

## **Are we good and are we safe? Measuring quality and assessing risk in an adult autism diagnostic service**

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### **Abstract**

*Purpose* – Leeds autism diagnostic service is an adult autism diagnostic service for people of any intellectual ability which also offers consultancy to service users/carers or professionals, as well as a wide range of autism training. The service was set up as a pilot in 2011 and a paper describing the service development was published in this journal in November 2015. The purpose of this paper is to describe the approach taken to measure the quality of the service the authors provide and accurately assess risk in adults with autism.

*Design/methodology/approach* – The process of evaluating appropriate outcome measures is described, along with considering appropriate risk assessment tools for use in the community. Over 200 people each year complete the autism diagnostic pathway, and 164 patients were invited to respond to service evaluation questionnaires in 2014.

*Findings* – To date, the most useful outcome measures for this group include a prospective service user questionnaire which enables service user opinion to influence service development. In the absence of any appropriate autism-specific risk assessment tools, the service has developed one which it is currently piloting. This has proved particularly useful in the consultancy setting

*Originality/value* – This paper is a follow-up paper looking at the day-to-day issues that the team have had to grapple with – how do you assess whether what you are doing is providing the best possible service for the people that you serve and how do you accurately assess risk in this population?

*Keywords* Autism, Intellectual disability, Adults, Learning disability, Risk assessment, Outcome measures

*Paper type* Conceptual paper

### **Introduction**

In our last paper we discussed the trials and tribulations of setting up a new diagnostic service for adults with autism (Davidson et al., 2015). In this follow-up paper, we present our experiences of two key elements of the service: measuring quality and assessing risk.

Leeds autism diagnostic service (LADS) is an all-IQ autism assessment service for Leeds residents over the age of 18 (Figure 1). We aim to provide a gold-standard autism assessment within a multi-disciplinary team setting using diagnostic tools, direct observation and developmental history from a parent/relative. The service is accessible to all over 18 years old. We accept referrals from primary care, mental health services, intellectual disability (ID) services and self-referrals (Figure 2). At the

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time of writing over 200 patients per year complete the diagnostic pathway; the diagnostic rate is 32 per cent with no real gender difference. From 2015 we have also provided a consultancy service (mainly to other mental health teams, but is open to any health or social care service in Leeds) for a number of difficult-to-manage patients with autism.

LADS was formed as a pilot in September 2011, and permanently established as part of Leeds and York Partnership NHS Foundation Trust services in 2014. From the beginning we were interested in whether a service like ours provides benefit. Of course, as clinicians we assume that what we do is helpful, but how do we prove it? This led us to explore different ways of measuring service performance, patient satisfaction and clinical outcomes.

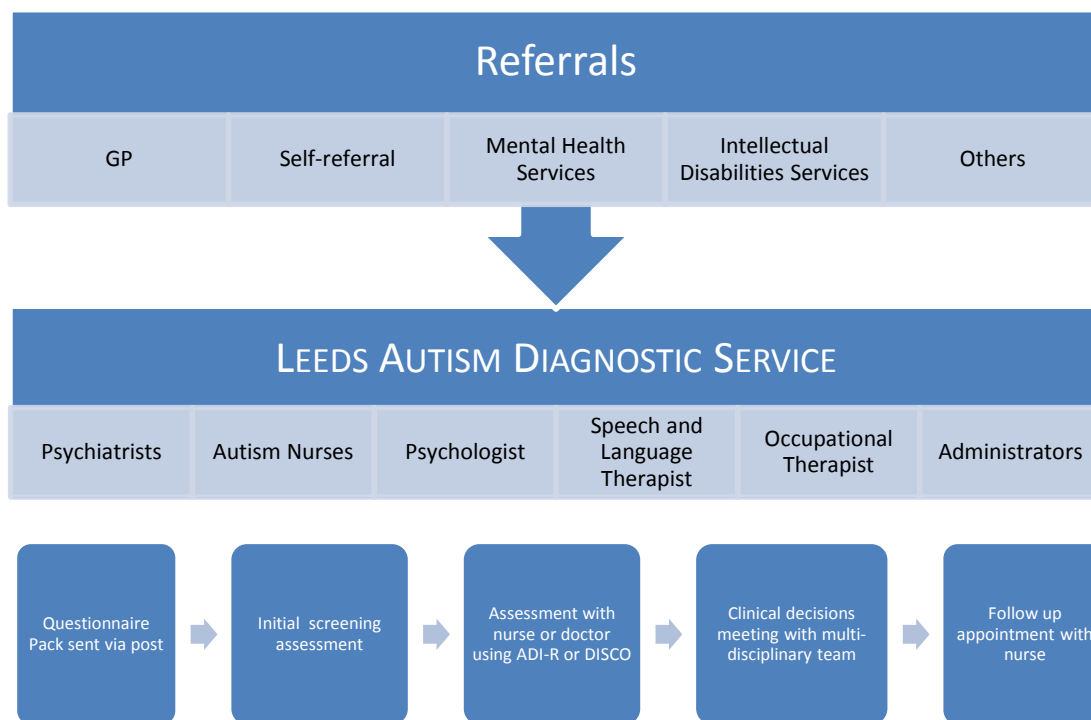
A second area which we were particularly interested in – and which has proved challenging – is risk assessment in adult autism. The National Institute for Health and Clinical Excellence (NICE) (2012) adult autism guidelines do specify that risk assessment should be a routine part of the diagnostic process, but in practice, with limited time and resources, what does an appropriate risk assessment look like? We came to realise that the standard risk assessment tool used by our mental health trust was not consistently capturing all the key risks in our patient population, at times to the consternation of Community Mental Health Team (CMHT) colleagues.

Figure 1 LADS logo



**Source:** Leeds and York Partnership NHS Foundation Trust (2012)

Figure 2 LADS referral and diagnostic pathway



**Source:** Created by LADS team, Leeds and York Partnership Foundation NHS Trust (2016)

In discussions with other UK experts in the field it became clear that many other adult neurodevelopmental services are grappling with precisely these issues of outcome measurement and risk assessment. In this context, we are sharing our experiences so that others might learn from our missteps and successes.

### Outcome measurement in adult autism

We are indebted to Henninger and Taylor (2013) for their excellent historical review of outcomes in adults with autism spectrum disorders. They describe the early attempts at outcome measurement (up to the early 2000s) as using “vague and unreliable criteria”. Some researchers – notably Michael Rutter – did attempt to measure outcomes in adulthood, but there was little attempt to operationalise or validate the measures used.

Rutter et al. (1967) used the categories good, fair, poor and very poor. A good outcome was defined as “leading a normal or near-normal social life and functioning satisfactorily at school or at work” whereas a very poor outcome was “unable to lead any kind of independent existence”. Although these definitions are clearly open to considerable subjective interpretation, Rutter’s scheme was commonly used (sometimes with minor modifications) in adult autism research for several decades. Notably despite the apparent lack of specificity in Rutter’s criteria, the various studies using them display similar overall results: around two-thirds of adults with classical infantile autism have poor or very poor outcomes; whereas the majority of those with Asperger syndrome have fair outcomes (defined as

“making social and educational progress in spite of significant, even marked, abnormalities in behaviour or interpersonal relationships”).

Since the early 2000s, efforts were made to improve the validity and reliability of outcome reporting in adult autism. Numerical scales with more specifically defined criteria have been introduced. Most notably, Patricia Howlin et al. introduced the overall outcome rating (OOR) scale in 2004. The OOR looks at three domains – work, friendship, and independent living – to produce a final score between 0 and 11 (0 best, 11 worst). Recently there has been interest in the Spectrum Star (Hahn, 2012) which has been used in specialist residential settings but has yet to be validated in peer-reviewed journals.

Rutter’s and Howlin’s schemes focus on long-term social outcomes. Trials of “treatments” for autism (psychosocial interventions or medication) may also attempt to measure symptoms: either the core autism features social-communication problems and restricted, repetitive behaviours (RRBs); or associated secondary symptoms such as anxiety. The most widely used rating scale of autism traits is the Social Responsiveness Scale (Constantino and Gruber, 2005). RRBs can be measured using The Repetitive Behavior Scale (RBS) (Bodfish et al., 1999). Several tools for measuring psychopathology in children and adults with ID and autism have been reviewed (Underwood et al., 2011, 2015) but there is limited evidence on their effectiveness. The Clinical Global Impression rating scale (Guy, 1976) is a measure of overall functioning that is commonly used in psychiatric clinical trials, but it is not specifically validated for use in autism. Many other rating scales are available, but to our knowledge none (including those mentioned above) are recommended for routine clinical use in autism. In their comprehensive review of clinical trial outcome measures in adult autism, Brugha et al. (2015) report that none of the measures were specifically validated for use in adults with autism. They conclude: “on the basis of existing data there is no single assessment instrument or set of instruments that can be considered to be the standard measure of outcome in the field of autism treatment evaluation”.

One of the criticisms of using standard outcome measurement tools has been that they fail to capture the whole breadth of a spectrum condition like autism – e.g. living in residential accommodation with only a few challenging behaviours may be a poor outcome for an individual with Asperger syndrome, but a pretty good outcome for someone with Kanner autism and ID. This is certainly our experience in LADS which, as an all-IQ service, comes into contact with people with a vast range of ability and potential; our service user feedback would suggest that higher functioning does not necessarily correlate with higher well-being. In recent years there has been growing interest in devising individualised outcome measures, which measure what is actually important to the patient. Well-established examples include the surgical outcome measure SeiQOL (O’Boyle et al., 1993) and, in mental health, the Goal Attainment Scale (Kiresuk and Sherman, 1968), but such approaches have been slow to catch on in mainstream mental health services.

### **Our experiences so far with outcome measurement**

Our commissioners require us to collect data on key performance indicators, which are essentially process measures. Although these figures have some usefulness in terms of what we are doing, they do not capture the how – i.e. whether we are doing it well. From a patient perspective, does the diagnosis actually improve their lives, irrespective of how quickly they got it? In this section we describe the different approaches we have taken to outcome measurement and the key findings and lessons learnt.

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### *Referral data*

We routinely collect key performance indicator data on throughput – percentage of patients seen within 12 weeks of referral; time from referral to first appointment, and time from referral to final diagnosis. This shows that we do consistently see the vast majority of patients within eight weeks of referral. It also demonstrates that as soon as the service was launched in 2011, referrals for autism assessments in Leeds immediately increased by a factor of seven – from an average of around 20 per year pre-LADS (for out of area assessments spot-funded by commissioners) to 150 per year afterwards. This number has been steadily increasing year-on-year since – to 314 in 2015. It seems to be a case of “if you build it, they will come”. Obviously this has implications for commissioners and providers planning new services in other parts of the country, as merely providing enough resource to cover the previous level of demand is unlikely to be sufficient.

### *Patient satisfaction surveys*

During the pilot stage we asked every patient to complete a generic Trust approved feedback questionnaire. Feedback was universally positive, with 100 per cent of patients rating the service as “good”. A number of comments mentioned the lack of follow-up after diagnosis, which helped to bolster the case for improved autism services in the city.

In 2014 medical students from the University of Leeds conducted more detailed service evaluations, which included prospective and retrospective questionnaires. These were not subject to ethical approval as there was no face-to-face contact, and did not carry the potential to cause any harm or upset. Both questionnaires were created with the help of a service user involvement facilitator within our trust working as part of the “easy on the i” team. This information design team specialise in producing easy-to-understand information for service users; they also provided us with service user feedback around the practicalities of filling out the questionnaire. Both questionnaires were available in paper and online formats and addressed only to the patient. Consent was implied if the questionnaire was returned completed and data were anonymised, with no sharing of identifiable data.

We sent the retrospective survey to 117 service users who LADS had diagnosed with autism, receiving 29 responses to the postal survey and two to the online version. Unfortunately there was a response rate of only 26 per cent. The majority of respondents had an ID – 73 per cent, and in most of these cases the questionnaire was filled in with the help of a carer. It was notable that 38 per cent of respondents rated our pre-pack questionnaire as “hard to understand”, a finding which has prompted us to review the readability of our paperwork. The other most interesting finding was that when asked “Has having a diagnosis of autism made your life better?”, only 44 per cent said “yes” (33 per cent said “not sure”; 23 per cent said “no”). Perhaps this can be explained by the fact that over half of respondents reported getting no extra support post-diagnosis. The most prominent example of this was one written response saying they required “help with a complete mental breakdown”. Others reported wanting help with tasks of day-to-day living and finances. On the other hand, some people told us they have received additional support since diagnosis. The types of support described were wide-ranging, including local charities, brain in hand (assistive digital technology), specialist counselling, peer support groups, finance and housing. The questionnaire was not designed to explore what factors led to only some people receiving extra support, but it seems to us that this is a key issue worthy of further research. Perhaps having highly motivated and able family members, a sympathetic and

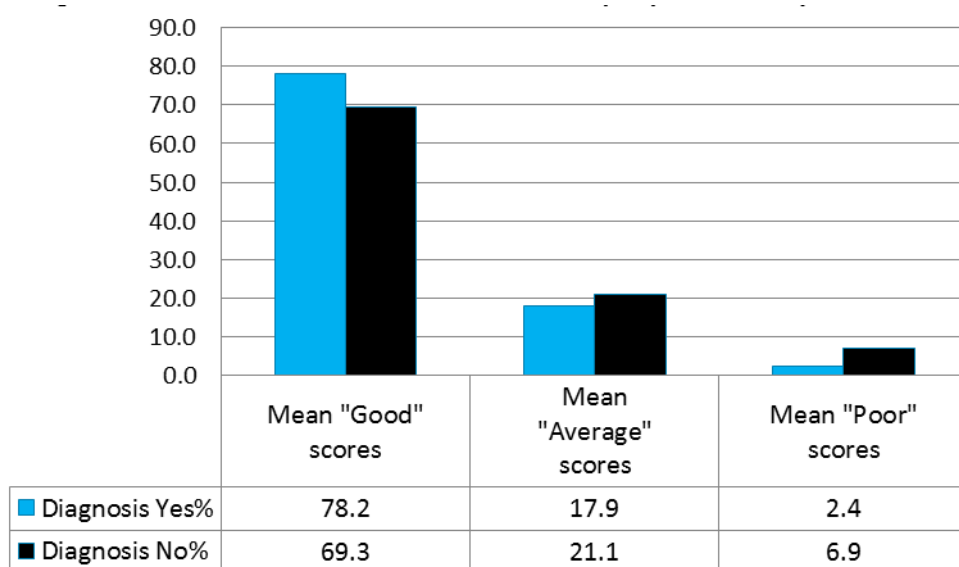
understanding GP, or greater financial resources can explain why some patients are able to access more support post-diagnosis.

The prospective survey was given to patients just after the Clinical Decisions Meeting, irrespective of final diagnosis, and garnered 57 responses. Of these, 28 (49 per cent) had received a diagnosis of autism and 19 (33 per cent) had an ID. Results showed that those referred by GPs were less likely to be diagnosed with autism than those who self-referred: 24 vs 62 per cent. This appears to contradict the hypothesis (mentioned in our last paper) that our relatively low diagnosis rates are in part due to allowing self-referrals who are less likely to be autistic than people screened by GPs. However, the sample size in this survey was small and we still need to validate this finding against our full database.

The results of the prospective survey also showed that there was generally more dissatisfaction with the service amongst people who were not diagnosed with autism (Figure 3): this backs up our own clinical observations, which are that if patients are told they do not in fact have autism, they are more likely to be unhappy (in some cases angry) and also more likely to make a complaint. We are not aware of any studies looking at the emotional reaction to an autism diagnosis, but there is such a study looking at ADHD diagnosis (Young et al., 2008). The authors suggest there are several stages:

1. initial relief and elation;
2. confusion and emotional turmoil;
3. anger;
4. sadness and grief;
5. anxiety; and
6. accommodation and acceptance.

Figure 3 Overall satisfaction with the service from prospective survey



**Source:** Created by authors

It may be that not receiving an expected diagnosis leaves the person stuck with feelings of anger and confusion, without necessarily progressing to the acceptance stage. It is not uncommon for us to be asked “well if it’s not autism, what is the reason for the problems I have?” Many of the people we  
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have diagnosed report a strong emotional reaction, including relief, but also in some cases a sense of grief and loss of identity. An example is James McGrath, lecturer at Leeds Beckett University, who was recently diagnosed with autism by LADS; he writes powerfully of his experience of receiving the diagnosis (Box 1). We believe this topic warrants further study.

The elements of the service with most dissatisfaction were the autism diagnostic observation schedule (ADOS) (Lord et al., 1989) activities, and accessibility of information about the service. The ADOS was originally designed for children, although the module we use has been adapted for adolescents and young adults, and we advise patients of this beforehand. However, perhaps this warning in fact primes them to consider the ADOS tasks “childish”. A few service users described these activities with comments such as “awkward [...] patronising [...] childlike toys”. Regarding accessibility of information, we have made efforts to ensure our literature is easy-read and we are improving our website and online information.

#### *Limitations of patient satisfaction surveys*

There are methodological issues with this type of outcome measurement. The response rate to the retrospective questionnaire was relatively low: a large-scale study found average survey response rate to be 52.7 per cent (Baruch and Holtom, 2008). The prospective survey, on the other hand, suffered from selective sampling because people were invited to fill in the questionnaire directly after the Clinical Decisions Meeting when they are told whether they have a diagnosis of autism or not. For some this is an extremely emotive time and could have resulted in respondents exhibiting an emotion bias in their responses; and in a few cases people with particularly extreme emotional reaction either refused, or were deemed not appropriate to invite to participate.

#### **Clinical outcome measures**

Finding an effective method of outcome measurement has been difficult. In part because few validated outcome measures exist for adult autism. In addition, there are intrinsic challenges in measuring outcomes in diagnostic-only services: does a diagnosis in itself actually make a measurable difference in quality of life? If it does, how soon after diagnosis is the improvement seen? Much of the benefit from a diagnosis is likely due to resultant follow-up care (social services input, reasonable adjustments in the workplace, financial benefits, etc.), which is dependent on the level of autism service provision in the local area and not on LADS itself.

Box 1: “World is suddener than we fancy it”: imagination, change and autism diagnosis

I underwent assessment assuming diagnosis would be little more than an abstract formality, confirming something I had in some way known all my life. I had expected it would feel like little other than a more clinical definition of my “eccentricity”, “oddness” and “Jamesness” as observed to me from teachers, peers and friends. But You clearly have Autism. We are all in agreement. Diagnosis brought a weird mix of shock and relief; but first and greatest was the shock.

The previous sentence might have specified that diagnosis brought shock to me. Yet for some weeks after, the very state of “me” felt almost absent. I had, however, known something very like this physical and emotional state before: it was grief. What was I mourning now? What had been lost? A small corner of uncertainty. Until that point, I hadn’t had to know for certain I was Autistic, even if many around me had seemed sure. For me, the medical diagnosis, at 36, brought an unprecedented collision between a changed self-perception, and a fear of how others might view me [...] The constant question of diagnostic aftermath is: am I feeling, remembering, or fearing in this way because I am Autistic – or is it just because I’m human? In other words: if even science does not yet understand quite what Autism actually is, how do I begin to understand who I am?

Edited extract reproduced with permission from the author: McGrath (2017, forthcoming)

As part of our care pathway we routinely send out the Patient Health Questionnaire 9 (PHQ-9; Kroenke et al., 2001), Generalised Anxiety Disorder 7 (GAD-7; Spitzer et al., 2006) and Short Warwick Edinburgh Mental Well Being Scale (SWEMWBS; Stewart-Brown et al., 2009) in our pre-assessment packs and ask patients to fill them in prior to the initial assessment. To our knowledge these questionnaires (or indeed any standard psychiatric measures) are not specifically validated for an adult autism population. We do find the PHQ-9 and GAD-7 useful as a guide to the level of depression and anxiety – which may be comorbid to autism, or in some cases mimicking autism. The SWEMWBS well-being scale is of less certain usefulness currently, but we are still collecting data to see if a diagnosis of autism makes a significant difference to quality of life as rated by this instrument.

When we first launched the service, we used the Therapy Outcomes Measure (TOMS; Enderby and John, 1997) at the initial and final appointments. TOMS is clinician rated, involving four domains on a five-point scale – impairment (the level of functional impairment), activity (ability to carry out functional activities), participation (social functioning; e.g. occupation, family life) and well-being (emotional and mental health). We developed an autism-specific TOMS data set with Enderby and John (2015).

Despite having co-developed a bespoke data set for adult autism, our experience of using the TOMS has been mixed. The LADS clinicians found it quite difficult to administer in a consistent fashion. Analysis of results found that the average TOMS scores for our patients changed very little between appointments. This may reflect that it takes a longer time following diagnosis for improvements in activity, engagement and well-being to bed in (we did not really expect to see improvements in the impairment score, as social/communication impairments in autism tend to be relatively fixed).

Overall, we are seeing progress being made in some parts of the country, but finding reliable and effective ways to measure outcomes in autism is an area of need for further development.

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### *Clinical audit*

In 2014 we conducted a clinical audit of the service. The standards and audit tool were taken from the NICE (2012) guidelines with only minor modifications. The key standards are:

- Diagnosis should be team based.
- An informant (e.g. parent) should be involved.
- Contemporaneous childhood documentary evidence (e.g. school reports) should be used.
- Purpose of assessment and how outcome will be fed back and should be discussed with the service user at the outset.
- All relevant features of autism should be enquired about during the course of the assessment.
- Risk assessment should be carried out. A risk management plan should be developed if needed.
- A care plan should be developed. If necessary a crisis plan also.

Secondary standards in the NICE guidance include: use of a formal assessment tool (e.g. Diagnostic Interview for Social and Communication Disorders (Wing et al., 2002)) particularly for complex cases; biological tests should not be used routinely but are indicated in certain circumstances; provide a “health passport”; arrange a second opinion if diagnostic uncertainty or disagreement. These aspects were not audited in this cycle but we will consider them for future audits.

A random number generator was used to select 20 cases from 2014 to audit. The results showed that we were at 90 per cent+ compliance with all standards except:

- purpose of assessment and how outcome will be fed back should be discussed with the service user at the outset;
- risk management plan; and
- written care plan.

This led us to develop a care pathway checklist, incorporating all the crucial elements of the care pathway, including discussion of purpose of assessment/feedback. We are introducing a standard care plan template which can be modified according to the service users-specific needs. The finding that we are not routinely assessing all relevant risks prompted the piloting of the adult Leeds autism risk management tool (ALARM), discussed in more detail below.

### **Risk assessment in adult autism**

Those working in mental health or ID services are no strangers to risk assessment and management. Risks are generally divided into: risk to others; risk to self, and neglect.

Despite the popular media and some case reports describing increased violence in people with autism in the community, this is not proven in a recent review of prevalence studies (Im, 2016). Studies in forensic psychiatric settings have established that the risk profiles for violence in offenders with autism are different in a number of ways (Murphy, 2013; Barkham et al., 2013). Although there is little evidence of a higher risk of violence, there are differences in characteristics of offences and motivations, and co-morbidities with autism may increase the risk of association to violence (Gunasekaran, 2012). These factors include cognitive ability, preoccupations, sensitivities and social

awareness (Sabet et al., 2015). Currently there is need for more research in this area, and Barkham et al. (2013) argue that with the heterogeneity of the autism spectrum and the idiosyncratic characteristics of autistic individuals, there is a strong argument for individualised case formulation to manage risks in forensic settings.

There is a good evidence base for the association between autism and increased risk of mental health problems (Emerson et al., 2011). Although there have not yet been any systematic reviews of studies into suicide risk, a retrospective study (Takara and Kondo, 2014) concluded that depressed adults with co-morbid atypical autistic traits are at higher risk for suicide attempts and may engage in methods that are more lethal. However, the inclusion of the diagnostically ambiguous pervasive developmental disorder not otherwise specified group makes comparisons difficult. Another research study by Cassidy et al. (2014) found that adults with Asperger's syndrome were nearly ten times more likely to report suicidal thoughts compared to the general population. As risk factors for secondary depression have much in common with factors associated with Asperger's syndrome (e.g. social isolation or exclusion, and unemployment), appropriate service planning to manage risks in this group was recommended.

In their meta-review, Chesney et al. (2014) looked at suicide and all-cause mortality in a number of mental disorders. They did not find any data on suicide mortality with autism but all-cause mortality risks for the condition were around 2.8 and at least as high as heavy smoking and schizophrenia. There is growing evidence to suggest that autism is associated with increased mortality and increased risk of a range of health problems due to combined biological and social factors (Emerson et al., 2011). This is supported by the Hirvikoski et al. case-control study in 2016 showing higher mortality in people with autism in Sweden, particularly for suicide and epilepsy.

### *ALARM*

Having established an autism diagnostic service it soon became clear that, in our view, the FACE Risk Assessment (Clifford, 1999) used by the trust was not an optimum tool for this population. The risk profile of people with autism, particularly in an all-IQ population like ours, tends to be different to that in a general adult mental health population: for instance, arson, cyber offences (like computer hacking), challenging behaviour and inappropriate sexual behaviour are relatively more common (Chaplin et al., 2013). Furthermore, the FACE is primarily a "tick box" assessment tool and in our view it did not capture the vast diversity of our patient population, both in terms of clinical presentation and level of functioning. To date, there appear to be no published studies on specific risk assessment tools for people with autism in the community. However, Gunasekaran's 2012 review of the literature recommends that risk assessment in autism should take into account individual patient characteristics. In light of this we developed the ALARM, a bespoke autism-specific risk assessment tool, and piloted it in 2013.

The tool was designed to be quick to fill in. Although no specific training in using the tool is required, the clinician should have experience and knowledge of assessing autism and have carried out a face-to-face assessment. After completing it, the ALARM should be shared with the service user.

The ALARM has five sections:

1. summary of historical risks;

2. individual characteristics that predispose to risk;
3. current risks;
4. potential circumstances which may affect risk; and
5. suggested measures to reduce risk.

The documentation has free-form text boxes to encourage narrative summaries of risk. In our view, capturing these qualitative descriptions is more informative and less subjective than checklists, tick boxes and numerical scales. An established concern is that reducing qualitative information into nominal categories may provide paper-trail evidence of a checking process but the quality of information may not be enough to inform future decision making (Hawley et al., 2006).

The tool incorporates an assessment of historical and current risk, and takes into account predisposing factors with a separate section for autism-specific factors. Guidance and aides-memoire to autism risks and risk factors are provided in the documentation rubric. The section on “potential circumstances which may affect risk” includes sections for likely precipitating factors and possible perpetuating factors. The final page “suggested measures to reduce risk” is the most important. It is split into measures that the service user can take, family and carers can take, and services can take. The suggested actions should be realistic, achievable and, if possible agreed with the service user. These can include work with family/carers, occupational interventions, improved communication strategies, medication, social awareness training and avoidance of trigger factors.

In order to pilot the ALARM, we decided to use it at the screening stage of the Autism Diagnostic Pathway where it would have exposure to the widest range of people as possible. Our aim was to test its ease-of-use and relevance even with people who may not have an autism diagnosis. Notably, we have received favourable feedback from our adult mental health colleagues that they were impressed with the structure of the “suggested measures to reduce risk” section, as it emphasises an active role for the patient and their family, rather than leaving services with all the responsibility for managing risk.

Although still at pilot stage, we are continuing to use the ALARM in our follow-up appointments and consultancy cases to gather further feedback from both clinicians and service users about its ease-of-use and usefulness.

## **Discussion**

Over the past five years we have learnt much – mostly from the people we assess who continue to intrigue, baffle and impress us. When asked directly for feedback, people with autism tend to be very honest – which is both a blessing and a challenge. It means that our care pathway has been amended, our assessment room redecorated and the information/paperwork we provide reworded. People with autism are traditionally seen as resistant to change, so it is perhaps ironic that we have not been allowed to stand still even for a second. When a colleague recently returned from maternity leave she was shocked at how much of the LADS process had changed!

We are an experienced team of clinicians, working together for the last five years, with 1,000 referrals and over 300 confirmed diagnoses. Despite this, we maintain a constantly increasing, ever present clinical uncertainty for a condition which is so heterogeneous and multifaceted. Getting the diagnosis right is something we are never complacent about. We pride ourselves on the robustness of our

diagnostic pathway, including following NICE guidance, regular clinical audit, and training the team in autism assessment schedules. Each patient is seen by several team members and the weekly case-based discussions is comprehensive and no disparate opinion ignored. Complex cases are discussed with national experts in peer group supervision settings. LADS is now part of a pilot looking at accreditation standards for diagnostic services with the National Autistic Society.

Finding a method of measuring clinical outcomes which satisfies us, our commissioners, other professionals and our patients continues to be a challenge. This is common to other local diagnostic-only services, and the consensus is that patient satisfaction outcomes are key. Certainly we have learnt that service user/carer questionnaires are best delivered at the time of assessment, i.e. prospective is far superior to retrospective in terms of return rates, accuracy and getting information that is relevant and up to date. Encouraging patients to fill them in when the experience is fresh and they are still on the premises is definitely the preferred option – although this can be awkward if the appointment has not “gone well” (e.g. when a hard sought diagnosis was not given).

Risk is another major issue for the service. Other professionals ask for help when people with autism on their caseloads cause concerns that often they are unprepared for. The ALARM has become a crucial part of our consultancy appointments as it sets the scene and usually identifies unstated concerns that family members have. The ALARM remains a work in progress – the section on “what can be done” is proving the most helpful for everyone concerned and provides constructive positivity in difficult situations that can otherwise seem desperate. Resisting the drive from hard pushed CMHTs to case manage every risky patient with autism can be difficult sometimes, but in the longer term enabling all professionals to be able to work effectively with people with autism (including accurate assessment of risk) is – in our view – a far preferable option. Our open-ended offer to share our knowledge and experience of autism is gradually being taken up – a recent free all day conference for Trust staff was oversubscribed. From April 2016 we will have a full time social worker in post as a six-month pilot, meaning use of the ALARM will also be considered from a local authority perspective and adapted accordingly.

Going forwards, the service is trying hard to de-medicalise autism and empower people with autism to embrace their specific skills and integrate into the neurotypical world. We are incredibly grateful to all our service users who have assisted in training, interviewed staff and provided ideas for improving our service. We continue to learn from them on a daily basis as we constantly ask the question – are we good and are we safe?

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