Identification of adults on the autism spectrum: a suggested pathway and good practice principles

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Editorial comment

This paper reports on the development of a set of principles to guide the design of identification (diagnostic) assessment pathways for adults who might have autism or Asperger syndrome. It suggests best practice in this area and puts forward a triage-based autism identification pathway. The authors suggest an innovative approach based on an assessment of the maturity of the pathway (using the 'maturity model' technique). Given the numbers involved who need a diagnostic assessment and the limited funds available, they propose that not all those seeking a diagnostic assessment need to be seen by a clinician or a multi-disciplinary team. They argue that adults seeking clarification or confirmation of an autism diagnosis, where there are no serious current issues affecting their lives, could be seen and advised by specialist autism support workers who are not clinicians. The use of specialist support will enable cost savings to be achieved but it will take time to develop the necessary support resource.

Introduction

To guide the design of adult autism diagnostic assessment pathways and to guide clinicians during the process of identifying autism in adults, we have developed a set of guiding principles. The first step in developing these principles was to identify the basic stages of identification and issues relating to assessment pathways (such as the training of personnel involved). The second step was to identify the different stages in the pathway. Seven key issues relevant to identification pathways emerged from our research and three basic stages of a pathway were identified. Using our experience of adult autism diagnostic practice, a triage-based autism assessment pathway is suggested. At a time of austerity, an innovative approach to evaluating these pathways against best practice is suggested based on an assessment of pathway maturity (using the 'maturity model' technique). Following the ideas of Gunilla Gerland (2013), an autistic adult, it is proposed that autism work is a distinct specialist field in its own right. Such work requires knowledge not yet fully included in the curricula for qualifications obtained by professional groups involved in diagnostic assessment (and support) of children and adults with autism (eg educational psychologists, general practitioners, psychiatrists, and speech and language therapists). Our best practice pathway model requires such knowledge to be embedded in the professional qualifications of all professionals working in the field of autism. Our triage-based approach to identifying autism provides a role for autism specialists, who are not diagnosticians, whilst preserving the primary diagnostic function of clinical professionals.

Persons with autism have the right to equality of respect

Article 1 of the Universal Declaration of Human Rights (UDHR, 1948) states that all human beings are 'equal in dignity and rights'. Persons with autism have a right to equality of respect which necessitates being treated non-judgementally and respectfully. This has been formalised in the United Kingdom in the NICE guidance on the recognition, referral, diagnosis and management of adults on the autism spectrum (see NICE Clinical Guideline Number CG142, 2012) which states that professionals working with adults with autism should 'offer support and care respectfully' (p 7). A respectful approach requires professionals to work in partnership with the adult with autism (NICE, 2012). Kinge cited in Gerland (2013, p 31) stresses that helping others involves expanding and developing our own understanding of them and just as importantly:

> *'… showing our understanding in ways that expand their own awareness and understanding of themselves so that they can accept and respect themselves as they are.'*

This is of particular importance in the case of autism, where self-awareness and self-respect will often be in short supply.

High-functioning autism is *not* mild autism

It is unfortunate that many authors have written of high-functioning autism (HFA) and Asperger syndrome (AS) as being mild autism (eg Ehlers, Gillberg and Wing, 1999; Ketelaars et al, 2008; Rutter, 1996). Whilst it may seem intuitively obvious that an individual who is able to function in society, and sometimes functions very well, is 'less autistic' than a person who needs support for their day-to-day living, this is not always the case. Apparently mild symptoms of autism on the surface may hide many social difficulties (Chown and Beavan, 2012), high levels of anxiety (White et al, 2009), and debilitating sensory sensitivities (Gerland, 1996). It is clear from the autobiographical writing of autistic authors such as Temple Grandin (1992; 1996; 2011) and Wendy Lawson (2001; 2011) that intellectual ability may enable the 'hacking out' (Beardon and Worton, 2011) of an understanding of others, but that social difficulties can involve a lifelong 'battle' so that HFA is not necessarily mild autism. Social difficulties, anxiety, and sensory sensitivities, as well as intelligence, influence the extent to which a person with autism functions in society.

A person with autism can be of many ages

An essential characteristic of autism is that of an 'unevenness in development that differs over the life span of the individual' (Ozonoff et al, 2005, p 524). In this regard, Gerland writes:

> *'In addition to the triad of impairments you could say that what characterizes the autism spectrum is a significant unevenness in development. This means that in practice* ***a person can be of many ages****. The individual can in one area be far ahead of their peers, in another just like their peers and in a third area far behind their peers.'* (Gerland, 2013, p 144, author's own emphasis in bold).

The profiling of autism should identify strengths and weaknesses. If an assessment initially uncovers some aspect of superior performance, this does not preclude the identification of autism. There are cases where the diagnosis has not been considered by GPs and others not trained in autism, because the adult is at university or can talk very knowledgeably about a topic.

Autistic women may present differently to autistic men

Of the 12 individuals whom Asperger and Kanner originally reported on, only three were female, so right from the beginning there appeared to be a ratio of four autistic males to every one autistic female (Asperger, 1944; Kanner, 1943). This 4:1 ratio has persisted with slight variations over the years (eg Baird et al, 2006; Yeargin-Allsopp, 2003) although some have argued that the ratio in HFA and Asperger syndrome is even more biased in the male direction with a ratio of 10 males to one female being suggested in the past (Ehlers and Gillberg, 1993; Gillberg and Ehlers, 1998; Jamain et al,

2003). Many autobiographical accounts are by women, and Internet sites visited by people with autism such as Aspie Village demonstrate a near 50/50 gender split. Some researchers are questioning the received opinion that autism exists much more in males than in females. They suggest that the reasons for this apparent bias may be that:

- diagnostic criteria are based on male behaviours and questions can be unintentionally male-centric (Gould and Ashton-Smith, 2011; Lai et al, 2011);
- women may be better able to mask autism through coping mechanisms and 'may achieve more progress in compensatory socio-communication ability' than males do (Lai et al, 2011, p 5);
- women may develop 'acting' skills to compensate for issues relating to social convention that are highly skilled (Beardon and Edmonds, 2008)
- autistic women present differently to autistic men (Åsberg et al, 2010; Gould and Ashton-Smith, 2011; Kopp and Gillberg, 1992; Lai et al, 2011; Wing, Gould and Gillberg, 2011).

Wing, Gould and Gillberg (2011) write that:

> *'With increasing experience of autism over the years* ***it has become evident to those in the field that many girls and women with autism spectrum conditions have a clinical picture that differs in some ways from those in boys and men*** *making diagnosis more difficult in certain cases.'* (p 771, author's own emphasis in bold).

We encourage clinicians to take special care when working with women. Lai et al (2011, pp 8–9) advise clinicians to include not only direct interview and observation, but also information on childhood behaviours, self-report and neuropsychological assessments. They argue that judgments made only from immediate interactions might be biased due to camouflaging, that may be especially pronounced in females. Women often only reveal their difficulties in current social functioning via self-report, rather than this being apparent from observation. Even then, they may only reveal their difficulties to highly trusted individuals.

Sensory sensitivities in autism can be highly debilitating

Although many authors have written that differences in sensory processing are very common in autism and autistic authors such as Gerland (1996; 2013); Grandin (1992, 1996, 2011), Lawson (2001; 2005; 2011), and Williams (1992; 1996) have written eloquently on the effects of sensory issues in their lives, little research has been undertaken on the assessment of sensory sensitivities in autism. As sensitivities may often be as significant to persons with autism as their social difficulties it is surprising that, until recently, diagnostic criteria for autism have made no mention of them. Professionals should note that persons with autism can have hypo- and hyper-sensitivities involving any one or more of the senses including vestibular functioning and proprioception. Sensory sensitivities can be highly debilitating. Clinicians need to investigate these sensitivities carefully when considering an identification of autism; they are a possible indication of autism and will need to be reflected in any needs assessment.

All clinicians involved in autism identification must be trained in autism

Worryingly, it has very recently been written by a psychiatrist who specialises in autism that:

> *'Despite the start of awareness training, clinicians working with adults are still much less likely [than those working with children] to be aware of [autism] and to ask any questions that may alert them to the person having [autism].'* (Carpenter, 2012, p 123).

It must go almost without saying that any clinician or other professional involved in the process of identifying autism must have a thorough understanding of autism that goes beyond the theoretical. Our recommendation is that clinicians should be trained in autism as an integral part of the study for their clinical qualifications and the associated practical 'on the job' experience. Ideally, members of identification teams should be trained together to better enable the delivery of consistent practice and procedures. Training must, of course, be up-to-date and of the highest possible quality in terms of development and delivery. Persons with autism should be involved in both the development

and delivery of this training. *All* those involved in the identification process should access training on diagnostic assessment; no-one should be exempt.

Until national action is taken to ensure that clinicians are appropriately trained to identify autism, the situation regarding identification will remain unsatisfactory. However, action can be taken in the interim to improve the current situation. This requires autism specialist support workers and clinicians to work together to develop each other's expertise. Clinicians can supplement the autism specialists' understanding of autism with advice and guidance on assessment practice; autism specialists can provide clinicians with an in-depth understanding of the everyday lives of people with autism. Regular regional workshops involving clinicians and support workers will, over a period, ensure a knowledge transfer between them that will improve the quality of autism identification and subsequent recommendations across a pathway. It is essential that people with autism are involved in these practitioner workshops, both in their development and their delivery. To maintain momentum, without the workshops becoming a burden for those involved, we suggest these are held quarterly. Suggested standing agenda items are given in Appendix 1.

There is a role for both individual and multi-disciplinary working

Many authors and national guidance on diagnostic assessment (eg NAPC, 2003; SIGN, 2007) have emphasised the importance of a multi-disciplinary diagnosis in autism (eg Cumine et al, 1998; Ellis, 1994; Le Couteur et al, 2008; Moore et al, 1999; Wing, 1996). This is partly because autism affects many areas, and because the behaviour of a person with autism can be very different depending on the context. The person's past history is also very important so that involving family members or professionals or volunteers who know the person well is vital. Whilst multi-disciplinary working is inherently a strength of clinical practice and should improve the quality of diagnosis, it can also cause complications and make the process of obtaining a diagnosis unnecessarily difficult if not handled properly (Partridge et al, 2003). There have been many complaints from parents of poor communication and inadequate co-ordination between professionals working in a multi-disciplinary setting (Beresford, 1995; Stallard and Lenton, 1992) and there is no reason to suppose that multi-disciplinary working is any easier for professionals working with adults.The workshops proposed above regarding the training of clinicians in autism can be a vehicle for improving multi-disciplinary working. Cross-disciplinary workshops will lead to improved understanding of the different clinical perspectives.

Our contention is however, that the identification of autism need not always require a multi-disciplinary team; a single clinician can be equally effective in identifying autism as well as perhaps being more autism-friendly and cost-effective. Carpenter (2012) writes that,

> *'It appears that multi-professional diagnosis is needed for a comprehensive assessment and not for diagnosis of the presence of autism spectrum disorder. '* (p 124).

We suggest that clinicians should involve specialists from other disciplines when, in their clinical judgment, this will clarify the identification assessment, but that they should not feel obliged to do so, if they are confident that a diagnosis can be made without this.

In their summary of the NICE guidance, Pilling et al (2012) make the important point that people with autism:

> *'… often fall through the gaps between medical and social care, especially if they do not present with a mental health disorder or learning disability.'* (p 3)

This reflects the current structure of service provision in the UK. Whilst Pilling et al. (2012) acknowledge, correctly, that the delivery of integrated health and social care services is challenging for professionals, effective multi-disciplinary working should assist them in meeting this challenge.

Principles for the referral stage (pre-identification)

Access to the identification process must be as easy as possible and fair. Self-referral should be possible as a route into the adult autism identification pathway.

All elements of the referral process should be fair and as simple as possible to negotiate. It is our experience that adults with autism have often undertaken extensive research into the nature of autism before they seek a diagnosis, have spent considerable time thinking about their situation and a possible diagnosis, and may well have guessed correctly that they are autistic. Anyone who suspects that they may be autistic is likely to benefit from a professional assessment even if they are not autistic. However, if funding is required to gain access to a diagnostic assessment service, then the reality is that only those adults whose quality of life is very poor and who are deemed to be in difficulties as a result of their condition, are likely to be funded.

Screening and diagnostic assessment instruments

Although focused on autism in children, it is relevant to note that:

> *'… none of the autism screening tests currently available has been shown to be able to fulfill the properties of accuracy, namely high sensitivity, high specificity, and high predictive value (proportion of patients with positive test results who are diagnosed correctly) in a population-wide screening program.'* (Al-Qabandi, Gorter and Rosenbaum, 2011, p 215)

Completion of screening questionnaires such as the 10 item Autism Quotient (Woodbury-Smith et al., 2005) can suggest that a person may be autistic but a positive result on such a simple instrument is no guarantee that the individual actually is autistic. More importantly, a negative result does not rule out autism. By itself, a negative result with a screening questionnaire should never deny access to an identification pathway.

In addition to the risk of false negatives referred to above, there is also a slight risk of false positives when an individual self-diagnoses based on their reading and completion of screening questionnaires. Although there can sometimes be a tendency to read more into something than is justified clinically, it is rare that anyone 'wants' to be autistic and unlikely that someone would conclude that they may be autistic unless there are clinical issues of some sort.

Our recommendation is that whether a person is referred by a GP or other professional or self-refers, their situation should be assessed purely on how the person presents.

Self-referrals and possible pathway

Self-referrals will often simply want to know whether or not they are autistic to better understand themselves, explain past behaviour, and enable them to develop coping strategies. In our opinion, these are ideal cases for assessment by autism specialist support workers, rather than a full specialist team. As anxiety in autism is often qualitatively and quantitatively greater than the anxiety people without autism face, all referrals (and the subsequent components of the pathway) should be handled as quickly as possible as persons with autism often find delays extremely stressful.

Principles for the identification stage

The principles set out here in relation to the identification process are based on good general process practice (eg that practice should be open to scrutiny) and good autism practice (eg that any sensory sensitivities must be allowed for). Any adult with autism, not just young adults, may require support through the pathway and may come with an advocate or a parent or carer. A parent or carer may be able to provide additional information to the clinician or identification team including their development in childhood, and details of behaviour that a less self-aware person with autism may not necessarily provide. The identification process must be made as autism-friendly as possible. An autism-friendly process must have as few restrictions as possible, and be open to scrutiny throughout. It must take due account of a client's communication needs and sensory sensitivities. It would be useful if the person(s) involved in the identification are made known to the client beforehand. Clients should also be allowed to have their (reasonable) comments on the findings of the process included in the final report.

The basic structure of the assessment session and an indication of the areas of questioning during the session could be made available to the client at least a week before the session to reduce the stress of having to understand the nature of questions as well

as compose their responses. It should be ensured that neither the venue nor the timing will cause problems for the client (eg in relation to any sensory sensitivities (venue) and in relation to travelling time from home (timing)). In this regard the client and/or their advocate should have the opportunity to influence both the choice of venue and the start time and the right to request reasonable adjustments to the venue. To reduce anxiety, familiarisation with the layout of the venue in advance is likely to be helpful for the client. It is necessary to check that the space is comfortable, the temperature is suitable and that the room is appropriately lit and quiet. There may be a need for a break or breaks for the client during the session. Break arrangements should be considered in advance. A brief written note for the client explaining how the identification session will be conducted and setting out the arrangements for breaks etc. will help to reduce their anxiety. This should include a note of approximately how long the session is going to last, the persons who will be present, and the nature of the follow-up to the session. It would help if the client was advised to have something to eat and drink and to go to the toilet before the session as they may not do so if this is not suggested to them. It is imperative that traditional counselling is not forced onto a person with autism as it can be damaging; an autism needs-led approach is required based on a thorough understanding of the individual based, in turn, on knowledge of, and experience working with, persons with autism.

Post-identification stage principles

Ideally, the identification process should link seamlessly with subsequent support from adult care services, where necessary. A client's needs in terms of ongoing support in relation to day-to-day living, accommodation, work, relationships and the need for an advocate/personal assistant should be indicated in the diagnostic report. Where a client has been supported through the identification process by an advocate, the advocate should be involved in the preparation of the needs assessment by the clinician. Counselling and/or similar autism-specific support should be available for an adult who has been identified as autistic following the assessment.

Where support is needed, the relevant adult services and agencies should be involved so that the report can include their response to the support needs identified by the clinician or support worker. This helps to explain what happens next. It also assists the development of partnership working with Adult Services. Where there is no specific support requirement it may, nevertheless, be valuable for an autistic adult to be able to talk over their diagnosis with someone who understands autism. Matters that they may wish to discuss include disclosure of autism to their family, friends or their employer. This service could be provided by an autism specialist support worker.

The need for a personal assistant/advocate (if the client does not already have one) should be considered at this stage. Counselling should be available for an adult who has been identified as autistic since the identification may itself be a traumatic event for which the client requires support. All counsellors working with people with autism, and other persons providing post-identification support, should have a thorough understanding of autism and experience in working with people with autism.

Need for reflective practice by professionals

Best practice in autism involves developing autism-friendly professionalism. The NICE guidance (2012) requires professionals working with adults with autism to

> *'… take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.'* (p 7)

Professionals must understand what they are doing from the client's perspective in order to identify areas where they can improve. Reflection-on-action involves spending time exploring why professionals acted as they did and in so doing reflective practice becomes the basis of improving practice and professionalism. Gerland argues that:

> *'… a high (and rather unusual) level of professionalism is where staff can have second-degree theory of mind and see the service itself [not just a particular client's situation] with the … client's eyes.'* (Gerland, 2013, p 175)

Reflective practice should focus on both the individual client and the totality of the service provided to a client group as a whole.

It is usual for professionals working with potentially vulnerable groups (eg within counselling services or psychology services) to have supervision sessions to formally discuss practice and ensure that both the professional involved and the population are being best supported. We fully support the notion that the post-identification autistic population (even those who are high-functioning) falls firmly into the category of 'potentially vulnerable', so strongly suggest that clear supervisory structures are in place for frequent and regular contact between professionals to reflect the need for discussion around good practice.

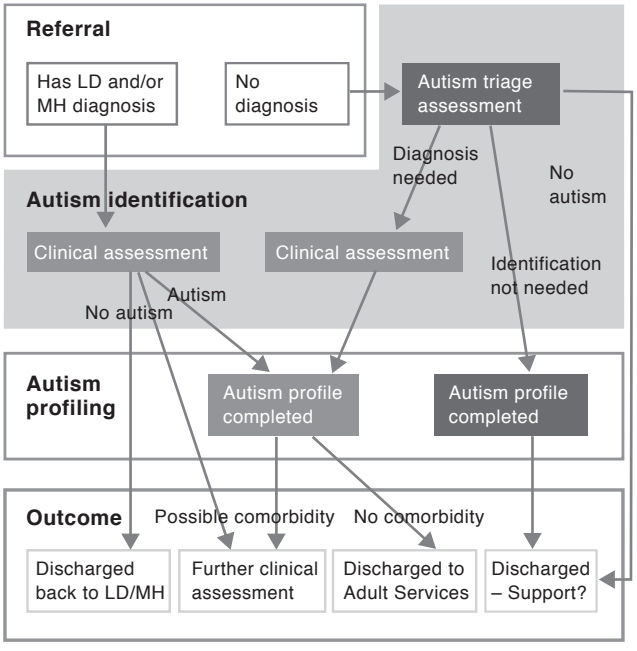
Tiered adult autism identification pathway service provision

To support the provision of appropriate autism identification services for all adults, whatever their individual needs, in terms of the identification itself and for ongoing support afterwards, there is a need to provide a tiered service based on triage principles. Not all clients will need the services of a clinical professional; the use of specialists in autism will reduce the demand for clinical services whilst maintaining service standards because best use will be made of the expertise of both the clinical professionals and the specialists. In addition, the design will carefully prioritise the use of a full multi-disciplinary team identification approach. Clearly, the multi-disciplinary approach is highly resource intensive; there is no need for such a resource hungry method to be used for all clients. Our design allows the flexibility of using the multi-disciplinary team approach where there are significant benefits to be had from this approach, but using alternative approaches where it will not adversely affect outcomes. Our recommended four-tier approach to pathway service provision is set out in *Appendix 2*.

Adult autism identification pathway framework

Our proposed adult autism identification pathway framework is shown in *Figure 1*.

Figure 1: Autism identification pathway framework



As described earlier, we have divided the pathway process into three sections: referral, identification, and post-identification, with the final section divided into autism profiling and outcomes. The autism profile is our term for a needs assessment. We prefer 'autism profile' as autism involves strengths as well as weaknesses whereas 'needs' assessment suggests a sole focus on deficits requiring support and/or reasonable adjustments. We advocate a holistic approach that seeks to describe the whole person. Persons with autism often have a substantially more uneven profile than their non-autistic peers (Kushki et al, 2011; Minschew et al, 2005). Attempts to improve, let alone eradicate, weaknesses may prove fruitless or involve more effort than seems sensible; there may be more to be gained if attention is given to a client's strengths, particularly where an ability is linked to a special interest.

Where referral is via learning disability (LD) or mental health (MH) services, the framework allows for the identification of autism, development of an autism profile, and referral on to further clinical assessment where necessary (Tiers 3 and 4). In the case of a referral from elsewhere (including a self-referral), the

framework allows for the client to be kept out of the clinical system (Tiers 1 and 2), or to be referred on to an individual clinician or multi-disciplinary team for clinical identification (Tiers 3 and 4). If a client already has a LD and/or an MH diagnosis they should be seen by a clinician rather than an autism specialist support worker.

The possible outcomes from the pathway are:

- client discharged back to LD/MH services (either with or without clinician identification of autism)
- client referred on for further clinical diagnosis of further suspected conditions (either with or without identification of autism)
- client discharged to Adult Services where autism is identified without co-occurring conditions
- client discharged by the autism support worker either with or without an identification of autism.

Where the client has been assessed by a specialist autism support worker and autism has not been identified, a clinical assessment may be required as the difficulties that initially suggested autism may indicate the need for further assessment.

Clearly, the sooner a diagnosis is available to the client, the sooner they will be able to develop an improved understanding of themselves and the sooner any necessary intervention and/or support can commence. However, any delay in obtaining this can be very stressful for a person with autism, particularly if they can see no good reason for the delay. Hence, each component of the pathway should be completed within a set period and the period between completion of one component and the start of the next component (eg from point of referral to first contact) should be regulated.

Adult autism identification pathway (maturity model) implementation matrix

The maturity model-based implementation matrix for a project to implement a best practice adult autism identification pathway is shown in *Figure 2* below. The maturity model concept is an approach to planning implementation of almost any process. It involves a phased development from current status to a desired end state. It allows for the move from current status to desired end state being achieved over more than one planning period and hence is especially suitable at a time of austerity. This approach enables the move from present position to good/best practice to be planned over an achievable period reflecting the availability of funding and other restraints on implementation. The over-arching objective is always to achieve the desired end state but for each planning period, the objective is to reach the next stage in the maturity of the process. Crawford (2006) writes that:

> *'Until just a few years ago, the concept of "maturity" was seldom used to describe the state of an organization's effectiveness at performing certain tasks. Today, we find this maturity concept being used increasingly to map out logical ways to improve an organization's services.'* (p 50)

The maturity model approach has been used in areas as diverse as project management (Crawford, 2006), knowledge management (Kochikar, 2000), business continuity management, risk management (Hillson, 1997), IT outsourcing relationships (Gottschalk and Solli-Sæther, 2006), and performance measurement (Wettstein and Kueng, 2002). The maturity model approach is, in itself, partly a means of measuring performance. The first author of this paper has designed and developed a maturity model for implementation of work to remove barriers to further education for students with autism (see Chown and Beavan, 2011; 2012) and previously led the design and delivery of maturity models in other fields. The maturity model approach lends itself to application in the context of the implementation of an adult autism identification pathway. In this context we have used the term 'implementation matrix' to avoid confusion between 'maturity model' and 'pathway model'.

Our implementation matrix for a project to implement an adult autism identification pathway consists of five levels of maturity from the 'basic pathway' where the access adults have to identification of autism is largely ad hoc, through the implementation of a project to deliver good/best practice, an interim stage where a good practice pathway is beginning to have an impact on identification and support, to the provision of a good/best practice pathway.

Figure 2 Adult autism identification pathway implementation matrix

Maturity Level	Maturity Elements					
	Referral process	**Identification process**	**Post-identification process**	**Pathway evaluation process**	**Training of clinicians**	**Multi-disciplinary working**
Level 1 Basic pathway	Access to identification is largely ad hoc	Identification is dependent upon which clinician is seen	Access to support services is largely ad hoc	No pathway evaluation process	No process to ensure training of clinicians in autism	Any training is delivered on a silo basis
Level 2 Pathway project	Project to embed an adult autism identification pathway is in place	Project to embed autism specialist support service is in place	Project to embed access to support services is in place	Project to develop an evaluation process is in place	Project to develop local autism training is in place	Project in place to develop multi-disciplinary training
Level 3 Interim pathway	Access to identification improving but not fully embedded and delays occur	Autism specialist support improving identification but delays still occur	Access to support services improving but not fully embedded and delays occur	Pathway evaluation process in place	Training in autism being delivered locally	Multi-disciplinary training being delivered locally
Level 4 Good practice pathway	Access to identification fully embedded and point of referral to identification session time-scale targets met 95% of the time	Autism specialist support service fully embedded and identification time-scale targets met 95% of the time	Process to enable access to support services fully embedded and discharge time-scale targets met 95% of the time	Evaluation beginning to influence clinical practice Clinicians beginning to evaluate pathway from client's perspective	All clinicians have received training locally	Multi-disciplinary teams working effectively
Level 5 Best practice pathway	All autistic adults can access the pathway in a timely manner from point of referral	All autistic adults can access autism-friendly identification services in a timely manner	All autistic adults can access all the support services they need in a timely manner	Evaluation process fully embedded and lessons being learned Clinicians evaluating pathway from client's perspective	*Autism training embedded in professional qualification curricula**	*Multi-disciplinary work training embedded in professional qualification curricula**

*The best practice items for the training of clinicians and multi-disciplinary working require national action to embed training in autism and partnership working in the study programmes for clinicians' professional qualifications

N.B. All time-scale targets other than for the preparation of the final report are subject to the availability of the client.

The implementation matrix also reflects the design of the best practice identification pathway presented in this paper as well as Gould and Wing's (n.d.) recommendation that adult identification services should encompass processes of formal and informal evaluation. Whilst the Gould and Wing recommendation was focused on models used by the diagnostic team and enhancement of links with other specialist diagnostic teams and autism services, we propose that the entire pathway be the subject of regular evaluation (annually and whenever significant changes are being proposed to the pathway after initial implementation). The best practice items for the training of clinicians and multidisciplinary working cannot be achieved at this juncture. These items require national action to embed training in autism and partnership working in the training and qualification programmes for clinicians.

We have also developed a set of evaluation criteria for assessing plans to develop and deploy identification pathways (or current stages of development, where appropriate). This has been achieved by operationalising the implementation matrix.

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Appendix 1: Knowledge Transfer Workshop: Standing Agenda Items

1. Review of training – does it need updating, how effective was it, how up to date are we in having all staff trained in consistent practice?
2. Review of problematic identification; discussion of issues arising from difficult assessments and possible resolutions; identification of any need for changes in process.
3. Recording of data and demographics, to be analysed annually for trends to assist in service provision.
4. Review of relationship between identification services and adult social care/health; identification of issues and resolutions required.
5. Recording of where we are at on the maturity model and evaluation; identification of barriers to positive change and resolution of those issues.
6. Feedback on any issues arising from the identification processes.

Appendix 2: Tiered adult autism identification pathway service provision

Tier 1: The specialist autism support worker does not identify autism in the presenting individual and hence no further progress along the pathway is necessary. In the event that the client requests a second opinion (and has a legal right to do so), then we propose escalation to Tier 3 with a clinician providing a diagnostic assessment.

Tier 2: Specialist autism support worker provides an autism profile. The individual is identified as being autistic by the specialist autism support worker who develops the autism profile. There is no requirement from the individual for a clinical assessment; hence no further progress along the pathway is required.

Tier 3: The specialist autism support worker proposes a clinical assessment. The individual is identified as being autistic by the specialist autism support worker, clinical involvement is required, and the clinician provides the necessary assessment and autism profile (with input from the specialist autism support worker's initial assessment) without other disciplinary input.

Tier 4: Full multi-disciplinary team identification. The individual is identified as being autistic by the specialist autism support worker, clinical involvement is proposed, and the clinician decides that a full multi-disciplinary team assessment is necessary.