, yet many autism services limit access based on IQ score. The Department of Health 2009 enabled enthusiastic clinicians in Leeds with a strong interest in autism to apply for funding to develop an all IQ adult autism diagnostic service and here we present the experience. The paper aims to discuss this issue.

Design/methodology/approach – The process of establishing and then expanding the service is described. Details of the diagnostic pathway and tools used are provided.

Findings – The number of referrals was higher than expected – a baseline of 20 per year rose to 150 per year as soon as the service opened. Other unexpected findings include relatively low diagnosis rates (32 per cent), high rates of past trauma and patient dissatisfaction when a diagnosis of autism is not given.

Originality/value – To date, the service has assessed 517 patients, and plans are underway to collaborate with the local adult ADHD team to form a unified adult neurodevelopmental disorders service.

Keywords Autism, Assessment, Services, Intellectual disability, Learning disability, Adults

Paper type Conceptual paper

Introduction

Autism is a spectrum condition, meaning that people can be mildly affected to very severely affected (Wing, 1988). About 50 per cent of people with autism will also have intellectual disability (ID) (also known as learning disability; defined as IQ of 70 or below) (Emerson and Baines, 2010; Fombonne et al., 2011). There is a well-acknowledged problem of people with autism “falling through the gap” between services – i.e. IQ too high for ID services; not “mentally ill” enough for mental health services (Barnard et al., 2001). This reflects traditional National Health Service (NHS) service boundaries between ID and general psychiatry. Here, we present our initial experiences in setting up a new all-IQ autism diagnostic service for adults. The ethos of the service is to break down the artificial “service silo” barriers to assessment which so frustrate people with autism: we see patients of any age over 18, of any IQ, and accept referrals from all sources including self-referrals.

The experience of getting a new service off the ground proved exciting, frustrating and satisfying in equal measure. We hope that by sharing our story we will inspire other clinicians to push for a better deal for autistic people in their local area. There are many obstacles to setting up a service –

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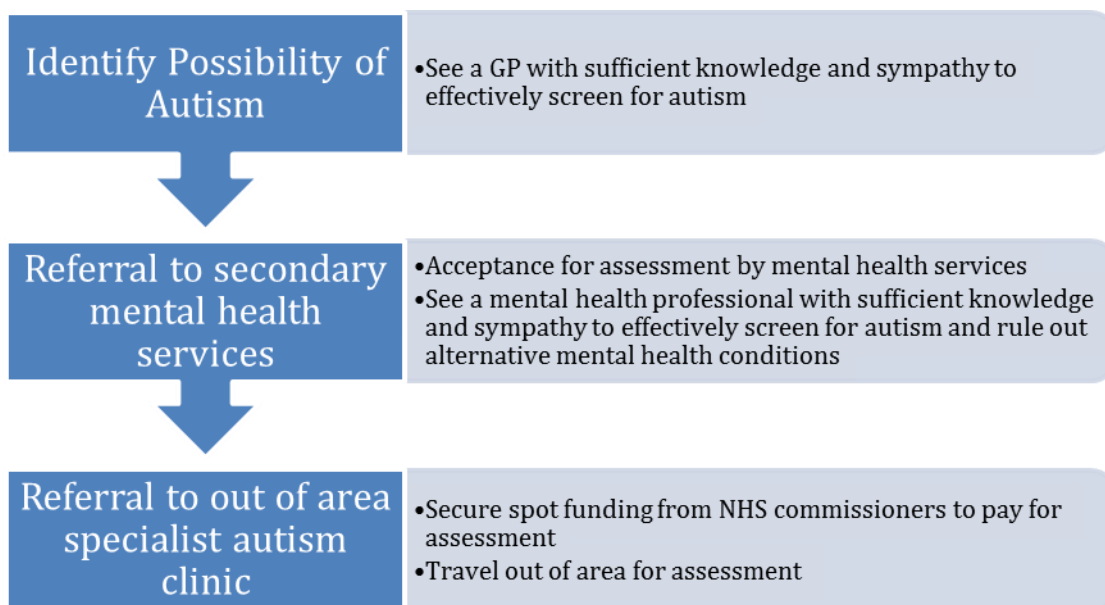
convincing people of influence, finding the money, negotiating the complexities of NHS politics, recruiting the team and setting up systems – but the end goal of improving the lives of people with autism is worth the effort.

The situation in Leeds prior to the Leeds Autism Diagnostic Service (LADS) opening

Leeds greater metropolitan area has a population of approximately 750,000 (ONS, 2011). Mental health services (except child and adolescent mental health) in the city are provided by Leeds and York Partnership Foundation Trust (LYPFT). The local authority estimates there are approximately 6,450 adults with autism in Leeds. However, in 2011 only 436 people with a recorded diagnosis of autism were registered with General Practices (Leeds City Council, 2011). We know from previous research that at least two-fifths of people with autism in the UK are undiagnosed (Baron-Cohen et al., 2009).

The LADS was formed as a pilot in September 2011 and commissioned permanently in 2014. Prior to 2011, the pathway to diagnosis in the city was ad hoc. Certain clinicians within South Leeds ID team had an interest in autism and carried out assessments, but this was by no means the case across the board. For people without ID the care pathway was essentially arbitrary, with many hurdles to overcome – the route to diagnosis is shown in Figure 1.

Figure 1 Previous route for diagnosis prior to development of local autism service



Falling at any one of these hurdles meant diagnosis did not happen. Patients and their families required a great deal of perseverance, determination and resilience to successfully negotiate them.

To make a diagnosis of autism one first has to recognise it. Sometimes patients themselves, or a family member, will recognise the features of autism and ask their General Practitioner (GP) for a referral. Often they will not. Many people with autism have mental health problems like anxiety, depression and psychosis and come into contact with mental health services (Skokauskasa and Gallagher, 2010; Ghaziuddin et al., 1998; Davidson et al., 2013). Unfortunately health professionals do not always have sufficient knowledge and experience to identify autism. A National Audit Office

(2009) survey found 80 per cent of GPs felt they needed additional training to manage Autistic Spectrum Disorder (ASD) patients effectively. When we surveyed LYPFT clinical staffs' knowledge of autism in 2012, only 2.7 per cent could correctly answer all of six multiple-choice questions. In all, 50 per cent of staff said they were not confident in their ability to recognise autism. One of the goals of LADS is to provide autism training to public service professionals in the city.

What about after diagnosis? Given it is a spectrum condition, the needs of people with autism will naturally vary widely between individuals. However often they will include mental health, employment/occupation, social engagement and accommodation needs. Generally these have to be met by a variety of provider organisations. However, best practice according to the NICE (2012) guideline is to have a locally based specialist autism team to coordinate services and provide expert assessment and advice.

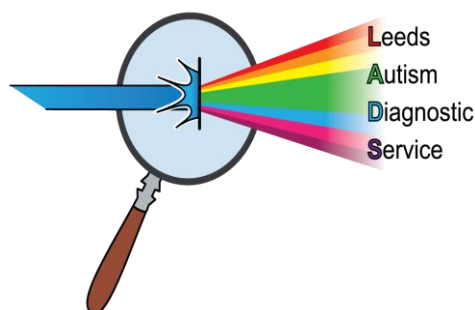
Launching the service

One of the authors (AS) has pushed for better autism services in the area for many years but was frequently a lone voice. It is no exaggeration to say that without the Department of Health (2009), things would not have changed for many more years. The Act, and subsequent accompanying Autism Strategy (2010), placed a responsibility on local public bodies to have a "clear pathway to diagnosis" by 2013. In response, the Leeds local authority appointed an autism lead, commissioning and development officer, and constituted an autism partnership board. The ground was much more fertile for innovative new ideas to take root.

The key first step in establishing any new service is to gather together a group of like-minded people who are passionate about the cause. At the beginning we had an ID psychiatrist, a secretary (unpaid for autism work), a nurse with huge enthusiasm for helping people with autism and a psychiatric registrar. There was no proper administration support, no service manager and effectively no budget. We lobbied the local NHS commissioners (who fund healthcare providers) to give LADS the monies which they had been spending on out of area autism assessments. This amounted to about £50,000 (€70,500 or US\$78,000) per year, enough to fund a pilot project.

There were a few debates about what to call the new service. Any nod to the "extreme male brain" theory is unintentional! (Baron-Cohen, 2002). Our logo was designed with the help of service users Figure 2.

Figure 2 LADS logo



At its inception the team was what could be bought with £50,000 (€70,500 or US\$78,000): half a day of an ID consultant psychiatrist; a general adult consultant psychiatrist (in line with the ethos of an all IQ service); 1.5 days of an occupational therapist and 1.5 days of a specialist autism nurse, all fitting LADS work around their “day jobs” in general adult mental health and ID services. Over time, several successful business cases have established LADS as a permanent service and allowed the team to expand. The bids have been careful to specify exactly what can be realistically provided at each stage of the service development. As of March 2014 the team consisted of:

- clinical lead, consultant ID psychiatrist with extensive experience in autism – 3 days;
- consultant general adult psychiatrist – 1 day;
- consultant general adult psychiatrist – 1/2 day;
- autism nurse – full-time;
- speech and language therapist – 4 days; and
- administrator – full time.

We have plans to recruit more staff, in particular a clinical psychologist. We are aware that the team is more “psychiatrist heavy” than most. This was a conscious strategy, as our view is that psychiatrists are particularly skilled at crucial elements of the assessment process: awareness of physical health and genetic causes; identification of mental health differential diagnoses and comorbidity, and assessment of risk.

As the team has become more established, it has been a popular destination for staff with an interest in autism. We have had visits and placements from students, nurses, managers and doctors (including most recently our Trust’s medical director). Importantly, the local authority has been active in joint working from the outset: eight social workers spent time with the team as part of becoming autism champions.

Estates and equipment

During the pilot phase we booked clinical space on an ad hoc basis in a locality community mental health team base. Feedback from patients suggested problems with the lighting for people with hypersensitivity and some concerns about the number of professionals involved in a clinical decisions meeting. In addition, appropriate office space for the team was needed.

Negotiations with the locality manager have resulted in the acquisition of two rooms - one to be used as office space and the other as a dedicated assessment room. The assessment room has been adapted (from a physiotherapy suite) and equipped with neutral colours and lighting, a two way mirror and audio-visual (AV) equipment. The choice of colour of paint and carpets was made with service user input. The mirror is for visitors to observe assessments from the next room (thus with fewer people in the clinic room so the patient feels more comfortable). The AV equipment allows recording of assessments for training and assurance purposes. We also have a range of sensory equipment to aid the assessment process and reduce anxiety: for example tangles, sensory balls and weighted blankets.

The diagnostic pathway

Our aim is to provide a gold standard level of diagnostic assessment. In designing and developing the care pathway we were particularly influenced by the NICE (2012) guideline CG 142 “Autism:

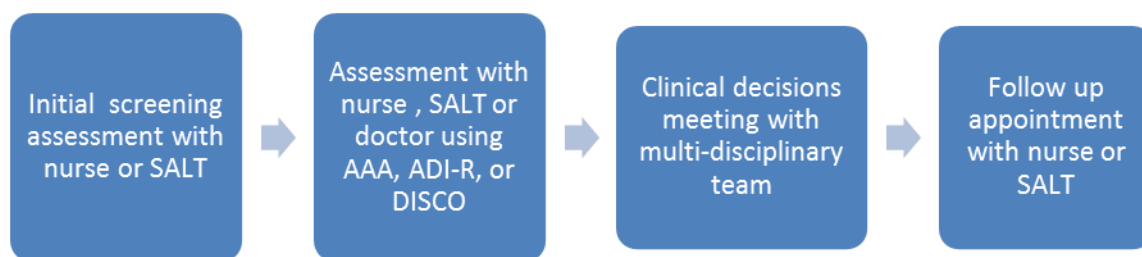
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recognition, referral, diagnosis and management of adults on the autism spectrum". Our key considerations were:

- ease of access – no artificial barriers based on IQ, upper age limit or referral source;
- multidisciplinary approach – the final diagnostic decision is always a team decision, as opposed to a single clinician; and
- use of multiple sources of evidence including collateral history, validated assessment tools, and direct clinical observation.

The diagnostic pathway is shown in Figure 3.

Figure 3 LADS care pathway



Before the assessment

Referrals come via the LYPFT Single Point of Access. We accept referrals from any source, including self-referrals. Our target is for an initial appointment within twelve weeks of receiving the referral, as per NICE (2014) quality standards. Currently the waiting time to initial appointment is six weeks.

On receipt of a referral, the patient is sent out a questionnaire pack to complete. This includes:

- LADS questionnaire – based on a form provided by Dr Janine Robinson (Chartered consultant clinical psychologist from Cambridge Lifespan Asperger Syndrome Service – CLASS) as part of a two day adult autism diagnosis training course, this includes questions on family history, education/employment history, past medical and psychiatric history, past trauma (physical/sexual abuse) and substance misuse.
- The Adult Asperger Assessment (AAA) screening instruments; the Autism Spectrum Quotient (AQ), the Empathy Quotient (EQ), and the Relatives' Questionnaire (RQ) (Baron-Cohen et al., 2005).
- Patient Health Questionnaire 9 (PHQ-9) – short depression rating scale (Kroenke et al., 2001).
- Generalised Anxiety Disorder 7 (GAD7) – short anxiety rating scale (Spitzer et al., 2006).
- Short Warwick Edinburgh Mental Well Being Scale (SWEMWBS) – generic wellbeing scale (Stewart-Brown et al., 2009).
- consent for release of information under the Data Protection Act – to permit us to access past health (and social care) records.

A covering letter is included. All of our clinical documentation has been reviewed by the Trust easy on the i team (www.easyonthei.nhs.uk) to ensure it is appropriate for people of all intellectual ability. We also consulted Professor Stuart Murray (Professor of Contemporary Literatures and Film at the University of Leeds and author of books on autism) (Murray, 2008, 2011) who gave us useful advice. This article is © Emerald Group Publishing and permission has been granted for this version to appear here <https://www.leedsandYorkpft.nhs.uk/our-services/services-list/autism-diagnostic-service-lads/>. Emerald does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from Emerald Group Publishing Limited.

on framing our correspondence in positive and hopeful language. If patients do not return the questionnaires, we ask for them to be completed in the waiting area prior to the first appointment. Sometimes it is unfeasible to expect the self-reported questionnaires to be completed, for instance if the patient has a severe ID.

Initial screening

This stage was added most recently, due to concerns that people with serious mental health problems had been inappropriately sitting on an autism waiting list. The screening appointment lasts 60-90 minutes, with one clinician, and is semi-structured. The purpose is to determine whether or not to proceed with the full diagnostic pathway, as some patients clearly do not meet the criteria for autism in which case detailed assessment is unnecessary. To decide this we take a structured brief history, and also use adapted Dewey stories (Dewey, 1991) and occasionally elements of the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 1989) plus emotions cards. Sometimes the developmental assessment is done at this appointment if the need for one is obvious and the relative is in agreement.

Developmental assessment

At this stage a relative (normally parent) who knew the patient as a child is interviewed. The interview is carried out by a single member of the team and typically lasts two to three hours. The default assessment tool is the Autism diagnostic interview revised (ADI-R) (Le Couteur et al., 2003). We use the Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al., 2002) occasionally: we find the DISCO takes longer to complete (up to seven hours in some cases) but can be more useful when assessing complex, high functioning or female individuals.

It is not that uncommon for a parental history to be unavailable, either because the parents have died, live far afield, or become estranged from the patient. If necessary we use telephone or email to obtain a collateral history. In any case, we always ask for contemporaneous information from childhood. This is most often school reports and medical reports, but we have also received items as diverse as artwork, photographs, written stories and old home movies.

Clinical decision meeting

This is the stage when a diagnosis is made. It is always multidisciplinary (at least two team members). The patient and appropriate relatives/carers are invited. All the information collected already is reviewed prior to the appointment – typically this includes:

- referral letter;
- past psychiatric record;
- Child and adolescent mental health services (CAMHS) reports if applicable;
- school reports;
- other evidence from childhood – e.g. pictures, home movies;
- AAA information – AQ, EQ and RQ;
- LADS questionnaire; and
- developmental interview results (quantitative scores and qualitative description).

At the start of the interview, patients are always advised of the following:

The outcome of today's decision, whatever it may be, will not change who you are. If a diagnosis of autism is made it will merely mean that other people are able to understand what it is like to be you and may be better able to understand you and therefore help you.

During the interview, we use a modified ADOS to observe the patient's social and communication style. We generally use emotions cards as well to test facial expression recognition. We also ask targeted questions to probe areas of the history that need further clarification.

After the assessment phase is complete (usually 60 minutes), we ask the patient and supporters to wait outside whilst the team discusses our findings and arrives at a decision. As would be expected with a spectrum condition, some cases clearly meet the clinical criteria for autism, some are obviously not autistic, and some are more complex: the latter group prompt the most debate. We generally use the International Classification of Diseases tenth revision (ICD-10) definition of ASD, although at times when there is diagnostic uncertainty we turn to the more operationalized Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V criteria). We do encounter a number of people who have social skills deficits and significant functional impairment, but who nevertheless do not meet the full criteria for autism. At present we do not often use the diagnostic category of social communication disorder – in part because it is of uncertain clinical and administrative (for benefits claims, “reasonable adjustments” etc.) significance in the UK at the present time. However, occasionally when adults have struggled with social communication in settings such as job interviews but do not meet the full criteria for autism, we have used the social communication disorder diagnosis.

After diagnosis a standardized template letter is written to the referrer and copied to the service user and GP. At present these are limited in length and detail, simply stating the assessments carried out and the final diagnostic decision. However, now that full-time administration support is in place, we have made amendments in line with suggestions from Carole Buckley, GP Autism Champion. It is of interest that the current limited information is happily accepted by all of the people who receive the diagnosis. The full details of the assessment are of course stored in the paper and electronic record and can be provided if a special request is made.

Follow up

If a diagnosis of autism is made, a single post-diagnostic follow up appointment is offered. This is to give the service user/carer an opportunity to ask more questions, provide written information and signpost to other services.

LADS has developed an information pack which includes relevant local resources as well as general information about autism.

For people with autism and ID, ongoing follow-up (if needed) is provided by ID services. The situation is more difficult for people without an ID. Community mental health teams often do not see autism spectrum disorder as part of their remit (despite it being considered a mental disorder in the DSM, ICD and the Mental Health Act code of practice). Ideally, LADS would provide some in-house follow-up such as psychological and pharmacological treatments, and group programmes to support other services. At present we are not commissioned for these resource-intensive options, but we have

explored innovative alternatives such as assistive technology. *Brain in Hand* is an example (see Box 1).

Box 1: Brain in hand

The team used budget underspend due to delay in staff recruitment to purchase five licences for a mobile phone application with mentoring support and became the NHS Northern pilot for Brain in Hand (2015). Brain in Hand (BIH) enables people with autism to come up with their own solutions to reasonably predictable problems associated with their autism. When they are calm, they input coping strategies into their secure website and this syncs with their mobile phone app (their own brain in their hand) which can then be accessed when in a stressful situation. There is also a traffic light system, where green is pressed if things are fine, amber if there are potential problems and red if high anxiety is experienced. Pressing amber three times in a row, or one red leads to a phone call from a BIH mentor, based at the Autism Diagnostic Research Centre in Southampton, who is able to listen and then talk the person through their own solution focused ideas. The inputted traffic light data can be monitored by the user and their support staff on their website so that patterns and difficulties can be analysed and even more effective solutions developed.

Consultation service

In April 2015, the commissioners agreed to fund consultation and training for a time limited one year period. LADS would provide consultancy advice to professionals or carers involved with people who already had a diagnosis, and provide training for health and other professionals in the Leeds area. A whole time band five nurse and a half time specialty doctor were seconded from other roles in Leeds for a year to assist with the diagnostic pathway, thereby releasing the lead clinician and autism nurse to provide consultancy and training.

Initially a few consultancy cases involved people who had been diagnosed with autism elsewhere, who we felt may not have received a diagnosis if they had gone through our diagnostic pathway. Therefore we devised another questionnaire pack, which included a request for evidence of the original diagnostic assessment and a caveat that in order to provide consultancy advice we may recommend they go through our own diagnostic process.

So far we have provided consultancy for ten cases.

These have ranged from community assessments, mother and baby units, accident and emergency departments, GP practices, in-patient LD and mental health services, chronic fatigue services and forensic joint assessments.

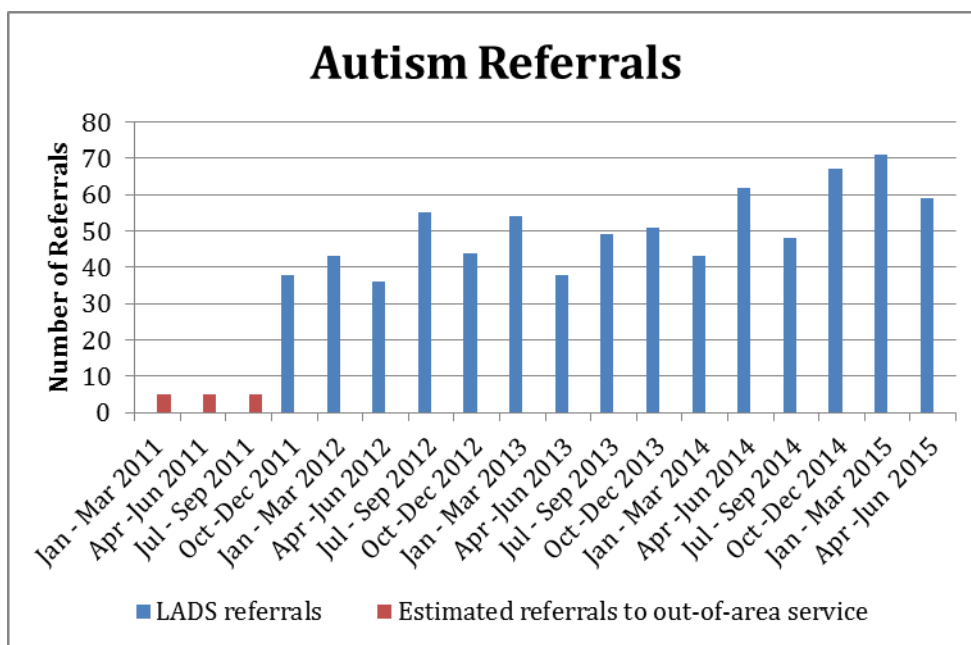
The training element of LADS aims to upskill other professionals working in Leeds so that people who have autism have access to a full range of autism-friendly health and social care services. We have tried to involve service users wherever possible and to date, our training activities include a one day Andrew Sims Centre conference, a presentation at the GP National Fringe meeting, target training for GPs and adding autism to the Leeds Medical School curriculum.

Our experience so far

LADS received 150 referrals in its first year (September 2011-2012). This was much more than we expected (given that there had only been twenty externally commissioned diagnostic assessments the previous year), and as a result waiting times quickly increased. The Trust has supported a drive to reduce waiting lists with financial support for additional clinical hours on a temporary basis: by April 2015 the waiting time from referral to assessment was on average six weeks. The success with waiting times we believe is in part due to our eschewal of lengthy written reports, and also the addition of an initial screening appointment to the diagnostic pathway.

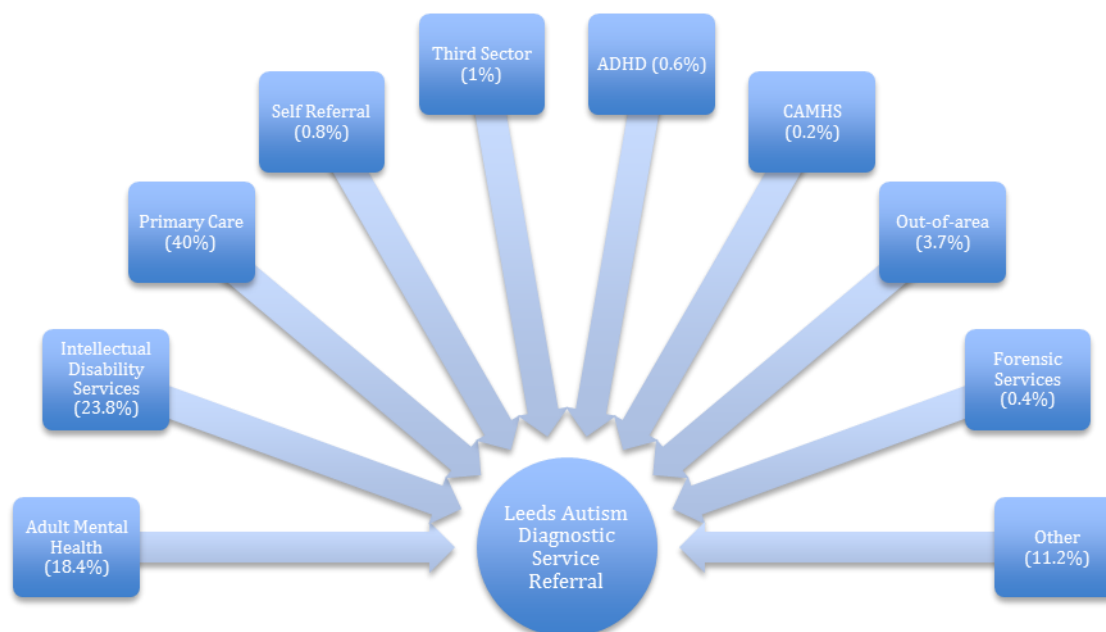
As the service has become more established the referral rate has increased further – averaging four to six per week in 2013, and by March 2015 nine per week (The service is commissioned based on a referral rate of four to five per week). This is shown in Figure 4. The ratio of male to female referrals has remained fairly constant at 70:30 per cent.

Figure 4



A breakdown of referral sources is shown in Figure 5.

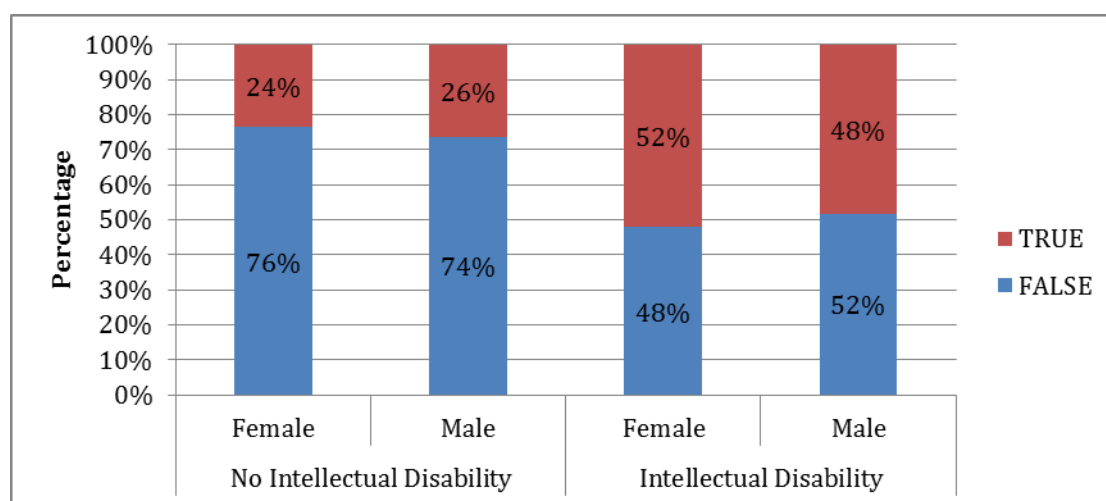
Figure 5



At the time of writing 517 patients had completed the diagnostic pathway. 166 (32 per cent) have received a diagnosis of ASD; 351 have not (68 per cent). We believe our approach gives a particularly robust final diagnostic outcome. This perhaps partly explains why our “conversion rate” (i.e. proportion of referred patients who end up with a diagnosis of ASD) is low compared with tertiary referral services such as Sheffield – but perhaps comparable with other open referral services.

It is notable that diagnosis rates are higher in patients with ID, see Figure 6.

Figure 6



We have observed significant rates of early trauma (abuse, dysfunctional families and bullying): in a sample of 40 recent patients, 63 per cent were diagnosed with autism and 25 per cent had significant trauma. The extent of abusive experiences has been unexpected and further research into this topic is

being considered. In the same sample, 25 per cent have a significant risk history. Examples include fire-setting, aggression to carers, and sexual fetishes and paraphilias. Our team does not case-manage patients, but if significant risk issues are present we do make appropriate referrals to other services to manage the risk. We have found that our Trust's standard risk assessment tool, the functional analysis of care environment risk assessment, is sometimes inadequate for this particular group because it does not always identify autism-specific risks, nor provide suggestions for managing them. We are currently piloting an in-house autism-specific risk assessment tool called the Adult Leeds Autism Risk Management tool.

Audit and outcomes

Although we sought to embed routine outcome measurement from the launch of the service, this has not been as straightforward as hoped. There is a paucity of well validated autism specific outcome measures available. We also had the problem of when to collect outcomes – we only have one follow-up appointment and does this give enough time for the benefits of diagnosis to become apparent? Finally, what are the most appropriate outcomes to look at for a diagnostic service? Process indicators like waiting times and referral rates have their place, but they fail to capture what is really important in peoples' lives.

At the initial pilot stage we routinely used the therapy outcome measures (TOMS) tool. We developed an autism specific TOMS data set which has since been incorporated into the TOMS manual (Enderby and John, 2015). However, we observed that only minor changes in TOMS ratings happened between initial appointment and follow-up appointment – our hypothesis to explain this is that it takes some time for the full benefits of an autism diagnosis to become apparent and measurable. For now we have put TOMS on hold, instead using qualitative outcome measures.

At present we routinely collect the following:

- Key performance indicators for the Clinical Commissioning Group – percentage of patients seen within twelve weeks of referral; time from referral to first appointment; time from referral to diagnosis.
- LADS qualitative feedback questionnaire – given to patients after clinical decision meeting.
- There are two service evaluations being undertaken by medical students at present. One is a retrospective questionnaire sent to all patients who were diagnosed with autism between September 2011 and January 2015. The second is a prospective questionnaire given to everyone that has attended the service regardless of diagnosis from January to July 2015.

Feedback has been generally very positive. A selection of representative comments are reproduced in Box 2.

Box 2: Patient feedback

“The staff were very competent”.

“It has greatly improved our lives and I don’t know how I managed without this service”.

“For the first time ever someone recognised a problem and actually followed it up with some action”.

(How could we make the service better) “If we had ongoing help and support following the diagnosis, maybe an online support group”.

In 2014 we audited a randomly selected sample of 20 cases against NICE standards. We found that in over 90 per cent of cases, the assessment was team-based, all relevant history items were enquired about, and direct observation of core autism signs and symptoms was carried out. The areas which need improvement are risk assessment and care planning, and we are currently implementing an action plan to address these.

Challenges/lessons learnt

We have encountered a number of challenges on our journey so far. Some expected, some not. Some unique to our particular field of adult autism, some any newly launched service would encounter.

One problem which will be familiar to all those who work in the field is the proportion of cases that are “blurry” and “difficult to call” – i.e. individuals who lie on the borderline of the spectrum between normality and pathology. As ultimately ASD is a clinical diagnosis, the question of “where to draw the line” in these equivocal cases can be difficult. Following clinical decisions meetings, we occasionally have disagreement between team members about whether the patient meets criteria for diagnosis. Usually we are able to come to a consensus one way or the other by carefully re-reviewing all the pertinent information and applying the DSM-V criteria in meticulous fashion. On rare occasions, a consensus is not reached; in which case our current practice is to invite the patient back for a second clinical decisions meeting with other members of the team, by way of a second opinion. Sometimes psychometric assessment is sought from our Trust neuropsychology department. In addition, particularly complex cases can be discussed with external autism experts via regional and national clinical networks.

Coming to a diagnosis is also more difficult when an informant history is unavailable. Obviously this occurs much more often in adult services than CAMHS. We can mitigate it to some extent by using contemporaneous childhood reports and other evidence, but ultimately a diagnosis of autism is crucially dependent on solid evidence of early life onset of social and communication difficulties. In some cases, despite our best efforts we have simply been unable to make a firm diagnosis due to the absence of a collateral developmental history. This can be frustrating for the patients affected. In such cases we include the following paragraph in our assessment letter:

In the absence of a good development history the team have been unable to reach a conclusion about whether or not the person meets the clinical criteria for autism/Asperger syndrome.

In as much as possible, we also try and flag up the possibility of an inconclusive outcome with the patient as early as possible. We find this helps to manage expectations. At times in the past, when lacking a collateral developmental history we have tried to compensate and gather more clinical information by arranging extra clinical decisions meetings – as many as five in one case. Unfortunately this approach rarely results in better diagnostic clarity and perhaps also serves to heighten expectation – and thus deflation when a final diagnosis is ultimately not reached.

When we started the service, we anticipated that the majority of the patients we assessed would turn out to have clear cut autism. In fact, this has not been the case. We have speculated on why this is so. Our impression is that the stigma around Asperger syndrome (less so classical “Kanner” autism) has diminished. This makes it more likely that individuals with mild sub-clinical symptoms – or even no symptoms at all – present to their GP seeking diagnosis (perhaps having “read up” about Aspergers on the internet and recognising similar behaviours due to different causes). We have also encountered a subgroup of patients who are essentially unhappy and lonely, and trying to find an explanation for this. In some cases the explanation will be some other psychiatric disorder (like depression or personality disorder); in other cases there will be no diagnosable mental health problem, and the reasons are social and familial factors beyond the purview of medicine.

Something that has particularly taken us by surprise is the phenomenon of patients getting upset or angry when not diagnosed with autism. Perhaps naively, we had expected that not receiving a diagnosis of autism would be regarded as a positive outcome. It seems that some people in the community have already self-identified as “aspie”, and react strongly when this is contradicted by a mental health professional. Maybe this should not have been so surprising, as those of us who work in general adult mental health settings have seen the same pattern in recent years with bipolar disorder becoming a less stigmatising and indeed sometimes “sought-after” diagnosis (Chan and Sireling, 2010). As a result of this, we have received a higher than expected number of written complaints (although still only five in total). Invariably these are from patients or carers who are dissatisfied at not having received a diagnosis of autism and disagree with our conclusions. The response to complaints generally necessitates an evidence report explaining the results of the assessments and the rationale for not diagnosing autism.

The future

These are exciting times for autism services in the UK. It is one of the few areas of mental health that is expanding at the moment. We were somewhat taken aback that the demand for our service has so exceeded initial expectation, but thankfully the Trust and the commissioners have been supportive in helping us to meet it. At the time of writing, we have plans to expand the service further, including spearheading the development of a unified neurodevelopmental service for adults by collaborating with the local adult ADHD clinic. In the first instance, this will involve hiring new staff such as a clinical psychologist. We intend to grow our post diagnostic service by setting up practical groups (e.g. anxiety management) (and have already provided advice and support for such groups in the area) and work closely with our colleagues in social services to help patients with accommodation, education and occupational issues. There are promising new developments in technological aides for people with autism, and our involvement with the Brain in Hand system is providing further insights into alternative sources of support. In time, we hope to secure larger accommodation to house the new service and provide bespoke clinical areas.

Almost four years after developing the pilot, we are continuing to learn and in so doing, further improve the services we provide. We are indebted to the people who have advised us on our process, provided valuable feedback and allowed us to assess them through a comprehensive, time intensive and multidisciplinary pathway to hopefully reach a relevant and valid conclusion. We are keen to remain a service that always asks service users for advice – as after all, they are the experts.

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