An Assessment of Mental Health Service Provision for High Functioning Autistic Adults in East Lancashire

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1. Terminology

Asperger syndrome, autism and ASC (autistic spectrum condition) are used interchangeably throughout this report to refer to adults with or seeking a diagnosis of Asperger syndrome (AS) or high functioning autism (HFA); other terms often used are autistic spectrum disorder (ASD) and pervasive developmental disorder – not otherwise specified (PDD-NOS).

It is noted that there is currently some debate over terminology used in relation to Asperger syndrome. Traditionally people with a diagnosis of autism or Asperger syndrome have been referred to as 'suffering from' a disorder or illness. Many people with a diagnosis of autism or Asperger syndrome do not consider themselves to have an illness or disorder and find this terminology portrays an unhelpful way of thinking about autism.

For the purposes of this report the preference would ideally have been to use the wording 'people diagnosed with autism' however as access to diagnosis is one area of difficulty being addressed by this project, not all people we gathered feedback from had been able to access a diagnostic assessment. Therefore the wording 'people with' is used as it is the terminology used and recognised in NHS statutory services. Where possible terminology has been kept neutral and does not imply a particular framework of understanding around autism. Specifically 'people' is used rather than 'patients; 'adults' is used when necessary to distinguish between the different adult and child service provisions; and 'service user' or 'client' are used when referring to people accessing mental health services or teams.

2. Summary

This report presents and discusses the findings of a two year project, commissioned by East Lancs PCT, assessing Mental Health service provision in East Lancashire for adult with (or seeking) a diagnosis of Asperger syndrome (also referred to as high functioning autism).

Adults with Asperger syndrome (AS) continually appear to 'drop through the net' in terms of assessment and provision of services and therefore often find themselves with inappropriate or no services at all, particularly in terms of mental health provision and in times of crisis.

This project explored current mental health provision for this client group by: assessing staff training needs in relation to autism; gathering feedback from service users about their experiences and opinions of the mental health service; and exploring potential service model options. Key findings and recommendations are as follows:

Staff Training Needs Relating To ASC's

70% of staff who took part in the assessment had little or no knowledge about autism and 77% felt that they would benefit from autism awareness training.

27% of respondents had received some form of autism awareness training from a variety of different sources, some in previous job roles. Of these, 70% felt they required further training in light of what they had learned and guidance in terms of how to communicate and work with adults with ASC's.

Recommendations

- Implementation of an ongoing structured, reliable programme of basic autism awareness training with monitored outcomes.
- Additional job specific training available for staff who require it.

- Follow-up specialist support available which staff can access should they require advice around working with ASC's.

Service User Experiences And Opinions

The most prominent themes identified were having to battle to receive any help or support at all, not feeling listened to and not having support needs taken seriously by practitioners.

It has been frequently mentioned by both service users and staff members that access to diagnostic assessment or specialist support is often blocked by systemic barriers including refusal to fund assessments and confusion regarding referral as there is currently no pathway in place.

Perceived apathy from some professionals in relation to autism has also been mentioned repeatedly with many adults reporting that they do not feel believed or understood by mental health professionals.

Environmental factors such as busy waiting rooms, with fluorescent lighting and loud sudden, unpredictable noises came up also a major barrier to accessing services for many autistic adults.

The feeling from service users seems to be that adults with autism and Asperger syndrome who do not have an accompanying Learning Disability are excluded from accessing mental health services, with support available for this service user group only at the point of crisis.

<u>Recommendations</u>

- Implement a clear care pathway for adults with ASC's including provision for access to diagnostic assessment and mental health support.

- Post-diagnostic support including referral for community care assessment in line with statutory guidance and signposting to relevant services.

- Access to low level support including: respite from daily life; social opportunities; vacations; daily living support for people with ASC's.
- Specialist support and advice for staff so they feel equipped and supported to work with this client group.
- More flexibility with the environment and location of appointments to meet reasonable adjustment requirements.

Potential Service Models And Pathways

The most effective service model option used elsewhere seems to be a managed care pathway team in the Liverpool area which provides support, advice and diagnostic assessments to other statutory services.

A similar Combination Model had previously been proposed by Lancashire Care Foundation Trust (2008) which consists of a small multidisciplinary team offering needs assessment, diagnosis, management plans and advice for local services. This model proposes only working directly with the service user where diagnosis and management planning is not straightforward and is beyond the scope of local services. Service user feedback also appears to support this type of service model.

<u>Recommendations</u>

- Combination service model, referred to also as a 'managed care pathway' model appear to be most effective option.
- Small specialist multidisciplinary team able to provide: assessment and diagnosis, needs assessment, management plans and advice for local services.

Since the inception of this project statutory guidance has been published governing the provision of services for adults with autism (DoH, 2010). There is much overlap between the findings of this project and the statutory guidance requirements; this is discussed in section 7.4.

3. Introduction

This report was commissioned by East Lancashire Primary Care Trust (ELPCT) to investigate the Mental Health needs of adults who have or are seeking a diagnosis of Asperger syndrome (AS) in East Lancashire and to provide evidence to inform current and future adult mental health service commissioning for this client group.

Feedback and opinions regarding the provision of mental health services to people with Asperger syndrome were gathered from adults with or seeking a diagnosis of autism or Asperger syndrome, and also from parents/carers and professionals working with this service user group.

Additionally service models used in other areas of the country were considered along with recent changes in legislation which govern the provision of statutory services to people with autism.

3.1 Project Background

The mental health commissioning team for East Lancashire had been contacted by various adults with Asperger syndrome who were finding it difficult to access mental health services that met their needs, difficult to access a diagnostic assessment, and felt that the mental health professionals they were coming into contact with did not understand the condition.

The mental health commissioning manager set up a steering group at the end of 2007 and through this commissioned a piece of work from Action for ASD to investigate and provide evidence of what mental health support needs adults with ASC's have and what experiences they have had when trying to access mental health services in East Lancashire.

3.2 Project Aims

The key project aims were:

- To investigate the training needs of mental health practitioners in East Lancs PCT with regards to ASC's.
- To establish a Service User Feedback Group of adults in East Lancashire who are seeking a diagnosis or have received a diagnosis of Asperger Syndrome. The group's purpose being to inform the project.
- To assess the needs of adults with a diagnosis of Asperger Syndrome or High functioning autism in East Lancashire with regards to access to diagnostic assessment and mental health services.
- To research into different models of provision across the country for adults with Asperger Syndrome.
- To aim to improve the experience and support pathways to diagnosis for adults seeking or who have a diagnosis of Asperger Syndrome.
- To develop an information resource for adults with Asperger Syndrome.

4. Context Of Project

4.1 What Are Autism And Asperger Syndrome?

Autism is a lifelong condition also described as an 'autistic spectrum disorder or condition' (ASD or ASC). Asperger syndrome (AS) is a form of autism that affects how a person makes sense of the world, processes information and relates to other people. Often referred to as a 'hidden disability', you can't tell someone has the condition from their outward appearance (NAS, 2010).

The characteristics of AS vary from one person to another but are often divided into three main areas:

- Social communication: People with AS sometimes find it difficult to express themselves emotionally and socially.

- Social interaction: Many people with AS want to be sociable but have difficulty with initiating and sustaining social relationships.

- Social imagination: People with AS can be imaginative. Many are accomplished writers, artists and musicians but can have difficulty with social imagination.

Other characteristics can include:

- Preference for specific routines, rules and rituals and a set order to the day. Unexpected changes can cause anxiety.

- Special interests, sometimes an intense or obsessive interest in a hobby or collecting.

- Sensory differences can occur in one or all of the senses. Senses are often either intensified or underdeveloped.

While there are similarities with classic autism, people with AS have fewer problems with language and are often of average, or above average intelligence. They do not usually have accompanying learning disabilities, but can have learning difficulties such as dyslexia or dyspraxia (NAS, 2010).

4.2 Prevalence In East Lancashire

Currently in East Lancashire there is no unified system of recording whether a person has a diagnosis of Autism, making it very difficult to map prevalence amongst statutory service users.

There is no referral pathway in place for diagnostic assessment of Asperger syndrome for adults in East Lancashire. Those who manage to access a diagnostic assessment are referred out of area for an NHS funded assessment or access an assessment privately.

Additionally many adults are undiagnosed and do not actively seek a diagnosis or come into contact with service providers. Hence it is not possible to ascertain how many adults with autism currently access NHS services within East Lancashire.

Current figures for England (NHS Information Centre, 2009) estimate autism prevalence of 1 in 100 of the population. For East Lancashire, a prevalence estimate is calculated using this information along with the latest Office for National Statistics population estimates (ONS, 2009).

Using 2009 population figures (see table 1) that would equate to approximately 3808 people with autism in East Lancashire, 3033 of whom would be aged 16 and above.

Table 1: Mid-2009 Population Estimates: East Lancashire.

	Children	**Working Age**	**Older People**	**Total**
	Age 0-15	Age 16-64M/59F	Age 65M/60F and over	
Burnley	17,500	51,500	16,600	85,600
Hyndburn	17,400	48,600	15,100	81,100
Pendle	18,300	54,000	17,000	89,300
Ribble Valley	10,600	33,700	13,300	57,700
Rossendale	13,600	41,400	12,100	67,100
East Lancashire	**77,400**	**229,200**	**74,100**	**380,800**

4.3 Legislation

Since the inception of this project major legislative changes have taken place to improve laws governing equality and disability. Relevant legislation which covers the provision of services for this population is detailed below.

4.3.1 Equality Act (2010)

The Equality Act (2010) brings together, strengthens and simplifies nine separate pieces of legislation governing domestic discrimination law including European equal treatment directives and the Disability Discrimination Act (1995), incorporating the Disability Equality Duty (2006).

The act creates a duty on public bodies including NHS services to ensure that people are not treated less favourably because they have a disability, this includes people with autism.

This act requires public sector organisations to make reasonable adjustments to the way that services are delivered for people with a disability to ensure that they are not put at a disadvantage compared to non-disabled people in accessing the service.

Reasonable adjustment means the removal of physical or other barriers along with the provision of additional support where it is needed.

4.3.2 Autism Act (2009)

The Autism Act (2009) placed a legal duty on the government to produce a strategy for adults with autism. The act was followed up by statutory guidance for local councils and health bodies. The guidance is enforceable and details what must be done to improve service provision for adults with autism.

4.4 Previous Research Nationally

There is a wealth of information now available about areas in which statutory services in England are failing to meet the needs of adults with autism. A number of large scale projects including work leading up to the Autism Act (2009) found that the needs of this population are not well understood by service providers and that adults with autism are often going without necessary help and support (Beardon & Edmonds, 2007; Rosenblatt, 2008; NHSIC, 2009; NAO, 2009; DoH, 2010).

Good practice guidelines for service providers (Powell, 2002) and a large scale AS adult consultation (Beardon & Edmonds, 2007) identified areas of unmet need in service provision for this client group and made recommendations for the following:

An ongoing and up to date specialist Asperger syndrome training programme for all staff providing services to the community;

A designated specific team to have key responsibilities for diagnosing adults with AS and assessing needs;

Clear diagnosis referral routes and support pathways for adults;

Post diagnosis support if required such as counselling, advocacy and advice;

Support with employment, housing, independent living and social opportunities;

Sensitive crisis services (not necessarily mental health in-patient).

4.5 Previous Research In East Lancashire

A mapping project exploring prevalence of ASD's in the Burnley, Pendle and Rossendale area's was commissioned by Social Services in 2006. 36 service users were identified by day and residential service providers. Mental health teams and adult learning disability community services identified 48 service users. These figures were markedly lower than the national prevalence estimates. It was established that information relating to whether a service user has a diagnosis of ASD was not readily available in adult services (Ponsonby & Ingleby, 2006).

A draft proposal was developed by Lancashire County Council to establish a commissioning framework across Lancashire, to support families and provide services to people with AS. This project found at the time there was no shared agenda across health and social care to provide or develop such services, no robust dialogue with families and individuals and no capacity for individuals to influence mainstream agencies within Lancashire (Rowbottom, 2006).

A regional level report produced by a working group of commissioners and autism specific service providers in the North West with the support of the NAS (2006) suggested that 'lip service' was paid to developing partnerships with service users and parents without any action being taken. This had led to a lack of trust. Parents wanted to be involved but felt their views would not be listened to. Furthermore the attitudes of some professionals had led parents (and adults with AS) to experience interactions as more confrontational and adversarial, and to have little sense of working in partnership.

5. Staff Training Needs And Opinions

70% of the staff who completed the training needs assessment indicated they had very basic, little or no understanding of ASC's; and 77% felt they would benefit from autism awareness training (See appendix A for full report).

Staff were also questioned about service provision for this client group to see how professional viewpoints compared with service user opinions.

Only 1 out of 80 mental health staff questioned felt that current service provisions are adequate for adults on the spectrum and 74% felt services within their team could be improved for this service user group.

5.1 Funding/Systemic Restrictions

For those staff who do have an understanding of ASC's and do feel able to provide support for this client group there still appears to be barriers in place preventing such services being provided. Both service users and staff reported repeated attempts to access support services or diagnostic assessments which were turned down or blocked by both health and social service commissioners on the basis of funding or eligibility criteria.

Examples:

Service User feedback: "*Psychiatrist tried to get funding from PCT but they wouldn't give it, said if I got a label it would make me worse.*"

Service User feedback: *"I genuinely don't think there was anything Mental Health could do... A consultant psychiatrist who stood up against policies got 'moved on'."*

Staff feedback: *"I have recently attempted to purchase psychological therapies for a young man with ASD - mainstream MH psychology do not provide to people with ASD and he does not have a learning disability so his needs cannot be met through LD psychology. Funding for the private service is on its 4th application to the PCT after 3 previous refusals. His Mental Health continues to deteriorate in the meantime. This group of people have been let down for too long and need specialist services specifically to meet their needs rather than trying to have them met through the existing mental health services."*

6. Service User Feedback

The project gathered feedback from adults with or seeking a diagnosis of autism/Asperger syndrome in East Lancashire on their views and experiences of accessing diagnosis and mental health services. Details of how this was conducted and feedback received are as follows.

6.1 Participants

Inclusion criteria – To be aged 18 or over, live in East Lancashire and either have or are seeking a diagnosis of Asperger syndrome/high functioning autism; or are a parent or carer of an adult who meets the above criteria.

Exclusion criteria – Under 18, live outside of East Lancashire, have additional learning disability so would meet the requirements to access learning disability services.

A total of 33 questionnaire responses were received, 19 from AS adults and 14 from parents/carers. Additionally, 7 people participated in focus groups, 7 were interviewed and 2 kept diaries (for detailed demographic information see appendix D).

6.2 Design

The service user feedback part of this project was concentrated around the key project aims (see section 2.2).

The main factors assessed were[1]:

- Examples of where and how the mental health service is currently failing this client group;
- How mental health teams can meet the needs of this client group, and what services are required in order to do this;

[1] Also Known as independent variables.

- What do adults believe will help them to function and prevent mental health issues.

Information was gathered regarding[2]:

- Reasons for trying to access a diagnostic assessment or mental health support services;
- Experiences of mental health service accessibility and barriers to services;
- Service user satisfaction;
- Service user mental health support needs.

A mix of quantitative and qualitative data was collected using questionnaires; semi-structured interviews; focus groups and diary keeping (see appendix B for detail of how this was conducted and appendix C for examples of the questionnaires and interview schedules used).

The specific research questions considered were:

- What are people's reasons for seeking a diagnosis?;
- What experiences are people having when trying to access a diagnostic assessment via the mental health service?;
- What experiences are people having when trying to access general mental health support?;
- What support needs do this client group have which are not currently being met?.

[2] Also known as dependent variables.

Feedback was gathered focusing around these research questions and relevant themes were identified using the questionnaire responses first of all as they represent the widest range of responses. The data was explored to look for any significant differences in responses from adults with Asperger syndrome and parents and carers. No significant differences were found and so quantitative data is displayed combined as an overall service user response. Information collected by interview, focus group and diary was then added to these indicated themes to provide additional information. Findings are presented in relation to these research questions.

6.3 Reasons For Seeking A Diagnosis

Most respondents said that they had always known they were 'different' to others. Some mentioned they had been told or felt there was something 'wrong' with them. Many described a lifelong search for answers and a sense of relief on finding an explanation. Often people had researched autism and Asperger syndrome themselves or with family members before attempting to access a diagnostic assessment.

Reasons for seeking a diagnostic assessment for autism/Asperger Syndrome tended to relate to three main themes:

Clarification and personal identity

The most frequent reason given for seeking a diagnosis was for clarification whether autism was the reason for the differences the individual felt in relation to others. A diagnostic assessment seems to be viewed by many as an affirmation of personal identity.

> Examples: *"I knew that I didn't really empathise with people and that I faked a lot of my sort of well most of my social interactions... [a diagnosis] took away a lot of the concern... I was just different in a normal way..."*

> *"I wanted to know what was wrong with me, in the sense that I didn't seem to feel like everyone else."*
>
> *"I don't feel so suicidal now that I have a diagnosis... I am feeling stronger to cope with life."*
>
> *"For me it was a relief and sort of answered millions of questions of over the years."*

Enable others to understand them better

It was felt that a diagnosis provided a way for others to be able to understand the person. Many respondents felt that they were often misunderstood or that their actions were not perceived by others in the same way they had intended. People felt that being able to explain that they have a diagnosis of autism would be helpful for allowing others to understand.

> Example: *"Everyone thought I was badly behaved and I knew I wasn't."*
>
> *"[He was] admitted to a Mental Health ward and they didn't know, it was trial and error with different things to see if it would help."*
>
> *"I want to be included but I'm excluded and others don't want to work with me."*

Access to relevant support

Many people hoped that a diagnosis would allow them to access relevant health and social support with areas of difficulty should they need to seek help. Some needed help and support currently, others had partners or parents providing support but were anxious for the future when/if this support is no longer available as they would be unable to live well independently day to day without it.

Examples: *"My son needs lots of support, learning to cook, budget, almost everything. He wants to live independently but I have to go everyday to see he's ok but there are going to be times when I can't go, he needs help from every angle."*

"[he] wouldn't be able to make activities happen, [community restart] only works because he lives with us... one thing that may eventually be needed would be some kind of a residential accommodation... we won't always be here."

6.4 Access To Diagnosis

Out of 33 responses, 5 (15%) had accessed a diagnostic assessment as an adult from an NHS practitioner. Others had been diagnosed during childhood 18 (55%). 11 (33%) had accessed a diagnosis privately or via other means than the NHS. 3 (9%) had not managed to access a diagnostic assessment as yet and 1 (3%) didn't indicate how diagnosis was accessed.

From the AS adult responses the median age of diagnosis is 32. 11 people received a diagnosis outside of East Lancashire, where specified people had travelled to Sheffield for this consultation.

From the parent/carer responses the median age of diagnosis is 15. 6 received a diagnosis outside of East Lancashire, where mentioned people had travelling to Sheffield, one person to North Lincolnshire.

9 respondents had paid for their diagnostic assessment, with prices ranging between £100 - £500.

24 out of 30 respondents (80%) either disagreed or strongly disagreed that it is 'easy to get referred for diagnosis' in East Lancashire (χ^2=17.73, df = 3, p<.01).

Themes identified around accessing diagnostic assessment:

Difficult or impossible for most to access an assessment

Barriers reported were mainly systemic, no knowledge/understanding and negative/apathic attitudes of staff towards autism (possibly due to limited knowledge/understanding).

Practitioners and additional diagnoses affected experience

Where people were able to access a diagnostic assessment via the NHS, the person often had a co-morbid diagnosis and/or felt the attitude of practitioners they came in contact with was positive or sympathetic.

Private and NHS assessments at same centre

Many accessing a private diagnosis had their assessment at the same centre that provides out of area NHS assessments in Sheffield.

A couple of respondents mentioned that the diagnostic assessment process itself is a stressful and quite negative experience. It was suggested that incorporating the following into the diagnostic process would be helpful in improving the experience:

- Being able to have the diagnostic assessment in a familiar location where the person feels at ease;
- Reducing sensory stressors in the surrounding environment such as fluorescent lighting, background noise and crowded waiting rooms;

- Having the assessment conducted by a professional who the individual is already familiar with and trusts;
- Making the process more about recognition rather than diagnosis as this would be a less intimidating approach.

Many respondents mentioned anxiety and uncertainty during the process indicating that it could be helpful to consider methods to help reduce anxiety when looking to implement a diagnostic process.

6.5 Reasons For Seeking Mental Health Support

13 out of 19 (68%) AS adult had at least one additional diagnosis of a learning difficulty or a mental health condition, 11 out of these 13 (85%) had multiple additional diagnoses (see table 2).

11 out of 14 (79%) parent/carers reported the person they care for had at least one additional diagnosis of learning difficulty or mental health condition. 9 out of these 11 had multiple additional diagnoses.

A wide variety of different diagnoses were reported. The most frequent from all respondents were anxiety (21 people, 64%) and depression (14 42%), followed then by ADHD (7, 21%) dyslexia (6, 18%) and dyscalculia (4, 12%).

Therefore from the sample of 33 people who responded, only 9 (27%) identified themselves as having no additional learning difficulty or mental health needs.

Table 2: Additional Diagnoses

Diagnosis	No. Respondents	%
Anxiety	21	64
Depression	14	42
Dyslexia	6	18
Dyscalculia	4	12
ADHD	7	21
Other	7	21

6.6 Access To Mental Health Services

Respondents were asked whether they had tried to access mental health services during the past 5 years, either via their GP, directly or via a different route. 22 responded that they had tried to access mental health services, of these 16 (72%) said it was difficult or not possible to access mental health support, 6 (28%) had found it easy (see table 3).

Table 3: Access To Mental Health Services

	Not Possible	Difficult	Easy
MH via GP	1	4	4
MH via Other	0	7	0
MH Direct	0	4	2
Total	1	15	6

23 respondents either disagreed or strongly disagreed that mental health services in east Lancashire are accessible for adults with Asperger syndrome, 7 were neutral, and only 1 person agreed that mental health services are accessible (χ^2=20.48, df = 3, p<.01).

6.7 Barriers To Mental Health Services

Themes identified from service user feedback around barriers to accessing mental health service were:

Systemic limitations

- Battle to find a professional who can help;
- No local autism specialists can be referred to;
- No particular team with responsibility for the client;
- Changing workforce, have to explain about autism repeatedly to different staff;
- Long waiting lists to see professionals or access a diagnostic assessment;
- Time limited interventions not helpful;
- Attempts to provide more specialised services blocked due to lack of funding;
- No service provision at all for 16-18 year olds;
- Environmental impact on sensory sensitivities and lack of flexibility regarding venue for appointments.

Staff attitude

- Apathy or abrupt manner towards client;
- Possible diagnosis of autism dismissed, client felt not believed regarding the nature of their difficulties;
- Client feeling laughed at by professional.

Staff knowledge and understanding

- Staff perceived to have very little or no knowledge about autism;
- No supervision/support available for staff wanting to work with ASC clients;
- Physiological and drug effect differences seem to be often not accounted for in clients with ASC.

The most prominent themes arising from the responses were having to battle to receive any help or support at all, not feeling listened to and not having support needs taken seriously by practitioners.

A few participants felt that the mental health service only wants to work with clients who can be 'cured' or 'fixed' and felt that they were excluded from accessing services as they were looking for support with individual needs relating to autism which is lifelong and not something that can (or should in the view of these participants) be fixed.

In cases where people have been able to access mental health support (usually due to a separate diagnosis of schizophrenia or a borderline learning disability) feedback suggests that people's experiences were of frequent staff changes, time limited interventions and frequent systemic changes which involved redesigning or withdrawing the provision.

These frequent systemic changes were reported to cause a great deal of stress and anxiety, particularly as change is often difficult for many people with autism.

6.8 Summary

26 out of 31 respondents (84%) either disagreed or strongly disagreed that current mental health services are adequate for adults on the spectrum (see table 4), 5 were neutral (16%), no respondents agreed that current services are adequate (χ^2=13.61, df = 2, p<.01).

26 out of 31 respondents (84%) either disagreed or strongly disagreed that mental health staff in East Lancashire understand ASC's, 5 were neutral (16%) and no respondents agreed (χ^2=15.75, df = 3, p<.01).

31 out of 33 respondents (94%) either agreed or strongly agreed that all staff within mental health services should receive autism awareness training. 1 indicated a neutral response and 1 strongly disagreed.

Table 4: Mental Health Services And ASC's

	S. D/D	Neut.	S. A/A	Blank
Current Mental Health Service provisions in East Lancashire are adequate for adults on the spectrum	26	5	0	2
Mental Health staff in East Lancashire understand ASC's	27	5	1	1
All staff within mental health Services should receive autism awareness training	1	1	31	0

Themes identified around accessing mental health support:

- Mental health services have no knowledge of and are 'not geared up for' autism.
- No support post 16; needs are unmet until crisis/breakdown point.
- Some pockets of good, helpful psychology support accessed via the Learning Disability service or due to an additional diagnosis.
- Time limits on services/interventions limit usefulness.

6.9 Service User Suggestions To Improve Mental Health Provision

When asked 'How would you like mental health services to provide services for autistic adults?' along with 5 suggestions, plus the option to choose 'other' and provide individual unique suggestions, the most popular options were:

- provide autism awareness training for all staff;
- have a skilled, experienced member of staff in each department.

These suggestions were closely followed by having representation by people with ASC's within the mental health service and having an autism specific mental health service. Only 1 respondent indicated that they like how services are provided now (see table 5).

Table 5: Views On Autism Service Provision Options

	Number of responses
I like how they provide services now	1
Provide autism awareness training for all staff	24
Each department to have a skilled, experienced member of staff, trained to support those on the autistic spectrum	24
Have an Autism Specific Mental Health Service	21
Have representation of needs by people with ASC's within mental health services	22
Other	12

Suggestions given by people who chose 'other' included:

"Have a service."

"Anything would be a start."

"A service which helps people understand their condition. "

"Maybe some counselling to help people see their own need would help."

"A named person for co-ordinating care with long term involvement."

"Push for Autism Partnership Boards."

Additional suggestions made relating to service provision:

"Flag up autism on computers."

"Use simple shorter language... [and] ...easier forms."

"Make AS more visible so people can learn about it."

"Provide information on what is available [and] signpost to services."

National audits, local commissioning reports and service models used in other areas have highlighted three main suggestions as to how mental health service provision can be improved, these are: training all staff within current services to be able to work with clients with autism and Asperger syndrome; training one person within each department or team to work with autism and Asperger syndrome; providing a specialist autism specific service as a separate team.

Respondents were asked to agree or disagree whether each of these options is the best way to make improvements to mental health services. All three options were judged to be good ways to make improvements to

service provision by the majority of respondents (see table 6), however the preferred option was providing a specialist service, with all respondents who completed this section agreeing or strongly agreeing that it would be the best way to make improvements ($\chi^2 = 8.91$, df = 2, $p<.05$).

Table 6: Best Way To Make Improvements To Mental Health Service

	S. D/D	Neut.	S. A/A	Blank
Training all staff within current services	6	6	19	1
Having one person in each team skilled & experienced in ASC's	6	9	17	1
Providing specialist service for adults with ASC's	0	0	29	4

6.9.1 Mental Health Support Needs

A strong theme was one of people often feeling excluded, misunderstood and bullied within mainstream society.

Suggestions of support options which would be helpful and aren't currently provided centred around the following themes:

- Respite and breaks for both AS people and their carers to maintain mental wellbeing and prevent crisis.
    - For AS people respite from the daily struggle to fit in with a neuro-typical society and 'switch off'.
    - Holidays and short breaks suitable for AS people.
- Counselling and/or other therapies to support with:
    - anxiety and anger management;
    - understanding autism,
    - self identity and the neuro-typical world.
- Assistance with accessing companionship, friends and support networks.
- Practical help with daily living – aspects such as budgeting, form filling, cooking, cleaning, and hygiene.
- Support/advocacy around employment and housing where people are looking to access work and live independently.

6.9.2 Service User/Parent Carer Understanding Of Asc

Many respondents mentioned they felt they repeatedly have to explain to different professionals about autism. It is often presumed that if a person has a diagnosis or cares for someone with a diagnosis they have a good understanding of ASC's. Respondents were asked to indicate whether they felt they themselves had an understanding of ASC's.

27 out of 33 respondents (81%) agreed that they have an understanding of ASC's, however there was uncertainty and mixed views overall about whether autism is a mental health condition or a learning disability (see table 7). This is similar to the findings when staff members were asked to agree or disagree with the same statements.

Table 7: Service User Understanding Of ASC

	S. D/D	Neut.	S. A/A	Blank
I have an understanding of Autism Spectrum Conditions	2	4	27	
Autism is a mental health condition	11	7	14	1
Autism is a learning disability	10	7	16	

Hence it seems people with autism and their families are seeking support, advice and understanding from mental health services, yet there is not a clear understanding of whether autism falls under the remit of learning disability or mental health. Staff members similarly held mixed views in relation to these statements and have identified that they are not provided with the necessary training, information and support systems to support this client group and know which service should be providing the support, creating confusion and uncertainty (see appendix A for full training needs assessment report).

7. Potential Service Models

Statutory service provision across the country varies considerably for this client group. Much attention has been given to different models of service provision for this client group and numerous different papers over the past decade (including work leading up to and as part of the government's autism strategy) have highlighted examples of good practice (Powell, 2002; NHSIC, 2009; DoH, 2010) and costings for effective options (NAO, 2009).

Taking into consideration examples of good practice which have been recently and repeatedly cited, three example teams with different service models were considered. The costings, staff involved and total staff numbers for each team are laid out in table 8.

The lowest cost model overall per annum is the Nottinghamshire team, however as the Liverpool Asperger Team has almost twice as many staff members and is jointly funded, comparatively it seems the Liverpool model is the most cost efficient of the three teams.

Table 8: Example Services Models Used In Other Areas

Area	Team	Set Up	No. Staff	Approx Annual Cost	Provider
Oldham	Vulnerable Adults	Team Manager Social Workers Clinical Psychologist Housing Link Employment Support	12	£477,690	Council
Nottinghamshire	Adults with Asperger's Team	Team Manager Social Care Staff	5.5	£225,000	Council
Liverpool	Asperger Team	Team Manager Clinical Psychologist Nurses Social Inclusion Officer Assistant Practitioner Social Worker Support Worker	10	£260,000	NHS + Council

7.1 Model Effectiveness

Feedback was gathered from team managers regarding the effectiveness of the model used, obstacles encountered and adaptations made or considered useful.

7.1.1 Vulnerable Adults Service – Oldham

This team is currently based within social care and incorporates a clinical psychologist, housing and employment. The model provides for all vulnerable adults who don't 'fit' into other services, allowing the team to support people without a specific diagnosis and facilitate appropriate assessment and support. Asperger syndrome assessment and support planning is covered by this service.

The team was set up to save unnecessary out of area placement costs for people moving to adult services from transition for whom local services were difficult to identify.

The ability to accept referrals without a specific diagnosis brought with it one of the first major hurdles the team had to overcome as this freedom essentially 'opened the floodgates' for any cases which didn't fit neatly into other services and initially resulted in the team being inundated with referrals which were not strictly within its remit and in reality belonged with other services. The service model structure is as yet not solidly established and there are plans to merge this service with others and form a 'complex cases' team.

In relation to the teams work with Asperger syndrome, the team manager felt that the most important lesson has been that target 'turn around times' are not beneficial with this client group as it can take a long time to build relationships. *For example, "one man initially took 6 months just to open the door, once established you can start to work on support and development, it takes time but can achieve amazing results*."

7.1.2 Adult Asperger Team – Nottinghamshire

This team consists of 5.5 social care staff and in the first eight months the team received over 150 referrals with an average of 3 per week.

The mental health diagnostic team stand outside of the social care team. There was initially a plan to integrate but this seems unlikely due to funding coming to an end for the diagnostic team. The service may then return to out of area referrals for diagnosis. There are currently over 50 people on the waiting list for an assessment.

The team found that people stay open to the service longer than anticipated and that they are rarely able to close a case in the initially planned timescale of a few months. Often, as the team are the first place which has been able to provide the services needed, if crisis occurs the person returns to the AS team rather than to standard statutory services.

Nottingham City Centre is separate service to the rest of the county and has its own clinical and diagnostic provision similar to the Liverpool Asperger Team which doesn't address social care needs; this area isn't covered by the social care team. Nottinghamshire identified that it is difficult to provide social care services which cover all the different areas of the county. A suggestion made for future provisions is to use social and support provisions already in existence in each major town, for example charitable organisations.

Another major barrier the team encountered to providing the right support is a lack of independent living services and flexible home-based respite services which could prevent many families falling into crisis.

7.1.3 Liverpool Asperger Team

Jointly funded by NHS trust and Social Services, the team provides: assessment and diagnosis; a person centred approach; specialist

knowledge; information and advice; awareness training and clinical interventions.

Since inception the team has had over 700 referrals, 460 of which received a full diagnostic assessment.

Currently the model used is a managed care pathway which means the team provide support and advice to other provider services and only take on direct work with a client if there is a real need to or if a diagnostic assessment is required.

Referrals come from other service providers, however the overall responsibility for the client remains with the referring provider and the Asperger team provide specialised input and assistance where needed.

7.2 Key Limitations Of Models

Team managers identified that time limitations on support or targets regarding throughput of cases were not realistic or helpful when working with individuals with AS/HFA. The feeling was that people often do not need a huge amount of regular support but that it can take a significant length of time to build trust and reach a point where developments can be made. Rather than ensuring an efficient service, targets and 'turnaround times' have therefore limited progress with clients.

Where teams were funded with the expectation of immediate, obvious results which were not fulfilled, funding had been lost and invaluable progress made with individuals undone.

Often teams had been established by one particular service. Either a health led team with little input from social services or a social services team with little input from NHS services. It seems that as one statutory provider commissions a service for this client group other providers don't always feel a need to become involved.

Another difficulty when trying to provide necessary support to adults and their families has been the lack of suitable services. There are often few, if any, local social groups/services for autistic adults and there are not sufficient independent living options of the kind that would meet the needs of an AS adult (flat with arms length support). Similarly there are few services which provide 'in situ' respite at family homes to allow parents/carers to have a holiday. Therefore although the need for such provision is identified, it is not possible to provide this.

Some of these issues have been addressed by the model adopted by the Liverpool Asperger team. Funding for this team currently is provided jointly by the local NHS trust and social services. Running costs have been reduced as the team has developed and are currently £260,000 per annum. Based on feedback received and costing comparisons the Liverpool team seems the most effective model from those considered.

7.2.1 Referral And Care Pathway Examples

For diagrams and information detailing the Liverpool Asperger team referral and care pathways see appendix E. Examples of a similar pathway and service model proposed for Bristol are also included as an alternative example (see appendix E).

7.3 Service Proposal For Lancashire

This Liverpool Asperger Team model closely resembles the preferred option put forward by Lancashire Care Foundation Trust in a proposal for providing a diagnostic and support service for Asperger syndrome in East Lancashire (Summers, Warburton & Patel, 2008). The options proposed were:

a) Multidisciplinary Regional Specialist Service – a specialist multidisciplinary team offering comprehensive mental health care for people with Asperger's syndrome, including assessment and

diagnosis, needs assessment, management plans, specific treatments and support.

b) Clinical Network Model – All services for people with Asperger's syndrome provided through local mental health services with certain professionals within these local services developing enhanced skills around Asperger's Syndrome.

c) Combination Model – Local mental health services provide initial point of contact and assessment, with certain professionals within these local services developing enhanced skills around Asperger's syndrome. A small specialist multidisciplinary team offers a more specialist service including assessment and diagnosis, needs assessment, management plans, advice for local services, but offers these services only for those individuals where diagnosis and management planning is not straightforward and is beyond the scope of local services. Specific treatments and support would be offered only to a tiny minority with the most complex needs. The specialist service would be much smaller than in model A, and could be managed within an existing LCFT service (Summers, Warburton & Patel, 2008).

Option C, the Combination Model was highlighted as the preferred option and a cost estimate of £370,523 per annum was outlined based on 12.5 team members, along with ad hoc involvement of SLT and a Medical Doctor where needed and 4 part time psychiatrist posts within other local services (Summers, Warburton & Patel, 2008).

7.4 National Audit Office Costings Report

The National Audit Office ran a complex economic cost-benefit analysis of the potential financial impact of providing multi-disciplinary support services for adults with high-functioning autism/Asperger syndrome.

The analysis compared current baselines of service provision, costs and outcomes with a scenario where this population are provided with better targeted health, social care and employment support, achieving outcomes which are comparable with existing specialist services (NAO, 2009).

Existing services examples used included the Liverpool Asperger team and similar teams based around the preferred option highlighted by LCFT.

Probabilities were estimated using results obtained from local authorities, NHS partners and published literature. Costs included in the analysis were costs to: the NHS; local government; central government and private individuals.

The report concluded that a specialist service for adults with high functioning autism/Asperger syndrome is unlikely to be cost-increasing. If the service identifies four percent or more of the total number of adults with high-functioning autism they are likely to lead to a net benefit for the public purse.

Furthermore, savings would increase considerably if the identification rates currently achieved by existing services were replicated. At the time of the report the Liverpool Asperger team were achieving an identification rate of approximately 14 percent (NAO, 2009).

8. Discussion And Recommendations

This project throughout has been focused around a set of key project aims (see section 2.2); in order to achieve these aims the research aspect of the project was conducted in the following stages:

Analysis of staff training needs which has been mentioned throughout the report and is provided in full in appendix A.

Gathering of service user feedback about how the mental health service can better meet the needs of adults with AS and what services or support

AS adults believe help them to function and prevent mental health issues arising.

Consideration of models of provision used in different areas of the country along with previous research looking at statutory service provision for this client group.

Findings and recommendations are discussed in relation to each of these stages.

8.1 Staff Training Needs

The training needs assessment found that most staff (70%) had little or no knowledge about autism and 77% felt that they would benefit from autism awareness training (see appendix A for full report).

Service user opinion also indicated that they considered one of the most important factors with regards to improving service provision was training for staff to improve knowledge and understanding.

Responses from people with autism who were able to access mainstream mental health support services appeared to indicate that a widespread lack of training and expertise in autism amongst mental health staff led to respondents receiving services which were felt to be ineffective, inappropriate and potentially harmful for this service user group.

Staff ability to understand and communicate well with this client group is of paramount importance, particularly as communication and social interaction are key areas in which people with autism have difficulties and an area in which many clients need the most support.

8.1.1 Recommendations

Implementation of an ongoing structured, reliable programme of basic autism awareness training which can be monitored;

Additional job specific training available for staff who require it;

Monitoring of outcomes is essential via a training co-ordinator, either within or outside of the Primary Care trust who can also ensure that training remains up to date and is adjusted in line with any necessary recommendations made;

Follow-up specialist support available which staff can access should they require advice around working with ASC's.

8.2 Service User Feedback

8.2.1 Mental Health Support Needs

Diagnosis and access to a diagnostic assessment comes up frequently as a major issue for both services users and mental health staff. For adults who are seeking a diagnostic assessment the process in itself is a time of uncertainty, anxiety and stress. Service user feedback suggests that the mental health service fails to recognise how important it is for people to receive confirmation whether autism may be the reason for the lifelong differences and difficulties they have experienced.

Responses received in relation to trying to access a diagnostic assessment included:

"First person I told was... a psychiatric nurse and she laughed. The most debilitating part is that it is traumatic asking people for things, has got worse over time."

"PCT would not pay for me to be diagnosed because they said it would not do me any good".

"[I] Told [a practitioner] about autism initially and said could not do anything, "what do you want me to do". Next time saw her, she didn't acknowledge it."

"[A psychiatric practitioner said] I could help you but I'm not going to do so. AS is a lifelong condition and you're just going to have to live with it... there are no services in this area for people like you..."

Because Asperger syndrome cannot be seen from the outward appearance it is often described as a 'hidden disability' (NAS, 2010) and as these examples indicate because the person is of average or high intelligence, this tends to mask the nature of their difficulties and people are often misunderstood, perceived as having 'mild' symptoms or not taken seriously by professionals. It is these kinds of misperceptions which have led to the need for legislation supporting the provision of services for this client group (DoH, 2010).

Further to a diagnostic assessment additional support needs relating to diagnosis were:

- Information about the diagnosis and what it means;
- Counselling/therapy post diagnosis if needed;
- Signposting to community resources and groups;
- Clear information about how to access help and support if needed.

The following suggestions were also made relating to support/help needed:

- Respite from daily life in the form of a crisis house or community based space for people experiencing mental distress or crisis;

- Vacations suitable for AS people;
- Daily living support (form filling, budgeting, cooking, cleaning);
- Social opportunities.

Most didn't feel they needed specific mental health support and only talked about accessing mental health services at points of crisis when support networks have not been in place or have 'broken down' around the areas mentioned above.

8.2.2 Mental Health Service Barriers

In addition to access to a diagnosis, access to mental health support is expected to be available on an equal basis to all, in a person centred way, dependent on the individual's mental health support needs. In reality the project has highlighted that for service users on the autistic spectrum, mental health services within East Lancashire are difficult, and sometimes impossible to access.

Feedback indicates that when accessing mental health support services it is vital that support is provided in a way which works for autism. When accessing support for mental health conditions such as depression or anxiety it is important that practitioners understand autism and are able to adapt working methods, listen, reassure and communicate well with this client group. The most common complaint was not being understood or perceiving a lack of understanding and apathy from practitioners.

In East Lancashire it has been frequently mentioned by both service users and staff members that access to diagnostic assessment is often blocked by systemic barriers including refusal to fund assessments and confusion regarding referral as there is currently no pathway in place.

Perceived apathy from some professionals in relation to autism has been mentioned repeatedly as a major barrier to accessing services. Many adults do not feel believed or understood by professionals within the

adults do not feel believed or understood by professionals within the mental health service and feel they are unable to access any useful help or support.

The sensory environment in which the mental health service and many statutory services are based is also a major barrier to access for many autistic adults. Sensory differences are present in many people with autism and busy waiting rooms, fluorescent lighting, or loud sudden and unpredictable noises can cause pain, discomfort and stress.

The feeling from service users seems to be that adults with autism and Asperger syndrome who do not have an accompanying Learning Disability are currently excluded from accessing mental health support services. When respondents have experienced problems they have felt unable to access prompt, timely intervention and it would appear that support services are typically only available for this service user group at the point of crisis.

8.2.3 Recommendations

Implement a clear care pathway for adults with ASC's including provision for access to diagnostic assessment and mental health support.

If required by service user, ensure diagnostic assessments followed up with post-diagnostic support, referral for community care assessment in line with statutory guidance and signposting to relevant community support services.

Facilitation of access to low level support including: respite from daily life; social opportunities; vacations; daily living support suitable for people with ASC's.

Access to specialist support and advice for staff so they feel equipped and supported to work with this client group.

More flexibility with the environment and location of appointments to meet reasonable adjustment requirements for this population. Sensory sensitivities differ for each individual and can cause pain and distress. People with ASC's may not be able to communicate these needs easily.

Facilitate representation of client group in provision of services for ASC, along with clear two-way communication between service providers and service user group.

8.3 Models Of Provision

From analysing information available on service models options and speaking to team managers the most effective option appears to be a managed care pathway team currently used in the Liverpool area which provides support and advice to other provider services and steps in only if a diagnostic assessment is required or there is a specific need for additional involvement. Jointly funded by NHS trust and Social Services,

the Liverpool team provides: assessment and diagnosis; a person centred approach; specialist knowledge; information and advice; awareness training and clinical interventions.

This model used by the Liverpool team is similar to Combination Model proposed by LCFT (2008) – Local mental health services provide initial point of contact and assessment, certain professionals within these services develop enhanced skills around Asperger's syndrome. A small multidisciplinary team offers a more specialist service including assessment and diagnosis, needs assessment, management plans, advice for local services, but only work directly with the service user for those individuals where diagnosis and management planning is not straightforward and is beyond the scope of local services.

When service users were asked how they would like services to be improved the most popular options were:

- having some professionals within general mental health service teams who have enhanced skills around Asperger syndrome;
- awareness training for all;
- providing an autism specific service.

Hence it seems the combined or managed care pathway seems to also fit with service user opinion in that it incorporates a specialist team, some staff members within mainstream statutory services with enhanced skills around autism, awareness level training available for all staff and additional support from the specialist team where needed.

8.3.1 Recommendations

Combination service model, referred to also as a 'managed care pathway' model appear to be most effective option.

Small specialist multidisciplinary team able to provide: assessment and diagnosis, needs assessment, management plans, advice for local services, direct work with individuals where diagnosis and management planning is beyond the scope of local services.

8.4 Impact Of Legislative Changes On Project

Since the inception of the project, legislative changes have now put a legal duty on local statutory services to ensure provisions for this service user group are improved.

The official statutory guidance (DoH, 2010) says that local councils and NHS bodies in England must improve:

- Training for their staff with regards to ASC's;
- Identification and diagnosis of autism in adults;
- Planning of services for people with autism, including the transition from child services to adult services;
- Local leadership and coordination of autism services.

To achieve this, the guidance requires local authorities and the NHS to:

1. Provide autism awareness training for all staff;
2. Must provide specialist autism training for key staff, such as GPs and community care assessors;
3. Offer a community care assessment for adults with autism regardless of IQ;
4. Appoint an autism lead in their area;

5. Develop a clear pathway to diagnosis and assessment for adults with autism;
6. Commission services based on adequate population data.

Two of the main requirements for services identified in the autism strategy are training for staff and the provision of a clear diagnostic and support pathway, the responses received in this project from both service users and professionals echoed the importance training and ensuring that a clear pathway is put in place.

More specifically, this project and the statutory guidance requirements overlap and fit together in the following areas:

8.4.1 Staff Training

The training needs assessment recommended that autism awareness training is provided for all staff; with job specific training available for those who require it. This is now a key statutory guidance requirement.

8.4.2 Identification And Diagnosis Of Adults With Autism

The statutory guidance states that local services must improve identification and diagnosis of people with autism. This project attempted to identify numbers of mental health service users with autism during the staff training needs assessment however it became apparent that currently there is no central method of recording whether service users have a diagnosis of autism. Staff estimates of how many people the autism spectrum their team support are discussed in the training assessment report (See appendix A).

One of the key project aims was to analyse service provision models and look at diagnostic and support referral pathways. Models have been discussed earlier in this report and sample pathways are provided in appendix E. One of the key requirements of the statutory guidance is

development and implementation of a clear pathway to diagnosis along with commissioning services based on adequate population data.

In conjunction with the statutory guidance, the National Institute for Clinical Excellence (NICE) is currently preparing a diagnostic pathway model which is due to be published in 2013.

8.4.3 Service Provision Modelling

The statutory guidance requires planning and commissioning of services for adults with autism. One of the project aims was to analyse models of provision and make recommendations for services which can realistically be provided. Some work around commissioning services for adults with autism has been carried out by Lancashire Care Foundation Trust and Lancashire County Council and has been considered as part of this project.

9. Concluding Comments

In conclusion, statutory guidance, service user feedback and findings from analysing previous research and models used all support a combined approach or managed care pathway model as a means to improving mental health service provision for this client group.

This means the provision of a small autism specific multidisciplinary team to work with and support mainstream services to work well with this client group. The role of the specialist team would be primarily a facilitative one with a diagnostic assessments, training, supervision and advice provided where needed (for detailed information regarding the team models considered see section 6).

The Liverpool Asperger Team which is now based on this type of service model has proven not only to be effective but also cost saving and is frequently cited as an example of good practice (Powell, 2002; NAO, 2009; DoH, 2010).

In line with the statutory guidance a service model similar to this could provide the necessary diagnostic pathway, staff training and access to support and advice for professionals in all of Lancashire's statutory services. A proposal made by LCFT highlighted a similar 'combined service model' as the preferred option for Lancashire.

A team based on this model could facilitate implementation of the recommended basic awareness level autism training for all staff and additional job specific autism training where needed is to provide some members of staff within mainstream departments with the skills and understanding needed to work well with this client group (see appendix A for the full training needs assessment report).

Separately from ASC specific service provision, suggestions for important adaptations or 'reasonable adjustments' to improve accessibility of mainstream services for this service user group included:

- Adaptations to environment where possible (i.e. replacement of fluorescent lighting; provision of a suitably lit, comfortable, designated quiet room for those with auditory sensitivities) or the ability for practitioners to be flexible with appointment locations if the sensory environment is not suitable and cannot be adapted;
- Use simple shorter language and easier forms;
- Flag up autism on computers so that staff members are aware of possible sensory and communication differences.

Service users also mentioned either relying on or expressed a need for low level daily support in the form of social opportunities, peer support networks (groups and activities) and assistance with daily living, including budgeting, form filling, employment support and housing.

This type of support for people with autism is scarce currently in Lancashire and where available it is provided by community based groups such as charities and not for profit organisations.

Service user feedback indicates that it is important to ensure these community support services which meet key areas of need and prevent crisis are incorporated into support service planning. Particularly people indicated that they often were not aware of services that exist and said that being provided with information on what is available for people with autism locally would be really helpful, as would making this information more readily available for all.

It is noted that recommendations made in this report may involve multi-agency approaches and implementation will be dependent on decisions made jointly by the PCT and other statutory services as to how services can be tailored to meet the needs of these service users.

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Appendices

A. Staff Training Needs Assessment Report

B. Methodology

C. Paperwork examples

D. Demographic data

E. Referral Pathway Examples

Appendix A – Staff Training Needs Assessment Report

Asperger Syndrome Adult Project: East Lancashire

Mental Health Staff Training Needs Assessment

Author: Emma L Dunn

March 2010

Commissioned by and prepared for East Lancashire Primary Care Trust Mental Health Commissioning.

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Abstract

As part of a larger project looking at improving Mental Health (MH) service provision for adults on the autism spectrum, East Lancashire Primary Care Trust (ELPCT) commissioned a staff training needs assessment measuring levels of autism awareness and training needs amongst mental health service staff. 87 staff members across 14 teams completed assessment questionnaires.

The assessment results indicated that 70% of staff had only very basic or no understanding of autism and 77% felt they would benefit from autism awareness training. In light of these findings and in line with Department of Health recommendations (2010), basic awareness level training is recommended for all staff that have not received any basic autism training as yet.

Feedback from staff who had received some basic autism awareness training indicated that 70% felt they required further job-specific training in light of what they had learned and some commented that the awareness training they attended had been very brief and left them with many questions. Therefore it is recommended that a basic awareness training programme should be followed by a post training review process to monitor training effectiveness and to identify further specific training needs for those staff who feel they require it in their specific job role. These recommendations could be implemented as a rolling 2 tiered training programme. Further details are discussed in the full report.

Introduction

This report was commissioned in 2009 by East Lancashire Primary Care Trust (East Lancs PCT). The purpose of the report is to provide an assessment of the training needs of Mental Health (MH) staff in relation to providing services for adults on the Autism Spectrum who are High Functioning, often diagnosed as Asperger Syndrome (AS). Recommendations are made as to the level of training required.

The assessment applies to staff providing Mental Health services on behalf of East Lancs PCT within the five boroughs covered by the trust. This includes staff from Lancashire Care Foundation Trust (LCFT) working within the areas covered by East Lancs PCT.

Background

What is High Functioning Autism/Asperger Syndrome?

Autism is a lifelong condition currently estimated to affect approximately 1 in 100 adults in England (NHS Information Centre, 2009); often described as a 'spectrum disorder', the condition affects people in many different ways and to varying degrees.

Asperger syndrome (AS) is a form of high functioning autism and a lifelong condition that affects how a person makes sense of the world, processes information and relates to other people. It is often referred to as a 'hidden disability'; this means that you can't tell that someone has the condition from their outward appearance. The characteristics of AS vary from one person to another but are generally divided into three main groups:

- Difficulty with social communication

  People with AS sometimes find it difficult to express themselves emotionally and socially.

- Difficulty with social interaction

Many people with AS want to be sociable but have difficulty with initiating and sustaining social relationships, which can make them very anxious.

- Difficulty with social imagination

"We have trouble working out what other people know. We have more difficulty guessing what other people are thinking."

People with AS can be imaginative in the conventional use of the word. For example, many are accomplished writers, artists and musicians, but can have difficulty with social imagination.

These areas are often referred to as 'the triad of impairments'; however they are not the only areas in which people with AS experience the world differently.

Other related characteristics are:

- Love of routines

To try and make the world less confusing, rules and rituals (ways of doing things) are often preferred; along with ordering their day to a set pattern. An unexpected delay or change to their day can make them feel anxious or upset.

- Special interests

People with AS may develop an intense, sometimes obsessive, interest in a hobby or collecting.

- Sensory difficulties

  These can occur in one or all of the senses. The degree of difficulty varies from one individual to another. Most commonly, an individual's senses are either intensified (over-sensitive) or underdeveloped (under-sensitive).

While there are similarities with classic autism, people with Asperger syndrome have fewer problems with language and are often of average, or above average intelligence. They do not usually have the accompanying learning disabilities often associated with autism, but often have specific learning difficulties such as dyslexia, dyspraxia, attention deficit hyperactivity disorder (ADHD) and epilepsy.

With the right support and encouragement, people with AS can lead full and independent lives.

The exact cause of AS is still being investigated. However, research suggests that a combination of factors - genetic and environmental - may account for differences in brain development.

AS is not caused by a person's upbringing or their social circumstances and is not the fault of the individual with the condition.

(Extracts taken from the National Autistic Society – 'What is Asperger Syndrome?')

<u>Access to Services for Adults with AS</u>

For many higher functioning autistic adults who have not received an official diagnosis their traits may go unnoticed by service providers. Even if autism is suspected it is often difficult to obtain a diagnosis from local services. For those who do have a diagnosis, 'many professionals are uncertain as to whether people are entitled to services, and if so who should provide them' (Jarrett, 2007). Nearly two thirds of autistic adults

(63%) told the NAS they did not have enough support to meet their needs (Rosenblatt, 2008).

It has been highlighted in autism literature that although general awareness of autism is increasing, as yet support services widely available to the mainstream service user group remain largely inaccessible to adults with ASC's due to a lack of understanding of the condition and how these services can be tailored to meet an autistic individuals needs (Powell 2002; Parker, Jones & Wheatcroft, 2008; DoH 2010).

Recent government recommendations have indicated that as part of a strategy to make services more accessible to adults with ASC's, autism awareness training should be 'included within general equality and diversity training programmes across all public services' and that it is 'essential that autism awareness training is available to everyone working in health or social care' (DoH, 2010).

Assessment Aims and Objectives

A first step towards implementing these recommendations for East Lancashire Mental Health services is to establish current autism awareness levels within the Mental Health service; and if possible to identify priority groups who regularly come into contact with adults with ASC's. In order to do this the following objectives were identified:

- To conduct an assessment of current training needs, relating to autism spectrum conditions amongst East Lancashire Mental Health Service team members
- Provide recommendations for a training programme based on levels of need identified
- Identify numbers of ASC service users accessing services to highlight priority areas

Method

Participants

The participants were NHS staff members working in Mental Health Services within the East Lancashire area, specifically covering the five boroughs of Burnley, Pendle, Rossendale, Hyndburn and Ribble Valley. The teams contacted within East Lancs PCT were the Primary Care Mental Health teams. Within Lancashire Care Foundation Trust the following teams were contacted as they provide Mental Health services on behalf of East Lancs PCT: 5 x Community Mental Health Teams, 3 x Crisis Teams, 1 x Early Intervention Service, 2 x Assertive Outreach teams.

Participants were contacted via an email to team managers who were asked to circulate the assessment to their staff members, a total of 87 responses were received.

Design

Mental Health Staff members were asked to complete a questionnaire focusing on awareness of Autism Spectrum Conditions and training needs. The main factors[1] looked at were training received and perceived understanding of autism. Information was also gathered regarding Number of ASC service users identified as clients of the team; desire to receive Awareness Training; Views on Autism Spectrum conditions and current service provisions[2]. The study considers and reports on staff opinions regarding their own training needs; and additionally looks at the different needs and views of staff who had received any training, compared with those who had not. Both quantitative and qualitative data were collected.

[1] Also known as Independent Variables

[2] These additional factors are the Dependent Variables

Measures

The assessment was conducted using a questionnaire, two versions were made available (see appendix 1a&b), one that could be completed online and returned via email; and one for printing, completing manually and returning by post.

An information sheet was also provided detailing the reason for the assessment, why the team had been included and how the information would be used (see appendix 1c). SPSS statistical processing software and Microsoft Excel were used to process the data.

Procedure

Team managers were contacted via email, they were asked to participate in the assessment themselves; and also to distribute the questionnaire to all of the staff in their team, either online or manually and return the completed questionnaires to the researcher by 23rd December 2009 (see appendix 2 for a copy of the email).

Results

Who responded?

Questionnaire results are based on a sample population of 33, including 19 adults with or seeking a diagnosis, and 14 parent/carers.

Responses were received from all geographical areas covered by the trust with the majority of responses from Pendle, Rossendale and Hyndburn areas (see table 1); however this may not be an accurate reflection of the spread of data as 26% of respondents did not specify a geographical area.

Table 1: Demographic Data

N=87	Median/Frequency	Percentage
Age		
Median	41	
Range	22 - 63	
Gender		
Male	23	26%
Female	61	70%
Unspecified	3	4%
Geographical Area		
Burnley	6	7%*
Pendle	29	33%*
Rossendale	14	16%*
Hyndburn	15	17%*
Ribble Valley	2	2%*
Not Specified	23	26%*

* Total percentages may not equal 100 due to some roles covering more than one area

Table two shows the job roles of respondents, as can be seen responses were received from staff in various different job roles within Mental Health services.

Table 2: The numbers of responses from each professional group

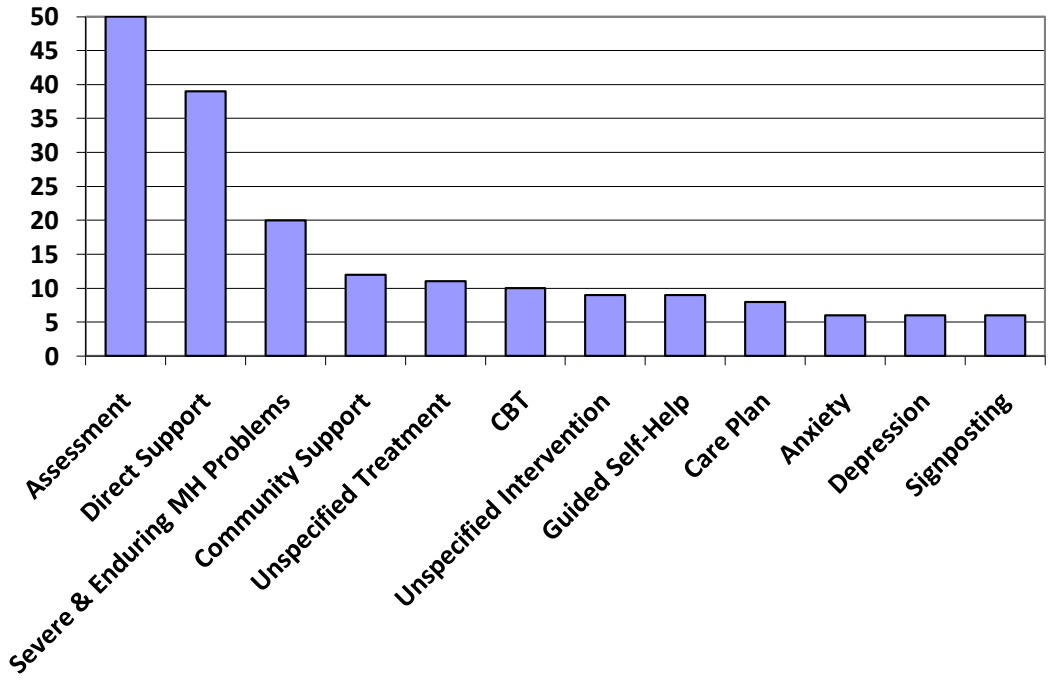
Job Role	N=87
Community Mental Health/Psychiatric Nurse	12
Community support Worker	11
Social Worker/Approved Mental Health Professionals	9
Team Manager (including Deputy Managers)	9
Occupational Therapist	8
Psychological Wellbeing Practitioner	7
Mental Health Practitioner	5
Care Co-ordinator	4
Counsellor	4
CBT Therapist	4
Crisis Practitioner	3
Clinical Treatment Practitioner	2
High Intensity Therapist	2
Locality lead – PCMHW	2
Clinical Psychologist	1
Single Point of Access Worker	1
Role Unspecified	3

Type of service provided by staff who responded to the assessment

Respondents were asked to give details of the type of services their team provided to service users. The responses were analysed and those services mentioned most frequently are displayed in figure 1 in terms of how many times they were mentioned[3].

The types of service most frequently mentioned were assessment and direct support for severe & enduring mental health problems (see figure 1). The types of mental health problems frequently mentioned were anxiety and depression, and the types of support frequently mentioned were CBT, guided self help, development of care-plans & signposting (see figure 1). Other types of support mentioned included psychology, counselling, medication management, daily living help, occupational therapy, goal setting and nursing.

Figure 1: Type of service provided by respondents



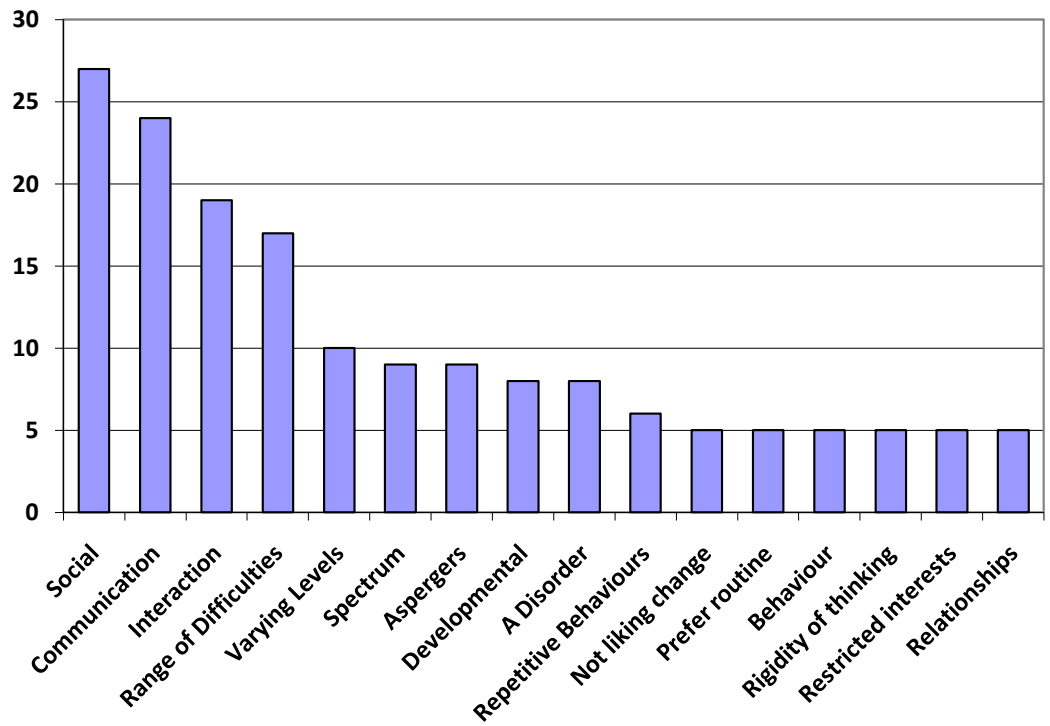
[3] Known as a content analysis.

Understanding of ASC's

When asked 'please give a brief outline of what you understand ASC to be', 48% indicated that they had very little or no understanding of ASC's.

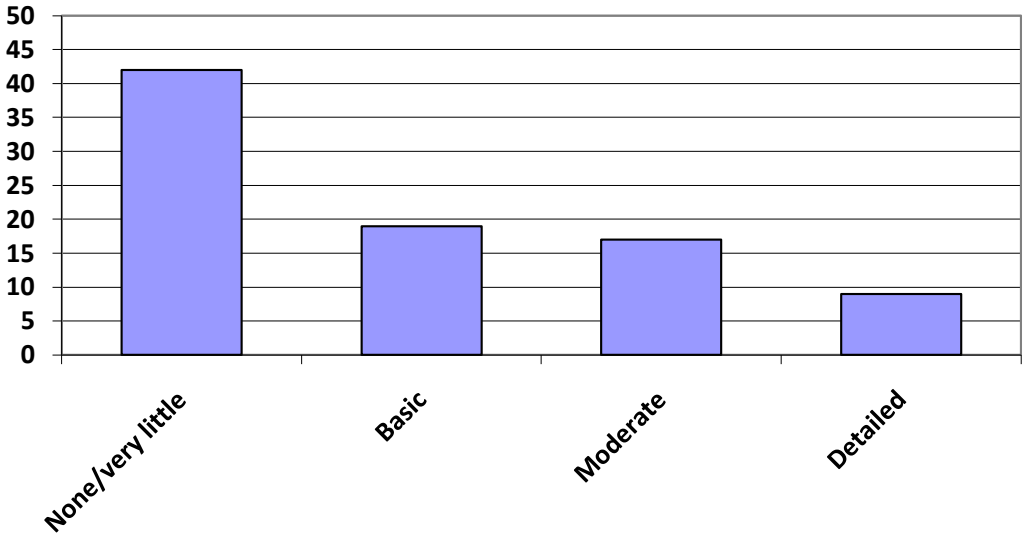
Amongst those who had some understanding of what ASC's are, the most frequently mentioned factors were Social, Communication and Interaction Difficulties (see figure 2). Other quite frequent responses included varying levels/degrees of severity, the spectrum, Aspergers and that it is a developmental disorder. Other factors mentioned included repetitive behaviours, not liking change, preference for routine, rigidity of thinking, obsessions, skills/specialist knowledge in one area, difficulty understanding others and relationships.

Figure 2: Words used to describe understanding of ASC's



Responses to this question (please give a brief outline of what you understand ASC to be') were then rated according to the descriptive terms used. Responses were grouped into No/ Very little, Basic, Moderate or Detailed understanding. Out of 87 responses, 61(70%) indicated no/very little or basic understanding of ASC's; 26 (30%) indicated they had moderate or detailed level understanding (see figure 3).

Figure 3: Autism Understanding Level



Service Provision for ASC adults

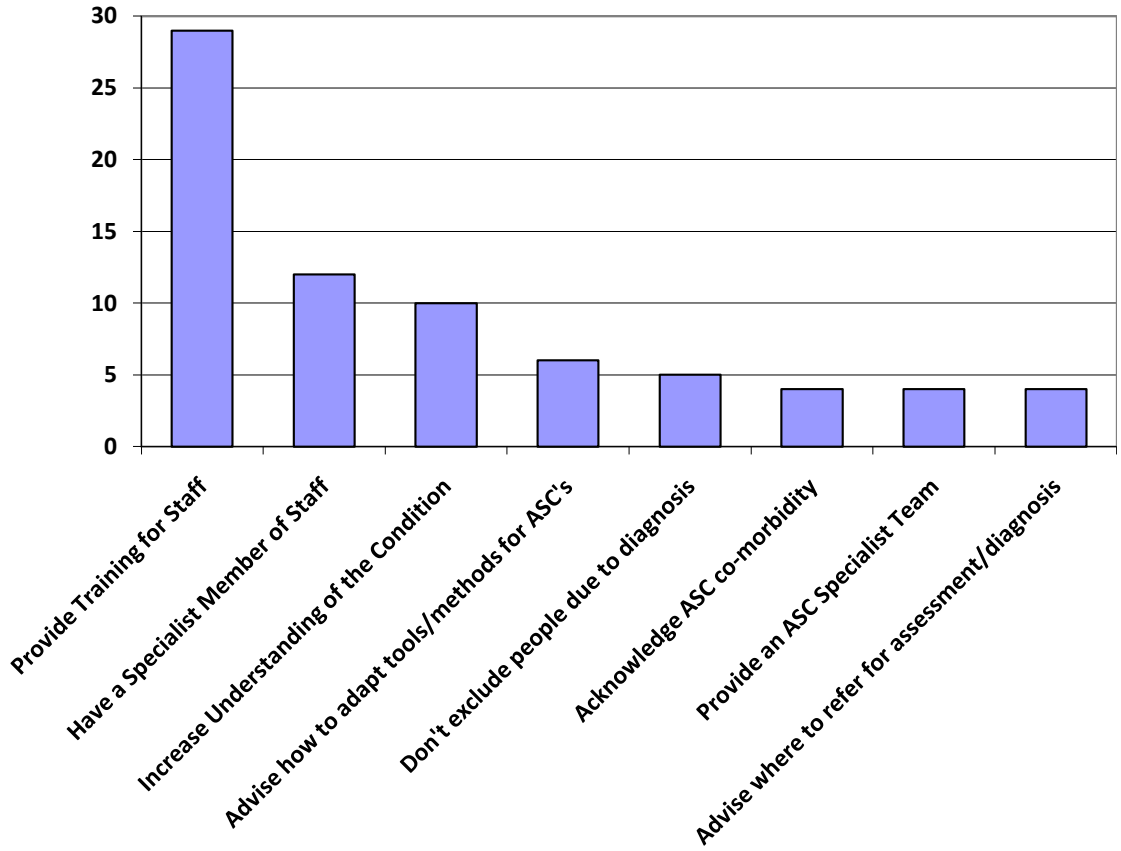
When asked 'do you think services within your team could be improved for adults on the spectrum (if so, how)?', suggestions included receiving guidance on how to work with ASC service users, having tools and resources to use with this client group, better link working with other services, provision of information on any specialist services and access to a diagnostician to refer clients to for assessment (see Figure 4).

The most frequently suggested improvements were to provide training, increase understanding of the condition and to have access to a member of staff with specialist knowledge in autism.

Other useful suggestions mentioned were to: provide advice on how materials and methods can be adapted for this client group; not excluding people due to their diagnosis and providing a specialist service that can be referred to for assessment/diagnosis and called upon for specialist advice/assistance.

Notably a few different people also mentioned acknowledging Autism and Mental Illness can be co-morbid as a way to improve service provision for ASC adults.

Figure 4: Ways to improve service provision



Current Service Provision

74% of mental health professionals within the sample agreed that services within their team could be improved for adults on the autism spectrum (see Table 3).

No respondents knew of a specialist service available to ASC service users, and only 1 respondent identified a team member who they considered to be a specialist in autism.

Table 3: Responses to Part 1 Quantitative questions

N=87	Yes	No	No Response/ Unsure
Service Users considered to be ASC	21	30	36
Specialist Service	0	81	6
Can be improved	64	11	14
ASC training in current job role	11	53	23
ASC Training outside of current job role	12	69	6
Total number of staff that had some training	23	64	-
Team Specialist?	1	55	31

Awareness and Training

With regards to basic awareness training, out of 87 staff responses, only 11 (13%) had received some form of basic autism awareness training whilst working in their current job role (see Table 3). 12 respondents had received ASC training outside of their current job role, either in a previous job elsewhere or via other means, therefore a total of 23 respondents (26%) had received some form of awareness training.

A similar number of respondents (21) were able to identify service users considered to have an ASC; the majority of those who responded (66) were not aware of any ASC service users, were unsure, did not answer this question or felt unable to identify these service users.

Out of those respondents who were able to identify service users considered to have an ASC, 12 (57%) were Community Mental Health staff, 5 (24%) were Primary Care Mental Health staff, and 4 (19%) were from Crisis Resolution Teams.

Details of Training Received

Those staff members who had received training were asked who provided the training and who it was provided for. The responses indicated that some basic awareness training was available via Lancashire County Council; a one-off course of awareness sessions had been provided by Lancashire Care Foundation Trust specifically for counsellors, and some training is available for AMHP's but this seems to be occasional one-off days outside of the trust. Hence it seems there is currently no standard awareness training available to Mental Health Service employees.

Further Training Required

Out of the 23 people who had received some form of training, 16 felt that they required further subsequent training. Specific areas that these staff members felt they required further training in were communication, sensory issues, job specific issues, and the mental health act.

Additionally many staff mentioned that the awareness sessions they had attended were brief and more extensive/specific training was required.

Gauging Opinions and Views of ASC's

Part 2 of the assessment questionnaire provided a list of statements which staff indicated a response to in terms of whether they agreed or disagreed (see appendix 1 for a sample of the questionnaire); not all staff responded to this part of the assessment and others completed the

section yet did not respond to all of the statements. Hence total response numbers vary throughout this section.

Out of 82 responses, only 32 (39%) agreed that they understand what autism spectrum conditions are (see table 4). Furthermore only 12 (15%) felt they had sufficient understanding of ASC's to do their job well in terms of providing support for adults with ASC's.

The majority of staff agreed that they would benefit from autism awareness training (77%), with only 4 respondents disagreeing that awareness training would be of benefit to them and only 1 respondent felt that autism specific training was not necessary (see table 4).

Most staff (70%) indicated that a specialist service for adults with ASC's would be more appropriate than trying to provide a complete service within current provisions. Similarly only 9 respondents (11%) agreed that their service is the appropriate place for adults with ASC's to access support and only 1 out of 80 respondents agreed that current service provisions are adequate for adults with ASC's (see table 4).

When asked to agree or disagree with the statement 'Autism is a Mental Health Condition' 36 people (44%) disagreed that autism is a mental health condition, 17 (21%) agreed that it is and 29 (35%) gave a neutral response. These responses indicate that the majority of respondents do not believe autism is a mental health condition or were uncertain.

In response to the statement 'Autism is a Learning Disability' 37 people (45%) agreed, 32 (37%) gave a neutral response and 11 (13%) disagreed indicating that the majority of respondents either believed autism is a Learning Disability or were uncertain.

Table 4: Responses to Part 2 Statements

N=87	S. Disagree/ Disagree	Neutral	S. Agree/ Agree	No Response
I understand what autism spectrum conditions are	30	20	32	5
I have sufficient understanding of autism spectrum conditions to do my job	49	18	12	5
I feel I would benefit from autism awareness training	4	13	63	5
Our team are able to support individual's disabilities, specific training is not really necessary	62	18	1	6
A specialist service for adults with autism would be more appropriate	5	19	57	6
Autism is a Mental Health Condition	36	29	17	5
Providing all staff with autism awareness training will allow the team to provide a better service	11	15	56	5
This service is an appropriate place for adults on the autism spectrum to access support	44	28	9	5
Current service provisions are adequate for adults on the spectrum	57	22	1	7
Autism is a Learning Disability	11	32	37	7
Autism awareness training is not necessary for our team	54	20	6	7
Training one individual within a team to specialise in autism is more appropriate than awareness training for all	44	18	18	7

The Impact of Understanding

Comparisons were made on several factors between those who had some understanding of Autism Spectrum Conditions (ASC's) and those who had very little or no understanding.

Significant association's were found between understanding of ASC's and the views on statements that Autism is a Mental Health Condition ($\chi^2(2) = 8.72$, $p<.05$) and that Autism is a Learning Disability ($\chi^2(2) = 13.31$, $p<.01$). Those with some understanding of ASC's were more likely to disagree with the statements 'autism is a Mental Health condition' and 'autism is a Learning Disability'.

A significant association was also found between Autism understanding and views on the statement that 'current service provisions are adequate for adults on the spectrum' ($\chi^2(2) = 7.67$, $p<.05$). Again, those with some understanding of ASC's were more likely to disagree with this statement.

There was also a significant difference in ability to identify Service users who have ASC's ($\chi^2(1) = 9.08$, $p<.01$). Those who had at least a basic understanding of autism were 25 times more likely to be aware of service users who have an ASC[4] compared with those who had no understanding of ASC's.

[4] Based on an odds ratio calculation.

Discussion

Training Received & Current Autism Understanding Levels

Assessment data shows that from 87 staff assessed, 23 had attended some form of training in autism; only 11 however had received this training in their current role.

Understanding of autism was measured separately, 42 staff indicated they had very little or no understanding of what ASC's are and 19 indicated only basic understanding of the condition, amongst these responses however some appeared to have gaps in knowledge and some respondents gave descriptions which were not quite correct . 17 respondents had moderate level understanding, here again some respondents gave explanations of ASC's which were not entirely accurate and displayed gaps in knowledge. Only 9 members of staff had detailed understanding of ASC's.

Ability to Identify ASC Service Users

The majority of respondents (76%) were either not aware of any ASC service users, or did not provide a response.

Those staff members who were able to identify service users with ASC's were primarily from Community Mental Health Teams (57%) with some from Primary Care Mental Health & Crisis Resolution Teams also able to identify ASC service users.

It would therefore appear from responses that Community Mental Health Teams are either more able to identify these service users, or come into contact with ASC adults more often than other teams within Mental Health Services. Primary Care & Crisis Resolution teams also appear to have some contact with ASC adults.

Caution should be exercised however when interpreting these responses as the lack of a clear pathway to diagnosis means that many adults will not have received an official diagnosis and may not themselves be aware

that they have an ASC. Also staff from all teams may come into contact with some adults and not recognise an ASC; additionally some ASC adults find that they are actually excluded from accessing services as a result of their diagnosis (DoH Autism Strategy, 2010). Hence, although it appears that Community Mental Health teams have the most contact with this service user group, it may be the case that other teams would come into contact with and be able to identify more ASC service users if they were adequately trained to recognise the condition and adapt service provisions.

Reflection on past training received and further training needs

From those respondents who had received previous autism awareness training, 70% felt that they still required further training in light of what they had learned. Comments relating to previous training received indicated that some respondents felt the training they had received was very brief, people had accessed different training sessions through various providers and the length and quality of the sessions varied. Overall most had found the awareness training useful but many indicated that in light of the awareness they had gained, they required further guidance in terms of how to communicate and work with adults with ASC's.

Does training equate to understanding?

It is often presumed that if a person has attended basic autism awareness training of some description that they will gain an accurate basic understanding of autism and be more able to recognise the condition.

This presumption however depends on the training being of a consistent level, with up to date information and from a reliable source. As concerns raised amongst professionals have highlighted, although 'over the last decade general awareness of autism has increased amongst professionals and the general public... there is little evidence as yet of any significant improvement in the lives of adults with these conditions (Powell, 2002,

cited in Parker, Jones & Wheatcroft, 2006) and 'despite this improved awareness, there is a lack of real understanding amongst professionals (particularly in adult services) and this remains a cause for concern' (Parker, Jones and Wheatcroft, 2006).

Additionally, understanding can be gained through hands on working, or personal life experience and so professionals who may not have received any form of awareness training can still have substantial understanding of the condition.

In light of these considerations staff understanding of autism was explored separately to having received any basic autism awareness training.

On analysing the results it appeared that understanding of autism is not necessarily consistent with training. Some staff who had received basic training had gained very little understanding around autism and still held some inaccurate beliefs, whereas others who had not attended any form of training had a substantial understanding of the condition. It is important to note that whilst some staff members had attended basic autism awareness training sessions, the training had not adequately fulfilled its objective as staff members did not leave with an accurate basic awareness of the condition.

In light of these findings it is therefore imperative that any training programme put in place is carefully chosen and known to be an accurate, up to date programme. Further this should be monitored post-training to ensure that it meets objectives in terms of raising general awareness amongst the workforce in the context of their job roles.

<u>Views on Service provision for ASC adults</u>

When asked for feedback relating to how their service could be improved for adults with ASC's, many respondents indicated that they felt uncertain

as to how services should be provided or could be improved with comments such as:

> *"I am not sure if our service is best place to meet this need or should there be a specialist ASD service"*

> *"How to manage in crisis. Do they come under mental health or learning disability team?"*

> *"If I understood more about autism & Aspergers then I could comment"*

Some staff indicated that ASC individuals are currently not accessing mainstream Mental Health services and there is a belief that the mental health service is not the appropriate place for this client group:

> *"To my knowledge we do not provide a service to people with this primary diagnosis"*

> *"Do not feel that mental health services can meet the needs of these adults as our therapies are not suitable"*

> *"This work should be commissioned for the Learning Disability team as they will have knowledge base & skills to work with people who have ASC."*

> *"I feel there is a need for adults on the Autistic spectrum to receive treatment but personally feel a new service should be provided and they should not be directed to an already overloaded mental health service"*

"LCT consultants will not see ASC adults as believed to fall under LD services - clarification about the expectations and skills needed to work with this client group would be welcomed."

"Being a sole therapist in a very busy mental health team, I feel I have enough work in my chosen profession. I was under the impression an Autism service was already in place to meet such clients needs."

The most frequently given responses suggested providing staff with training and increasing understanding of the condition to allow them to adapt materials and therapies. Some of the comments given were:

"More training given to staff so that adapted materials could be used."

"by training in how best to communicate with people who have ASC, and how to modify our treatment approach"

Additionally many respondents suggested providing a member of staff with knowledge of autism:

"Maybe someone with specialist knowledge would be able to inform other members of team"

"Maybe an allocated worker with an increased knowledge/awareness for advice"

One respondent detailed how difficult it can be for adults with ASC's to access any services:

I have recently attempted to purchase psychological therapies for a young man with ASD - mainstream MH psychology do not provide to people with ASD and he does not have a learning disability so his

needs cannot be met through LD psychology. Funding for the private service is on its 4th application to the PCT after 3 previous refusals. His Mental Health continues to deteriorate in the meantime. This group of people have been let down for too long and need specialist services specifically to meet their needs rather than trying to have them met through the existing mental health services.

Furthermore, a member of staff highlighted that improvements could be made *"by acknowledging Mental Illness & ASC can be co-morbid and not excluding individuals on the basis of diagnosis ".*

Hence, before deciding what changes need to be implemented in service provision, one of the first fundamental steps that needs to be taken to improve the lives of adults with ASC's is improving staff awareness across the Mental Health service, "If staff do not know about autism and how it affects behaviour and responses, then they can have no idea of how to adjust the way they deliver services, their approach to communication or their expectations. Where professionals do understand autism, however, the impact on services – and on the lives of adults with autism – is immense. " (DOH Autism Strategy, 2010)

An indication of how increased awareness of autism may impact on service provision can be seen when responses to the assessment are compared. Those staff members that had some understanding of ASC's were less likely to think of Autism as a learning disability (a common misconception) and were less likely to perceive current service provisions as adequate for ASC adults. Also, those with some understanding of the condition were 25 times more likely to be aware of service users who are on the autism spectrum.

Recommendations

As assessment data indicates that a large majority of staff have minimal understanding of ASC's, recommendations are made to provide basic autism awareness training to all mental health staff members who have not already received such training. This would provide a necessary first step towards improving service provision in East Lancashire; enable Mental Health professionals to identify service users who are on the autism spectrum, and give a base point from which staff can then judge whether they require further specific training within their job role.

Feedback from staff who had received previous training indicated that although the sessions had been useful, they were brief, half or one-day sessions *"barely touching on the basics"*, available from agencies outside of the Primary Care Trust without any post training monitoring or review. Furthermore, 70% of those who had received basic awareness training felt they needed further training more specific to their job role.

Additionally 'there appears to be agreement on the general importance of special training and skills for working with people with autism' (Parker Jones & Wheatcroft, 2006) and good practice guidelines published by the NAS recommend a 2 tiered system with a 'whole system' approach to awareness sessions, available at 'different times on different days to ensure all staff can make one of the training events' (Powell, 2002).

Hence, in line with feedback from East Lancashire Mental Health staff; DoH recommendations (2006) that 'key decisions should be made together with community-based professionals who are closest to individual users and patients; and NAS guidelines for implementing a training programme; it is recommended that a structured, reliable programme of basic autism awareness training which can be monitored is implemented; with further job specific training made available focusing on specific issues for those staff who feel they require it. This could be provided as a 2 tiered system with autism awareness sessions made

available to all staff in contact with adults who have ASC's and require a basic understanding of the conditions (DoH 2006, APPGA 2002, Powell, 2002); and allowing those who require further training within their role to progress to more specific topic areas.

In order to ensure the reliability and effectiveness of any training, monitoring of outcomes is essential. This programme of awareness training would therefore require a training co-ordinator, either within or outside of the Primary Care trust who can process feedback relating to the sessions and ensure that training remains up to date and is adjusted in line with any necessary recommendations made; and also facilitate 2nd tier job training for those who require it. Also it would be useful as staff have indicated, to have follow-up specialist support available which staff can access should they require advice.

Further guidance in terms of implementing Job Specific Autism training is detailed by Parker, Jones & Wheatcroft (2008).

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Appendices

1 (a) Questionnaire – Online Version

(b) Questionnaire – Printed Version

(c) Information Sheet

2 Copy of e-mail

Appendix 1 – Questionnaires and Information Sheet

1 (a) Questionnaire – Online Version

(b) Questionnaire – Printed Version

(c) Information Sheet

Asperger Syndrome Training Needs Audit

Training Needs Questionnaire – Online version

Name

Staff Number

Gender

Age

Instructions

The questionnaire is in two parts.

Part one requires written responses. Please read each question carefully and provide a response where possible (type in grey shaded areas). Please try to
provide as much information as you can here, in this section it is not imperative that you answer all questions, just those that you feel able to.

For part two please read each statement carefully and indicate
your response by ticking one box (click on the relevant box and a cross will appear). Please ensure that you have completed all questions in this section.

By completing this questionnaire you consent to the answers being used for training assessment purposes as outlined in the information sheet given. This assessment is being conducted by Action for ASD for and on behalf of East Lancashire Primary Care Trust. Please return completed questionnaires to Emma Dunn at Action for ASD before 23rd December 2009. Online version by email to emma@actionasd.org.uk; printed version by post to Emma Dunn, Action for ASD, Suite 7 Kings Mill, Queen Street, Harle Syke, Burnley, BB10 2HX.

Assessment Questionnaire – Part 1

1. **What team do you work for?**

2. **Where are you based (location/building)?**

3. **What is your job role?**

4. **Is your position permanent or temporary?**

5. **What type of services does your team provide (please give a brief outline, i.e. assessment, direct support work)?**

6. **Approximately how many service users access your service each month?**

7. **Briefly outline what you understand an Autism Spectrum Condition (ASC) to be (if you have no understanding at all or very little please indicate this).**

8. **If known, approximately how many of your service users are considered to be on the autism spectrum? (This can include Autism, Asperger Syndrome or even without an official diagnosis)**

Assessment Questionnaire – Part 1

9. Does your team currently provide any specialist services for adults with ASC's?

10. Do you think services within your team could be improved for adults on the spectrum (if so, how)?

11. What type of training is available to you that would help your work with adults on the autism spectrum (please outline the topics, if none please state)?

12. Is any ASC specific training provided? (If yes, answer question 13-16, if no go to question 17)

13. Who delivers the ASC specific training?

14. Which staff is this training delivered to? (permanent, temporary, certain teams, job roles)

15. When is this training received? (I.e. as part of induction, as on the job training, upon request)

16. How is competency monitored following training?

Assessment Questionnaire – Part 1

17. **Have you personally received any autism specific training, either through work or individually? (If yes, please give brief details of who provided the training, the length of the course and what it covered & answer question 18. If no go to question 19)**

18. *After having received some training in Autism, do you feel there are any specific areas you would need further training in to feel confident working with ASC service users(If yes, please give details, i.e. Sensory issues, communication)?*

19. **Is there anything else that would help you individually to feel more confident working with service users with ASC's (If yes, please give details)?**

20. **Is anyone within your team qualified to provide specialist input to service users with ASC's?**

21. **Any other comments?**

Assessment Questionnaire – Part 1

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I understand what autism spectrum conditions are	☐	☐	☐	☐	☐
I have sufficient understanding of autism spectrum conditions to do my job	☐	☐	☐	☐	☐
I feel I would benefit from autism awareness training	☐	☐	☐	☐	☐
Our team are able to support individual's disabilities, specific training is not really necessary	☐	☐	☐	☐	☐
A specialist service for adults with autism would be more appropriate	☐	☐	☐	☐	☐
Autism is a Mental Health Condition	☐	☐	☐	☐	☐
Providing all staff with autism awareness training will allow the team to provide a better service	☐	☐	☐	☐	☐
This service is an appropriate place for adults on the autism spectrum to access support	☐	☐	☐	☐	☐
Current service provisions are adequate for adults on the spectrum	☐	☐	☐	☐	☐
Autism is a Learning Disability	☐	☐	☐	☐	☐
Autism awareness training is not necessary for our team	☐	☐	☐	☐	☐
Training one individual within a team to specialise in autism is more appropriate than awareness training for all	☐	☐	☐	☐	☐

Asperger Syndrome Training Needs Audit

Training Needs Questionnaire – Printable version

Name_____

Staff Number_____

Gender_____

Age_____

Instructions

The questionnaire is in two parts.

Part one requires written responses. Please read each question carefully and provide a response where possible. Please try to provide as much information as you can here, in this section it is not imperative that you answer all questions, just those that you feel able to. Please provide as much information as you can, if necessary you may also attach additional sheets.

For part two please read each statement carefully and indicate your response by ticking one box. Please ensure that you have completed all questions in this section.

By completing this questionnaire you consent to the answers being used for training assessment purposes as outlined in the information sheet given. This assessment is being conducted by Action for ASD for and on behalf of East Lancashire Primary Care Trust. Please return completed questionnaires to Emma Dunn at Action for ASD before 23rd December 2009. Online version by email to emma@actionasd.org.uk; printed version by post to Emma Dunn, Action for ASD, Suite 7 Kings Mill, Queen Street, Harle Syke, Burnley, BB10 2HX.

Assessment Questionnaire – Part 1

22. What team do you work for?

_____

_____

23. Where are you based (location/building)?

_____

_____

24. What is your job role?

_____

_____

25. Is your position permanent or temporary?

_____

_____

26. What type of services does your team provide (please give a brief outline, i.e. assessment, direct support work)?

_____

_____

_____

_____

27. Approximately how many service users access your service each month?

_____

_____

28. Briefly outline what you understand an Autism Spectrum Condition (ASC) to be (if you have no understanding at all or very little please indicate this).

_____

_____

_____

_____

_____

_____

29. If known, approximately how many of your service users are considered to be on the autism spectrum? (This can include Autism, Asperger Syndrome or even without an official diagnosis)

_____

_____

30. Does your team currently provide any specialist services for adults with ASC's?

_____

_____

_____

31. Do you think services within your team could be improved for adults on the spectrum (if so, how)?

_____

_____

_____

_____

_____

32. What type of training is available to you that would help your work with adults on the autism spectrum (please outline the topics, if none please state)?

_____

_____

_____

_____

33. Is any ASC specific training provided? (If yes, answer question 13-16, if no go to question 17)

_____

34. Who delivers the ASC specific training?

_____

_____

_____

35. Which staff is this training delivered to? (permanent, temporary, certain teams, job roles)

_____

_____

_____

_____

36. When is this training received? (I.e. as part of induction, as on the job training, upon request)

_____

_____

_____

_____

37. How is competency monitored following training?

_____
_____
_____
_____

38. Have you personally received any autism specific training, either through work or individually? (If yes, please give brief details of who provided the training, the length of the course and what it covered, then answer question 18. If no, go to question 19.)

_____
_____
_____
_____

39. After having received some training in Autism, do you feel there are any specific areas you would need further training in to feel confident working with ASC service users(If yes, please give details, i.e. Sensory issues, communication)?

_____
_____
_____
_____

40. Is there anything else that would help you individually to feel more confident working with service users with ASC's (If yes, please give details)?

_____
_____
_____
_____

41. Is anyone within your team qualified to provide specialist input to ASC clients?

_____

_____

_____

_____

42. Any other comments?

_____

_____

_____

_____

_____

_____

_____

_____

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I understand what autism spectrum conditions are	☐	☐	☐	☐	☐
I have sufficient understanding of autism spectrum conditions to do my job	☐	☐	☐	☐	☐
I feel I would benefit from autism awareness training	☐	☐	☐	☐	☐
Our team are able to support individual's disabilities, specific training is not really necessary	☐	☐	☐	☐	☐
A specialist service for adults with autism would be more appropriate	☐	☐	☐	☐	☐
Autism is a Mental Health Condition	☐	☐	☐	☐	☐
Providing all staff with autism awareness training will allow the team to provide a better service	☐	☐	☐	☐	☐
This service is an appropriate place for adults on the autism spectrum to access support	☐	☐	☐	☐	☐
Current service provisions are adequate for adults on the spectrum	☐	☐	☐	☐	☐
Autism is a Learning Disability	☐	☐	☐	☐	☐
Autism awareness training is not necessary for our team	☐	☐	☐	☐	☐
Training one individual within a team to specialise in autism is more appropriate than awareness training for all	☐	☐	☐	☐	☐

Asperger Syndrome Training Audit Project

Participant Information Sheet

As part of a project looking at the needs of adults on the autism spectrum, Action for ASD are assessing what level of training in autism Mental Health staff within East Lancashire currently have; and what training staff feel they need to provide the most effective healthcare for service users on the autism spectrum. The aim of this audit is to identify current skill levels & understanding so that appropriate training can be sourced & implemented by the Primary Care Trust.

Why has my team been chosen?

Your role within the NHS trust sometimes involves working with people who are on the autism spectrum. Currently East Lancashire PCT and Action for ASD are identifying ways in which services provided for adults on the spectrum can be improved and one area being assessed is staff training requirements. By taking part you will be contributing to improving healthcare services in East Lancashire, benefiting both those who access the service and staff working within the trust.

What will happen to the results of the Training Needs Audit?

The results of this audit will be used to decide what training is required for staff in relation to autism and will aid in sourcing and implementing such training. To do this, answers to the questionnaire will be used to report on training requirements by the Research Officer from Action for ASD, by completing the questionnaire you consent to the answers being used and understand that you are free to withdraw from the audit at any time.

Will the information collected in the audit be confidential?

All information recorded during the audit will remain confidential and any reports produced will not include information that can be linked to or identify any particular individual.

Who is organising and funding the audit?

The audit is funded by East Lancashire PCT, and will be supervised by both the local Primary Care Trust and Action for ASD.

What will be required of me?

You will be asked to complete a questionnaire relating to understanding autism and training requirements. This will take approximately 5-10 minutes to fill in. Further to this audit you may then be offered training which is felt to be appropriate in light of the results of the overall staff audit findings.

Appendix 2 - Copy of e-mail

From: Emma Dunn

Sent: 09 December 2009 16:57

To: Team Managers

Cc: Project Supervisors

Subject: Staff training assessment

Attachments: Participant Information Sheet - Training assessment.doc; Assessment Questionnaire - Staff training audit (online version).doc; Assessment Questionnaire - Staff training audit (printable version).doc

Dear Team Manager,

As part of a service improvement project commissioned by East Lancashire PCT looking at the needs of adults with Asperger syndrome, Action for ASD have been asked to complete a staff training needs assessment looking at what training in Autism mental health staff have previously had, and what training is required.

This assessment is covering CMHT's, AOT's, Crisis Teams and the Early Intervention Service within LCFT as all of these teams work with adult service users within the East Lancashire area and come into contact with high functioning autistic adults. As part of the assessment, we require each member of your team (including yourself) to complete a training needs assessment questionnaire.

An information sheet which gives further details about the assessment is attached, along with a choice of two versions of the training needs questionnaire for your convenience:

- one for completing online, this can filled out, saved and returned to me by email at emma@actionasd.org.uk;
- one for printing and posting if you prefer, this can be sent to me at Emma Dunn, Research Officer, Action for ASD, Suite 7 Kings Mill, Queen Street, Harle Syke, Burnley, BB10 2HX.

Please can all staff members within your team complete one version of the questionnaire and return it to me before 23rd December 2009. Additionally, if you can let me know how many members of staff are in your team, and how you have distributed the questionnaires to them I would be very grateful; this will help with collecting the data together.

If you require any further information please do not hesitate to contact me. Also, if your team does not cover this area, or you are aware of another team who should also be included in this assessment (East Lancashire area only) please get in touch and let me know.

Kind Regards

Emma Dunn
Research Officer
Action for ASD
emma@actionasd.org.uk
www.actionasd.org.uk
01282 415455

Appendix B – Methodology

Procedure

A draft questionnaire was pilot tested and reviewed with a group of seven AS adult service users. The original questionnaire was subsequently edited and an updated questionnaire produced (see appendix C).

A publicised questionnaire was made available in variety of formats (online, email, paper, one to one chat) and focus groups were held as an alternative option.

An option was provided at the end of the questionnaire to 'tick' a box if the participant would like to take part further in interview/diary keeping (see appendix C).

A semi structured interview schedule was designed based on the research questions (see appendix C). A pilot interview was conducted and the schedule was modified as needed.

Interviews were recorded with Dictaphone and transcribed where possible. When this was not feasible, assistance with note taking was sought to account for interviewer note taking biases.

Quantitative data was processed using Microsoft excel and SPSS. Chi squared statistical testing was used to analyse the significance of responses received.

Qualitative data was coded using a 'theoretical', deductive thematic analysis driven by the commissioning body's research questions (Braun & Clarke, 2006). Discussion with service users and professionals, and analysis of previous work conducted locally highlighted four areas for consideration: pre-diagnosis; access to diagnosis; access to services and support needs. The thematic analysis was conducted with focus on these areas.

Appendix C – Paperwork Examples

i. Participant Information Sheet

ii. AS Adult Questionnaire

iii. Parent/Carer Questionnaire

iv. Consent Form

v. Interview Schedule

Adult Asperger Syndrome Access to Services

Participant Information Sheet

As part of a research project looking at how well East Lancashire Mental Health Services meet the needs of adults who are on the Autism Spectrum, Action for ASD are looking to establish what issues adults within East Lancashire have when trying to access Mental Health support services. By finding out from people with Asperger Syndrome what barriers they have when trying to access Mental Health services we will let East Lancashire PCT know how they could provide a better service.

Can I take part in the project?

If you are an adult, aged 18 years old or over on the Autism Spectrum (either with or without a diagnosis) or a parent/carer of an adult on the Autism Spectrum; and you live within the East Lancashire area then you can take part in the project.

Do I have to take part in the project?

It is completely up to you whether or not you decide to take part in this research. If you do decide to take part you can withdraw from taking part in the research at any time without giving a reason and ask the researcher not to use your responses.

Will the information collected in the assessment be confidential?

All of the information gathered during the assessment will remain completely confidential. Any reports that are written about this research will be anonymous; this means that they will not include any names, addresses, dates of birth or any other identifying information.

What will happen to the results of the research?

The results of this assessment will be used to decide what changes need to be made to healthcare services in East Lancashire so that a better service can be provided for adults with Asperger Syndrome.

By taking part in the project you agree that the answers and information you give about your experiences and views on Mental Health services can be used to provide feedback to East Lancashire primary care.

What are the possible benefits of taking part?

By taking part in this assessment you will be contributing to improving Mental Health services provided in East Lancashire, and benefiting both adults on the spectrum who need to access the services and staff working within the trust.

Who is organising and funding the assessment?

The assessment is funded by East Lancashire PCT, and will be supervised by both the local Primary Care Trust and Action for ASD.

What additional measures/activities will be required of me?

Should you agree to participate in the assessment then please complete a questionnaire relating to your experiences and views on Mental Health services in East Lancashire. Questionnaires that can be filled out online or downloaded can be found at www.actionasd.org.uk/adultresearch.html.

Further to this, if you would like to then you may then choose to participate further in the research project by taking part in an interview, or keeping a daily blog or diary of your experiences and feelings.

A Questionnaire about Mental Health Services for adults with an Autism Spectrum Condition* who live in East Lancashire

Instructions

This questionnaire is to provide feedback to East Lancashire Primary Care Trust about what experiences adults with Autism Spectrum Conditions have had when accessing Mental Health services.

The answers that you give on the questionnaire will be kept anonymous; all of the responses received will be used to write a report advising the Primary Care Trust about what kinds of difficulties adults have accessing services, and how mental health services can be improved when providing support for adults with Autism Spectrum Conditions. If you would like further information about this assessment before you decide whether to complete the questionnaire, please read the participant information sheet.

Please answer all questions that apply to you.

If you require assistance completing the questionnaire or would like to give feedback to the project but are not able to complete the questionnaire, please contact Emma by phone on 01282 415455 or by email at emma@actionasd.org.uk to organise an alternative method of feedback.

**Also known as Autism Spectrum Disorder, Autism Spectrum Condition is used here as this is preferred to the term Disorder. This can include Asperger Syndrome, High Functioning Autism, Pervasive Development Disorder Not Otherwise Specified, or suspected Autism without yet having a diagnosis.*

About You

What Village, Town or City do you live in?_____

What is your date of birth?_____

What is your gender? Male ☐ Female ☐ Other (please tell us) ☐
_____

Which of the following best describes your current work/education status? (Please tick all that apply to you)

☐ Full-time employment
☐ Part-time employment
☐ Voluntary Work
☐ Full-time education
☐ Part-time education
☐ Not in any employment or education
☐ Other (please state) _____

Which of the following social activities do you participate in? (Please tick all that apply to you)

☐ Go to the pub with family or friends
☐ Go to the cinema with family or friends
☐ Play sports (please tell which sports)_____
☐ Go to ASC group or social evening
☐ Go to non-specific group or social evening
☐ Online Forums
☐ Other (please state) _____

About your ASC Diagnosis

1. **How old were you when you got diagnosed?**

   _____

2. **From start to finish, how long did it take you to get a diagnosis?**

   _____

3. **Which of the following best describes your Autism diagnosis? (Please tick all that apply to you)**

   ☐ Autism
   ☐ High Functioning Autism
   ☐ Asperger Syndrome
   ☐ Not yet diagnosed
   ☐ Other (please state) _____

4. **Do you also have a diagnosis of a mental health condition or a specific learning difficulty?**

   ☐ Yes
   ☐ No

   If yes, please tick all that apply to you

   ☐ ADHD
   ☐ Dyslexia
   ☐ Dyscalculia
   ☐ Anxiety
   ☐ Depression
   ☐ Bi-polar
   ☐ Personality Disorder
   ☐ Other (please state)_____

About your ASC Diagnosis

All further questions about diagnosis mean your Autism Diagnosis

5. Did you receive your diagnosis through: (please tick one box)

☐ An NHS practitioner
☐ A private Practitioner
☐ Other (please tell us):_____

6. Where did you go to get your diagnosis? (please tick one box)

☐ In East Lancashire
☐ Outside of East Lancashire (please state which area):_____

7. Did you pay to get your diagnosis? (please tick one box)

☐ Yes
☐ No
(Optional) If yes, how much did it cost?:_____

8. If you tried to get a diagnosis as an adult was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

If you found it difficult or not possible, what were the difficulties?

_____
_____
_____
_____
_____
_____
_____

About your ASC Diagnosis

9. Why did you seek a diagnosis?

_____

_____

_____

_____

_____

10. Describe what you think your autism is, for example a disability, a difference, a set of unique skills?

_____

_____

_____

_____

_____

Access to Services

11. In the last 5 years have you tried to access any help or advice from a GP (General Practitioner) in relation to your autism? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

12. In the last 5 years have you asked for a referral to mental health services through your GP? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

Access to Services

13. In the last 5 years have you asked for a referral to mental health services through other services (such as social services)? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)
☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____

_____

_____

14. In the last 5 years have you tried to access any help or advice directly from mental health services? (Please tick one box)
☐ Yes
☐ No

If yes, was it: (please tick one box)
☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____

_____

_____

Access to Services

15. In the last 5 years have you tried to access help or advice from Learning Disability Services? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

16. In the last 5 years have you tried to access help or advice from any private service providers? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

Mental Health Services for Adults with Autism

17. What changes could be made to the way NHS services are provided for adults with autism?

_____

_____

_____

_____

18. How would you like mental health services to provide services for autistic adults (Please tick all that apply)?

- ☐ I like how they provide services now
- ☐ Provide autism awareness training for all staff
- ☐ Each department to have a skilled, experienced member of staff, trained to support those on the autistic spectrum
- ☐ Have an Autism Specific Mental Health Service
- ☐ Have representation of needs by people with ASC's within mental health services
- ☐ Other (please state) _____

19. If there are any additional comments you would like to add about mental health services please do so below

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Support and Help that you need

20. What help or support do you receive from the NHS for your autism (this can be by you visiting the hospital or people visiting you at home)?

_____

_____

_____

_____

21. What help or support do you receive from Social Services for your autism (this can be by you visiting the hospital or people visiting you at home)?

_____

_____

_____

_____

22. Do you receive help or support from the NHS for any other issues? If so, please give brief details?

_____

_____

_____

_____

23. Is there any form of support or help that you need from the NHS that you're not getting (if yes please state what type of support or help you need)?

_____

_____

_____

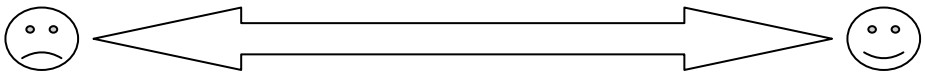
_____

_____

_____

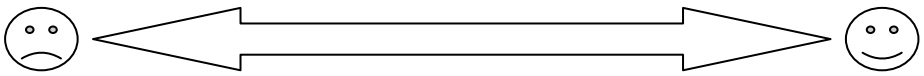
Your Opinions

Please read each of the following statements and indicate whether you Strongly Disagree, Disagree, are Neutral, Agree, Strongly Agree in the boxes next to the statement.



	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Mental Health Services in East Lancashire are accessible for adults with Asperger Syndrome	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
It is easy to get referred for an ASC diagnosis in East Lancashire	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Mental Health staff in East Lancashire understand ASC's	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Current Mental Health Service provisions in East Lancashire are adequate for adults on the spectrum	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
All staff within mental health Services should receive autism awareness training	☐	☐	☐	☐	☐

Your Opinions

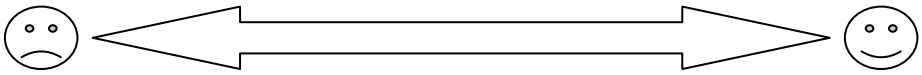


	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Training all staff within current services is the best way to improve services for adults with autism	☐	☐	☐	☐	☐

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Having one individual in each Mental Health Team who is skilled and experienced in Autism is the best way to improve services for adults with autism	☐	☐	☐	☐	☐

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Providing specialist service for adults with autism to be referred to is the best way to improve services for adults with autism	☐	☐	☐	☐	☐

Your Opinions



	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have an understanding of Autism Spectrum Conditions	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Autism is a mental health condition	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Autism is a learning disability	☐	☐	☐	☐	☐

In addition to the questionnaire, further more in-depth feedback will be collected from May 2010 via methods such interviews, diary keeping and blogs, if you would like to be involved in giving further feedback please tick the box and provide contact details below:

☐ Yes, I would like to be involved in giving further feedback

Name_____
(Giving your name is optional but useful for when we contact you)

Email or phone number_____

Thank you very much for completing the questionnaire. If you have filled out the online version please now click to submit your response. If you have downloaded a word document please save a copy and email it to me at emma@actionasd.org.uk. If you have printed off the questionnaire and filled it out by hand please post it to me at Emma Dunn, Action for ASD, Suite 7 Kings Mill, Queen Street, Burnley, BB10 2HX.

Submit

A Questionnaire about Mental Health Services for Parents/Carers of an Adult with an Autism Spectrum Condition* who live in East Lancashire

Instructions

This questionnaire is to provide feedback to East Lancashire Primary Care Trust about what experiences adults with Autism Spectrum Conditions have had when accessing Mental Health services.

The answers that you give on the questionnaire will be kept anonymous; all of the responses received will be used to write a report advising the Primary Care Trust about what kinds of difficulties adults have accessing services, and how mental health services can be improved when providing support for adults with Autism Spectrum Conditions. If you would like further information about this assessment before you decide whether to complete the questionnaire, please read the participant information sheet.

Please answer all questions that apply to you.

If you require assistance completing the questionnaire or would like to give feedback to the project but are not able to complete the questionnaire, please contact Emma by phone on 01282 415455 or by email at emma@actionasd.org.uk to organise an alternative method of feedback.

**Also known as Autism Spectrum Disorder, Autism Spectrum Condition is used here as this is preferred to the term Disorder. This can include Asperger Syndrome, High Functioning Autism, Pervasive Development Disorder Not Otherwise Specified, or suspected Autism without yet having a diagnosis.*

About You

What Village, Town or City do you live in?_____

What is your date of birth?_____

What is your gender? Male ☐ Female ☐ Other (please tell us) ☐

_____

Which of the following best describes your current work/education status? (Please tick all that apply to you)

☐ Full-time employment
☐ Part-time employment
☐ Voluntary Work
☐ Full-time education
☐ Part-time education
☐ Not in any employment or education
☐ Other (please state) _____

Which of the following social activities do you participate in? (Please tick all that apply to you)

☐ Go to the pub with family or friends
☐ Go to the cinema with family or friends
☐ Play sports (please tell which sports)_____
☐ Go to parent/carers group or social evening
☐ Go to non-specific support group or social evening
☐ Online Forums
☐ Other (please state) _____

Do you feel that being a carer restricts your ability to participate in social activities?

☐ Yes
☐ No

About the person you care for

1. **How many Adults with an ASC do you care for?**

   _____

2. **What is your relationship to the person/people that you care for?**

   _____

3. **How long have you been providing care for them?**

   _____

4. **How many hours each week do you usually provide care for them?**

   _____

5. **Where does the person/people you care for live? (please tick all that apply)**

   ☐ With you
   ☐ In their own home
   ☐ In supported living
   ☐ In full residential Care
   ☐ Other (please state)_____

6. **If known, how old was the person you care for when they got an ASC diagnosis?**

   _____

7. **Were you involved in the process of trying to get a diagnosis for the person you care for?**

   ☐ Yes
   ☐ No

   If yes, from start to finish how long did it take for them to get an ASC diagnosis?

   _____

About the person you care for

8. Which of the following best describes the ASC diagnosis of the person/people you care for? (Please tick all that apply to them)

☐ Autism
☐ High Functioning Autism
☐ Asperger Syndrome
☐ Not yet diagnosed
☐ Other (please state) _____

9. Do they also have a diagnosis of a mental health condition or a specific learning difficulty?

☐ Yes
☐ No

If yes, please tick all that apply to them

☐ ADHD
☐ Dyslexia
☐ Dyscalculia
☐ Anxiety
☐ Depression
☐ Bi-polar
☐ Personality Disorder
☐ Other (please state)_____

All further questions about diagnosis refer to their ASC Diagnosis

10. Did they receive a diagnosis through: (please tick one box)

☐ An NHS practitioner
☐ A private Practitioner
☐ Other (please tell us):_____

About the person you care for

11. Where did they go to get a diagnosis? (please tick one box)

☐ In East Lancashire
☐ Outside of East Lancashire (please state which area):_____

12. Was it necessary to pay to get the diagnosis? (please tick one box)

☐ Yes
☐ No
(Optional) If yes, how much did it cost?:_____

13. If the person you care for tried to get an ASC diagnosis as an adult was the process: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

If it was difficult or not possible, what were the difficulties?

_____
_____
_____
_____
_____

14. Who takes responsibility for trying to access any services for the person with ASC?

☐ You
☐ The person with the ASC
☐ Other (please tell us):_____

If you have been involved in accessing services please answer the Access to Services Section, otherwise skip to question 21 about Mental Health Services for Adults with ASC's

Access to Services

15. In the last 5 years have you tried to access any help or advice from a GP (General Practitioner) in relation to the person you care for and their ASC? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

16. In the last 5 years have you asked for a referral to mental health services for the person you care for through your GP? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

Access to Services

17. In the last 5 years have you asked for a referral to mental health services for the person you care for through other services (such as social services)? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)
☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____

_____

_____

18. In the last 5 years have you tried to access any help or advice directly from mental health services for the person you care for? (Please tick one box)
☐ Yes
☐ No

If yes, was it: (please tick one box)
☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____

_____

_____

Access to Services

19. In the last 5 years have you tried to access help or advice from Learning Disability Services for the person you care for? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

20. In the last 5 years have you tried to access help or advice from any private service providers for the person you care for? (please tick one box)

☐ Yes
☐ No

If yes, was it: (please tick one box)

☐ Easy
☐ Difficult
☐ Not possible
☐ Other (Please state)_____

What were the good or bad points about the experience?

_____
_____
_____

Mental Health Services for Adults with Autism

21. What changes could be made to the way NHS services are provided for adults with autism?

_____

_____

_____

_____

22. How would you like mental health services to provide services for autistic adults (Please tick all that apply)?

- ☐ I like how they provide services now
- ☐ Provide autism awareness training for all staff
- ☐ Each department to have a skilled, experienced member of staff, trained to support those on the autistic spectrum
- ☐ Have an Autism Specific Mental Health Service
- ☐ Have representation of needs by people with ASC's within mental health services
- ☐ Other (please state) _____

23. If there are any additional comments you would like to add about mental health services please do so below

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Support and Help that you need

24. What help or support do you and/or the person you care for receive from the NHS relating to their ASC (this can be by you visiting the hospital or people visiting you at home)?

_____

_____

_____

_____

25. What help or support do you and/or the person you care for receive from Social Services relating to their ASC (this can be by you visiting the hospital or people visiting you at home)?

_____

_____

_____

_____

26. Do you or the person you care for receive help or support from the NHS for any other issues? If so, please give brief details?

_____

_____

_____

_____

27. Is there any form of support or help that you or the person you care for need from the NHS that you're not getting (if yes please state what type of support or help you need)?

_____

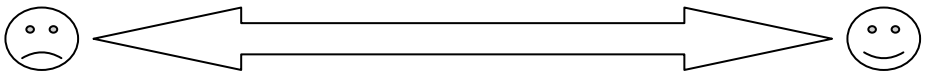
_____

_____

_____

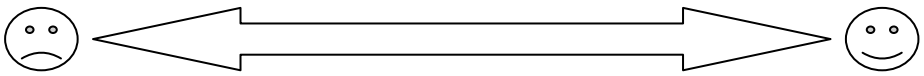
Your Opinions

Please read each of the following statements and indicate whether you Strongly Disagree, Disagree, are Neutral, Agree, Strongly Agree in the boxes next to the statement.



	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Mental Health Services in East Lancashire are accessible for adults with Asperger Syndrome	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
It is easy to get referred for an ASC diagnosis in East Lancashire	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Mental Health staff in East Lancashire understand ASC's	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Current Mental Health Service provisions in East Lancashire are adequate for adults on the spectrum	☐	☐	☐	☐	☐
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
All staff within mental health Services should receive autism awareness training	☐	☐	☐	☐	☐

Your Opinions

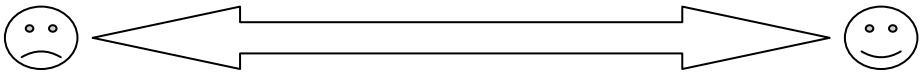


	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Training all staff within current services is the best way to improve services for adults with autism	☐	☐	☐	☐	☐

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Having one individual in each Mental Health Team who is skilled and experienced in Autism is the best way to improve services for adults with autism	☐	☐	☐	☐	☐

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Providing specialist service for adults with autism to be referred to is the best way to improve services for adults with autism	☐	☐	☐	☐	☐

Your Opinions



	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I understand what Autism Spectrum Conditions are	☐	☐	☐	☐	☐
Autism is a mental health condition	☐	☐	☐	☐	☐
Autism is a learning disability	☐	☐	☐	☐	☐

In addition to the questionnaire, further more in-depth feedback will be collected from May 2010 via methods such interviews, diary keeping and blogs, if you would like to be involved in giving further feedback please tick the box and provide contact details below:

☐ Yes, I would like to be involved in giving further feedback

Name_____
(Giving your name is optional but useful for when we contact you)

Email or phone number_____

Thank you very much for completing the questionnaire. If you have filled out the online version please now click to submit your response. If you have downloaded a word document please save a copy and email it to me at emma@actionasd.org.uk. If you have printed off the questionnaire and filled it out by hand please post it to me at Emma Dunn, Action for ASD, Suite 7 Kings Mill, Queen Street, Burnley, BB10 2HX.

Submit

Adult Asperger Syndrome Access to Services

Consent Form

Please read the statements below carefully and sign where indicated to confirm that you understand and consent to take part in this assessment.

1. I understand that my participation is voluntary and that I am free to withdraw at any time.
2. I understand that the Research Officer will record information about my views and experiences.
3. I understand that information I provide will be used in combination with the views of other people who take part in the project to provide a report to East Lancashire Primary Care Trust.
4. I agree to take part in the Adult Asperger Syndrome Access to Services project.

_____	_____	_____
Signature	Name (Printed)	Date

Brief before interview:

Outline that interview being conducted further to questionnaire they completed (if this is the case), who I am, that co-worker/tape is there to assist me in taking notes & making sure that I am conducting the interview objectively.

Explain confidentiality - that the persons information will be kept securely and confidential. However within our roles and responsibilities there are limits on confidentiality in the following specific circumstances.

1 if the person says something that leads us to believe they may harm themselves

2 if the person tells us something which leads us to believe they will harm someone else

3 if the person tells us anything which makes us suspect a child may be harmed.

Explain approximately how long expect the interview to take, but that this may vary depending on how much information they would like to give. If at any point don't understand or would like to stop/withdraw please say and can take their time in thinking and talking.

Also explain that I am interested in them and their experiences, there are no right or wrong answers; and that some questions may seem self evident but this is to get a full understanding of their experience and understanding.

Ask what would like me to do if they get upset? Can stop & have a break, who to contact if distressed... what are plans after the interview?

Ask to sign interview participation sheet.

Recap briefly info given in questionnaire (diagnosis they have, what age when got it, why wanted a diagnosis and support currently getting and need).

<u>Interview Schedule Questions – Speak slowly, clearly and allow time to phrase questions well. The interview does not have to follow the sequence on schedule, nor does every question have to be asked, or asked in the same way.</u>

<u>**give participant time, don't jump in too quickly and allow them to get used to talking.</u>

<u>** know that the participant is the expert on their experience, and so in some instances the interview may move completely away from the schedule & follow a course set by the participant.</u>

Pre-Diagnosis (for both diagnosed & seeking)

1. Starting from the very beginning, can you explain what first made you consider that you/the person you care for might be autistic?

   *Was this something you read/heard about yourself; was the possibility suggested by a professional?

2. Did you visit a GP for support/advice before you had considered trying to access an autism diagnosis?

*explore experiences with professionals (e.g. what happened, how was the experience?)

3. Did you visit any other mental health professionals for support/advice before you had considered trying to access an autism diagnosis?

   *explore experiences with professionals (e.g. what happened, how was the experience, do you feel they understood, which professionals were they, nhs/private?, would this put you off accessing mh services in future?)

4. Have you/they ever been diagnosed with any other disorders and/or given medication?

   *Were you provided with any support? & do you understand what the disorder is? Was this explained to you? Would this put you off accessing mh services in the future?

Diagnosis (diagnosed only)

*Mention that further to the questionnaire would like to explore a little further the process of how accessed a diagnosis.

5. How did you initially begin the process of trying to access a diagnosis?

   *Why did you pursue one?

6. Can you talk me through what happened (people you saw, how long it took, details of what happened along the way)?

   **Guide and prompt along the way with this to gather as much info as possible.

   **Perceived ease/difficulty of process

7. What kind of support or information did you receive throughout the process?

   **Guide and prompt along the way with this to gather as much info as possible.

   **Tell me about any difficulties you faced along the way?

   **Tell me about any positive experiences you had along the way?

8. What Impact has/would a diagnosis had/have?

Access to services

*mention support indicated they receive on questionnaire & check correct understanding.

9. Do you understand the difference between the learning disability service and the mental health service?

10. Find out about contact with different services (LD, MH & who have seen) & do they work differently, which structure is better?

11. Are you aware of what types of support are available from the different services and who is responsible for providing them?

12. Do you feel you are able to access the support that you need from the mental health service as it is currently?

    **if struggle to know what type of support need then maybe ask to detail/outline what would be a typical day now. And then if got the right support what a typical day would be then. Or draw a picture of how life is now, and how would be then?

13. If no, how come? What kinds of things stop you being able to use the service?

14. Where are the stumbling blocks? (Is it to do with different service provisions)

    Are people getting through to services at all, and if so how do they then perform?/What are the problems?

    ** Try to identify details of where system breaks down

15. What kinds of things could be done differently?

Support Needs

16. Can you describe a typical day for me? Provide some examples of the areas in which you would need support, and also the areas in which you would not.

17. Ideally, in a perfect world, how would the person you care for's/your life be?

18. Taking into considering what is realistically possible, what are the minimum practical support needs you/the person you care for would require to live comfortably day to day?

19. Is there anything else that you would like to add?

Debrief

Recap details of what will happen with info, right to withdraw & check how participant feeling emotionally. Advise that available to contact if have any questions.

Appendix D – Demographic data

Demographic Information

As can be seen in table 9, the AS adult responses were from a fairly even gender split sample of males and females (53% male, 47% female) and parent carer responses were primarily female (93%).

Geographically responses were received from 4 out of the 5 East Lancashire boroughs with most responses being in the Burnley, Pendle and Rossendale areas. No responses were received from the Ribble Valley area (see table 9).

69% of AS adult respondents and 93% of parent/carer respondents indicated that they or the person they care for have a diagnosis of either AS or HFA (see table 9).

Table 9: Questionnaire respondent demographics

N=33	AS Adult (N=19)		Parent/Carer (N=14)	
	Median/Frequency	%	Median/Frequency	%
Age				
Median	41		50	
Range	17-67		42-71	
Gender				
Male	10	53%	1	7%

Female	9	47%	13	93%
Unspecified				
Geographical Area				
Burnley	3	16%	7	50%
Pendle	8	42%	3	21%
Rossendale	3	16%	4	29%
Hyndburn	5	26%	0	0%
Ribble Valley	0	0%	0	0%
Not Specified				
Diagnosis Status				
AS	10	53%	8	57%
HFA	3	16%	5	36%
None or no answer	6	31%	1	7%

In addition to questionnaire responses 7 people participated in focus groups, 7 were interviewed and 2 kept diaries (see table 10).

Table 10: Focus Groups, Interviews and Diary keeping

	AS Adult	Parent/Carer
Focus Group	1	6
Interview	6	1
Diary	2	0

Of 19 AS adult respondents 3 were in employment (3 part-time, 0 full-time) and 3 were in voluntary work. 3 were in full-time education and the remaining 10 were not in any work/education, 1 of these commented that they had retired (see table 5).

Of 14 parent/carer respondents 7 were in employment, (2 part-time, 5 full time) and 2 were in voluntary work. None were in education and 5 were not in any work/education, 1 of these commented that they had retired (see table 11).

Table 11: Work/Education Status of Respondents

Work/Education	AS Adult	Parent/Carer
Not in Work/Education	7	2
Part Time Employed	3	2
Full Time Employed	0	5
Voluntary Work	3	2
Part Time Education	0	0
Full Time Education	3	0
Other	3	3

When asked what social activities they participated in, the most frequent responses were going to the pub or cinema with family or friends and going to a group/social evening (see table 12). Some respondents didn't participate in any social activities and only one accessed online forums. Of 5 respondents who chose 'other', 3 commented that they didn't ever or rarely participate in social activities (see table 6).

Table 12: Social activities

	AS Adult	Parent/Carer
None	3	3
Go to ASC specific Parent Carer group or Social Evening	7	3
Go to non-specific group or social evening	2	2
Go to pub with family or friends	8	6
Go to cinema with family or friends	7	4
Play sports	1	2
Online Forums	1	0
Other	4	1

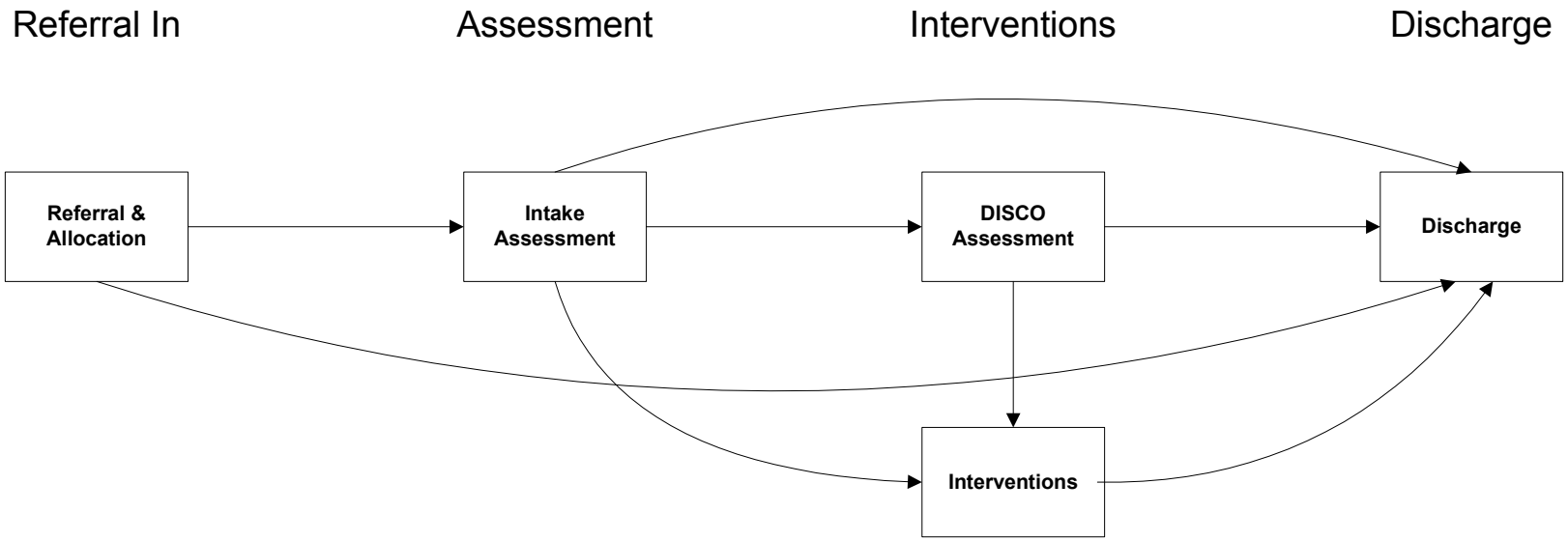
Additionally, parent/carers were asked whether they felt being a carer restricted their ability to participate in social activities. 10 out of 14 (71%) indicated that they feel restricted in this area.

Appendix E – Care Pathway Examples

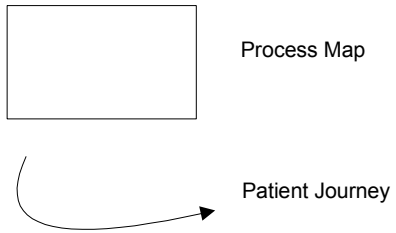
i. **Liverpool Pathways**

ii. **Bristol Pathway Proposal**

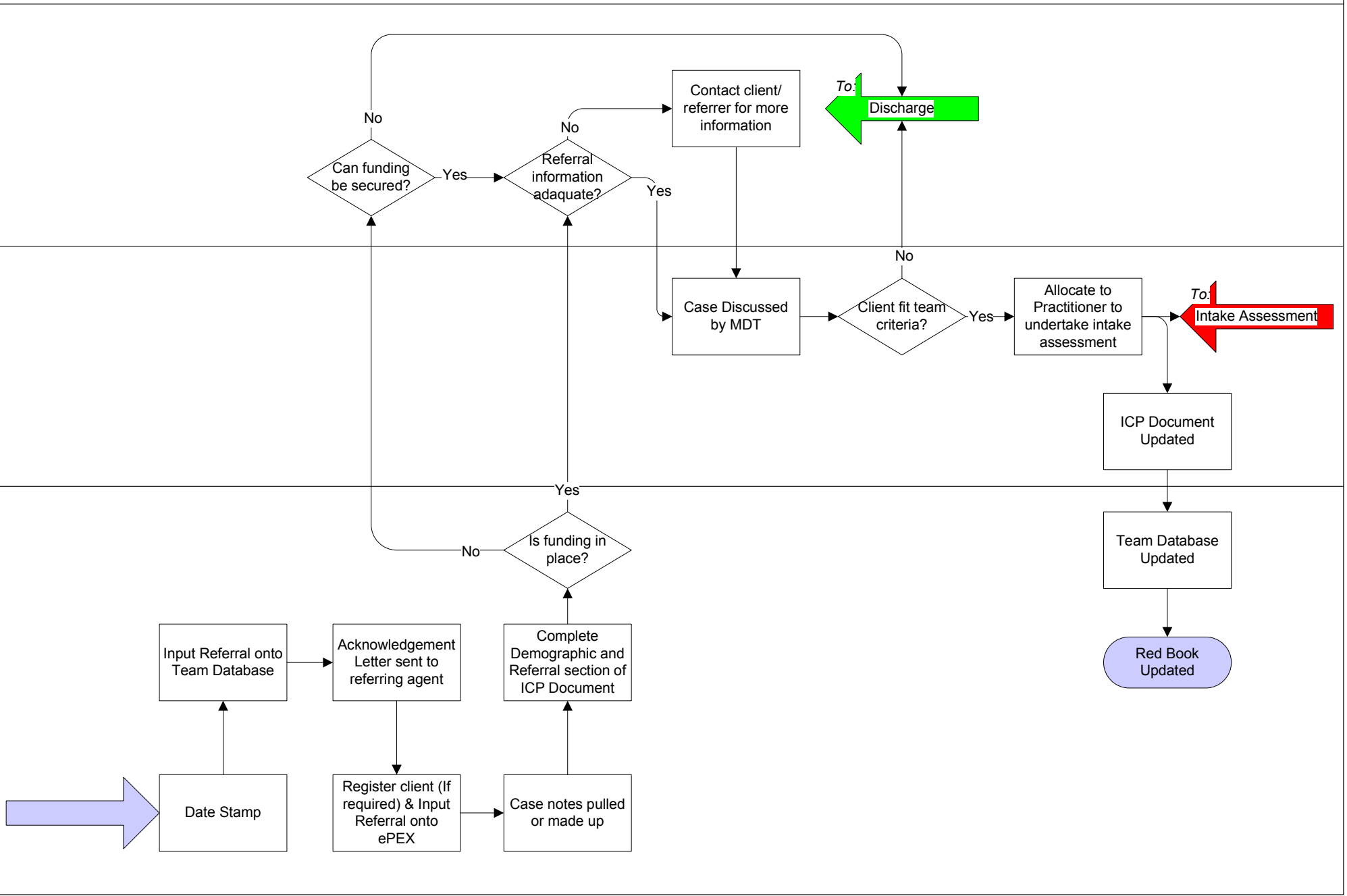
Mersey Care NHS Trust
Learning Disabilities Directorate – Asperger's Team
Future State - High Level Process Map



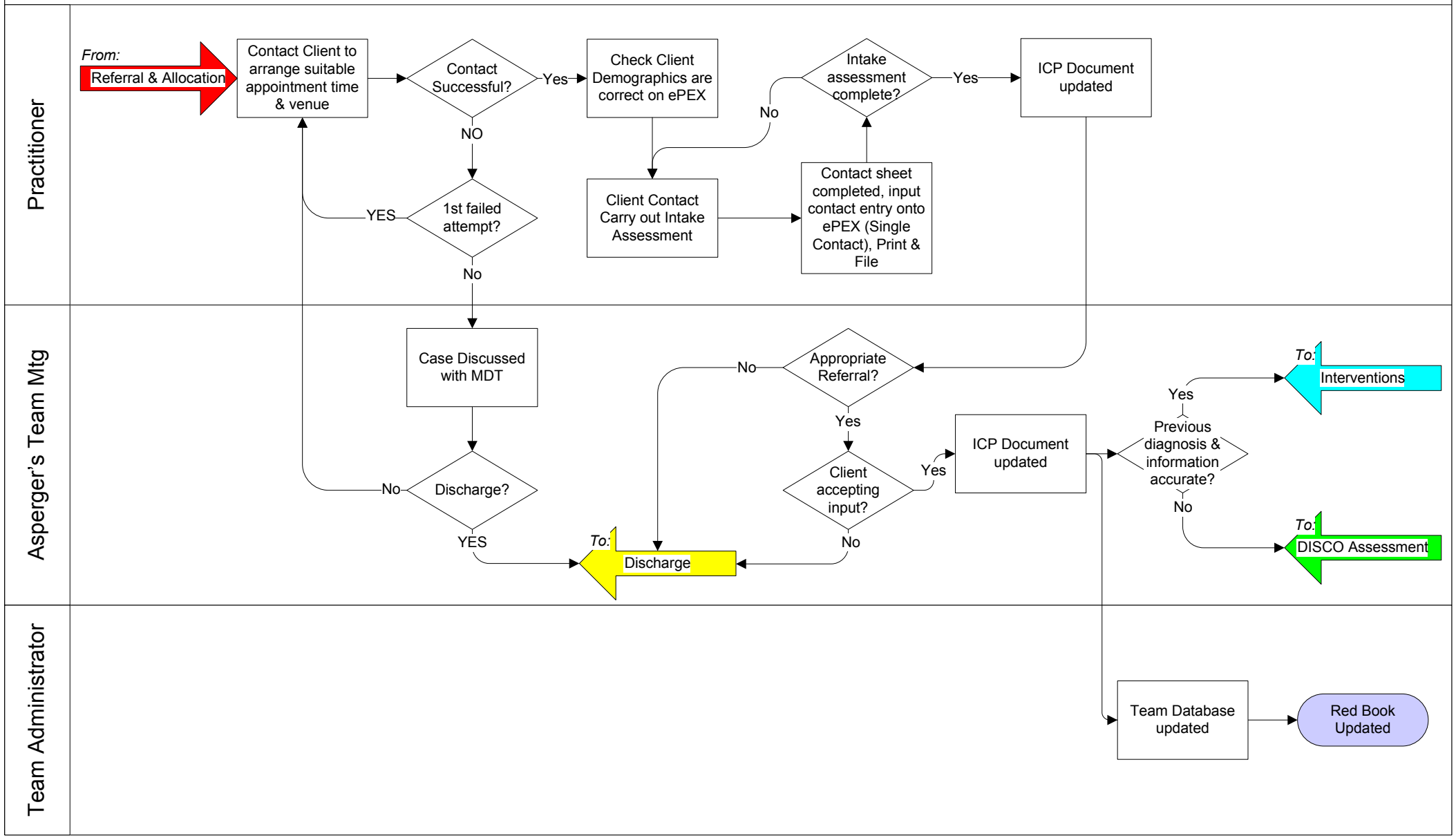
Legend



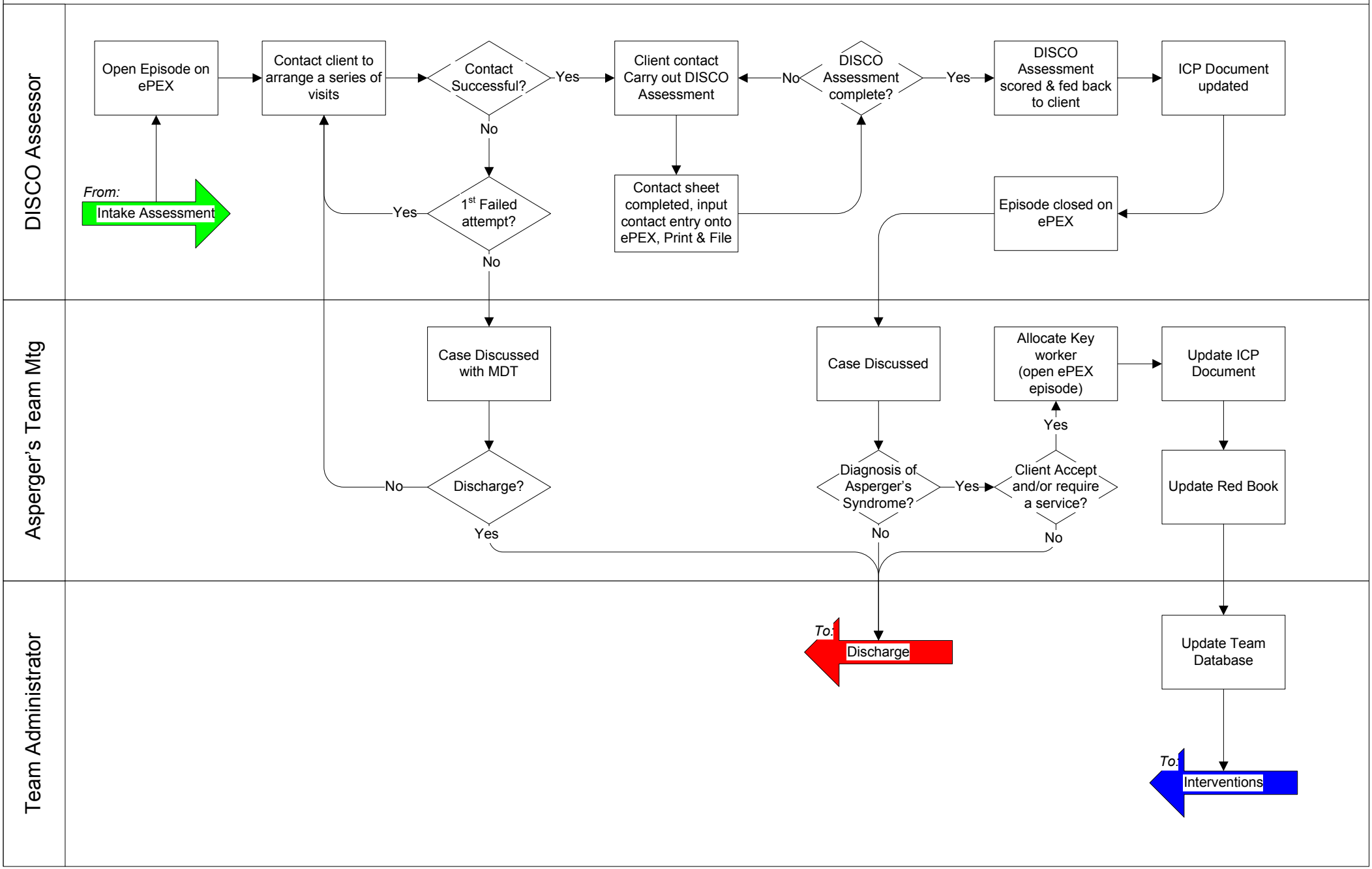
NCRS – LD – Asperger's Team – 'Future State' Referral and Allocation Process Map



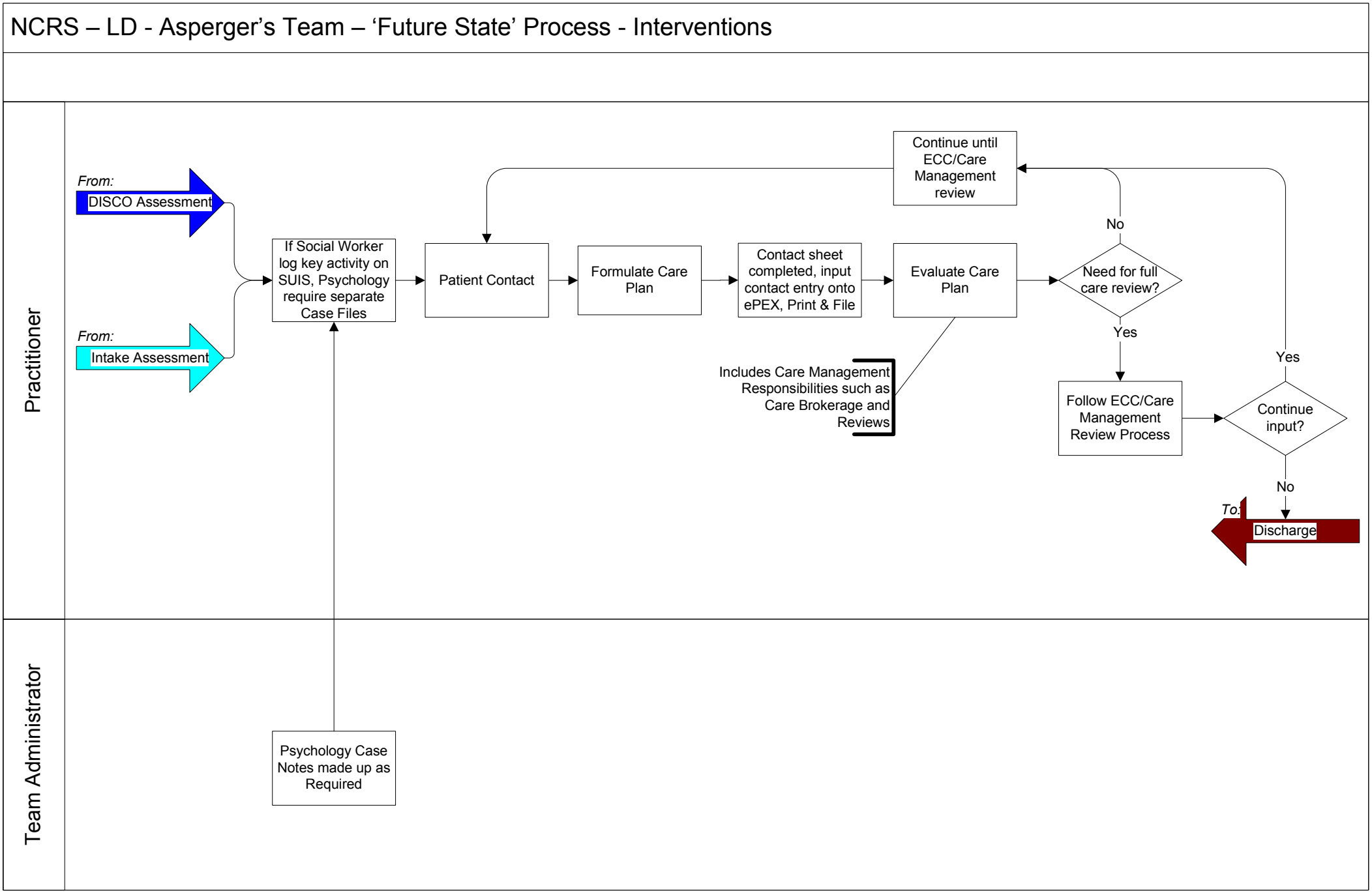
NCRS – LD - Asperger's Team – 'Future State' Process – Intake Assessment



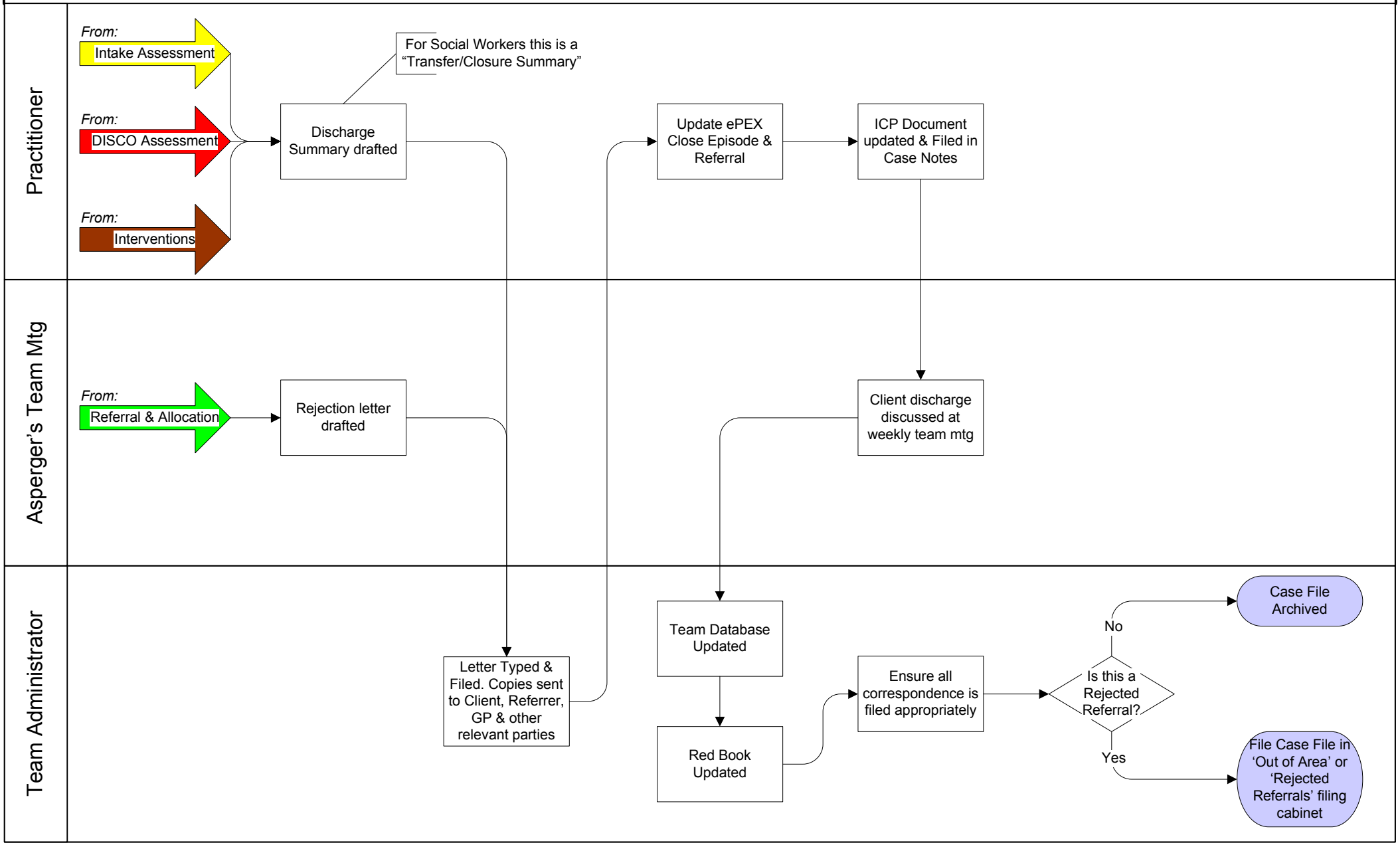
NCRS – LD - Asperger's Team – 'Future State' Process - DISCO Assessment



NCRS – LD - Asperger's Team – 'Future State' Process - Interventions



NCRS – LD - Asperger's Team – 'Future State' Process - Discharge



Mersey Care NHS
NHS Trust

MERSEY CARE NHS TRUST

LEARNING DISABILITY SERVICE

HIGH LEVEL SERVICE SPECIFICATION

Version Control

This copy - Version

Version	Author	Date	Meeting / comments from
1	Christine Austin	22/04/08	
2,3	Paul Skirrow	12/05/2008	

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Section 2 - Vision

Section 3 - Philosophy of Care

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Section 5 - Who is the Service for

Section 6 - Links to other providers

Section 7 - Care Pathways

Section 8 - High Level Service Specifications

Section 1: Introduction

"The Liverpool Asperger Team is one of the best known examples of autism good practice in England. It was established in 2003, following recommendations from a steering group regarding the need for an Asperger syndrome-specific multi-disciplinary team. Funded by the Central Liverpool Primary Care Trust and the local authority," (National Autistic Society, 2008).

Meeting the complexity of need for adults with Asperger syndrome requires a focused and tangible contribution from secondary care.

The service model means interventions and service provision will be relevant, timely and purposeful. This model describes the specific contribution and role of secondary care whilst recognising it is also part of a whole system approach to addressing need, whilst representing best value.

Conversely, high public expectations and increases in secondary care referrals mean Mersey Care NHS Trust needs to work in partnership to ensure all referrals are appropriate and early discharge schemes are in place if it is to meet challenging performance requirements.

The model is consistent with the rights-based strategy of the Trust and its strategic objectives: Across the country, Asperger syndrome as a discrete disorder has not been included in services or policy documents for Mental Health (such as NSF or updated Mental Health Act) nor Learning Disabilities (such as the 'Valuing People' White Paper; DoH 2001). For this reason, many people with Asperger syndrome are denied services in the UK, despite significant health and social needs. Liverpool is the first area in the UK where adults with Asperger syndrome can access support in line with their rights to assessment under the NHS and Community Care Act (1990) and their rights to 'effective remedy' under the European Convention of Human Rights. As a result, the team is cited as an example of best practice in reports from the Department of Health ('Better Services for People with an Autistic Spectrum Disorder'; 2006), Parliamentary briefing papers ('Autism', Parliamentary Office for Science & Technology; 2008) and publications by the National Autistic Society ('I Exist'; 2008).

Section 2: Vision

MISSION STATEMENT

The Liverpool Asperger Team is currently housed within the Learning Disabilities Directorate of Mersey Care NHS Trust, which exists to provide a specialist health service to men and women with learning disabilities and/or Asperger Syndrome, according to the four key principles of the Government White Paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (DoH, 2001). These key principles are: Rights, Independence, Choice and Inclusion. This is determined within a legislative, and policy framework (embracing Equality and Diversity) and available resources.

While the majority of individuals served by the team do not have (global) learning disabilities, the Liverpool Asperger Team works very much within the model of the Learning Disabilities Directorate. There is currently no single medication or psychological treatment that is recommended with individuals with Asperger syndrome, as with global learning disabilities and social interventions are often at the centre of the team's interventions (See Skirrow & Farrington, 2008).

As noted above, many individuals with Asperger syndrome have traditionally "fallen between the gaps" between mental health and learning disabilities services (e.g. National Autistic Society, 2001). The vision of the Liverpool Asperger team is to prevent this pattern from occurring for as many individuals in the Mersey region as possible, allowing individuals access to effective, person-centred support tailored to their needs.

In addition to this:

- The Liverpool Asperger Team provides a specialist service for people with Asperger syndrome, adopting a person centred approach, using creative and innovative interventions to assist the individual with the social and communication barriers that they may face in everyday life.

- It is expected that the team will be extended to develop an equitable service across the Mersey care footprint.

- The service can also develop to agree service level agreements with adjacent areas and to formalise the Consultancy and out of area service currently offered.

Royal College of Psychiatrists (2006) and the National Autistic Society (2008) recommend that *"commissioners should ensure that there is access to local, basic diagnostic expertise that would allow for the firm diagnosis of autistic spectrum disorders in clear cut cases. They should also ensure access to a second level of diagnostic expertise for those individuals where there is diagnostic uncertainty."* We feel strongly that the Liverpool Asperger Team fits within this vision for services.

Section 3: Philosophy of Care

The service model is for a Specialist Assessment and Treatment for adults with Asperger syndrome.

The Liverpool Asperger Team provide a clear diagnostic pathway for adults suspected to have Asperger syndrome. There is an open referral system with assessment and post-diagnostic support being offered. Various social groups have already been established, but, there is concern that some service users are still being excluded due to the limited availability of these groups.

The model supports the process by which people rebuild and further develop the important elements of their lives - purpose, social relationships, work, recreation and activities of the spirit.

It is the development of a valued role - a place to fit - within the community and within oneself.

It is not a “cure”. It is a process of adjusting one’s attitudes, beliefs, directions, roles and visions in life, in order to establish a positive self-image that is hopeful, involved and self-guided.

Recovery as a treatment approach has certain characteristics:

- It focuses on strengths
- It treats people with respect
- It assumes that people can arrive at valid decisions and solutions
- In that regard, it trusts the resourcefulness of service users
- It develops trusting, equal relationships and partnerships
- It communicates respectfully
- It understands discrimination and stigma and their impact
- It acknowledges cultural differences and ways these differences may impact on the course and nature of recovery
- It develops and blends individual, family and cultural and spiritual perspectives in living
- It assumes hope and success

The Principles of the service model

i. Listening

The network of secondary care services will listen to service users and carers and address the key issues and needs that service users and carers raise and articulate.

ii. Collaboration

All parts of secondary care must talk with each other and collaborate both inside and outside the Trust.

iii. Problem Solving

Barriers to services will be removed and problem-solving approaches will be the norm.

iv. Known and Coherent resources

There is a central, comprehensive inventory of available resources both service and intellectual, which aids access and choice.

v. Communication

Service descriptions, entry criteria and estimated openings for each element of the service should be communicated to service users carers, families, referrers, advocates and staff.

vi. Stakeholder Involvement and Voice

All stakeholders - but especially service users - must be actively included, involved and incorporated in all possesses that shape their care and the delivery of services for now and the future.

vii. Creative Whole Systems Services

Rather than relying on average ‘off the peg’ methods, Mersey Care NHS Trust will be flexible and creative in their response to people and engage in multi sector approach to service provision and delivery, which emphasizes an integrated approach.

Section 4: Key concepts of the service

In delivering the above a number of key objectives are identified for the service:

i. The whole person rather than a single problem should become embedded in every stage of service delivery, from assessment and intervention to aftercare;

ii. Needs based assessment and intervention. Adopting a recovery approach means interventions and service provision will be relevant, timely and purposeful that is as close to home as possible.

iii. Ease and swiftness of access supported by clear and readily available information.

iv. Access to a comprehensive range of social and health assistance through a single shared assessment system and care management process (see roles of the team

v. Greater recognition of and support to the role of carers and caring.

vi. Less reliance on residential, nursing and acute hospital care and greater emphasis on maintaining individuals' community support services.

vii. A community focused model that promotes the development of greater opportunities to be supported within the community and which for most people will be within their own home.

viii. Care and treatment options will wherever possible continuity of care, minimising the number of changes to the place in which the person receives support.

ix. A socially inclusive model that supports the empowerment of people to use ordinary services and facilities, with the aim of retaining or regaining a place in local community life.

x. A model of care that actively supports principles of non-discriminatory practice and service delivery and which in particular avoids unnecessary and disruptive transitions across a range of sectors.

xi. Effective risk assessment and management arrangements that safely supports appropriate risk taking necessary to reduce reliance on institutional care and maximise access to home and community support and independence.

xii. Mental health/Physical health promotion and prioritisation that increases awareness, targets prevention, minimises the impact of severe mental/physical needs and provides easy access to useful and understandable information.

xiii. Empowerment of service users and carers to have greater influence over their care arrangements by identifying needs through active and supported by routine carer assessments and provision of good information on diagnosis, prognosis, treatment options. This based upon integrated working and partnership with other agencies.

xiv. Education that helps service users and carers adopt caring and coping strategies.

xv. Secondary service provision will reflect the level of resources and investments provided and represent the best value for money available.

xvi. Service delivery and practice will comply with the statutory framework.

The Multi-disciplinary team

The team comprises of a number of professionals working together to provide both diagnostic and treatment services for adults with Asperger syndrome. Individuals are assessed within the service and, following the diagnosis of Asperger syndrome (see Section 5: "who is the service for", below), the individual gains access to direct interventions from the multi-disciplinary team and the wider managed care network (see "Links to Other Providers" below). The structure and roles of the multidisciplinary team are shown in Figures 1 & 2 respectively. The current intake process is also outlined in Section 7: "Integrated Care Pathway for the Liverpool Asperger Team."

Figure 1: The Structure of the Liverpool Asperger Team

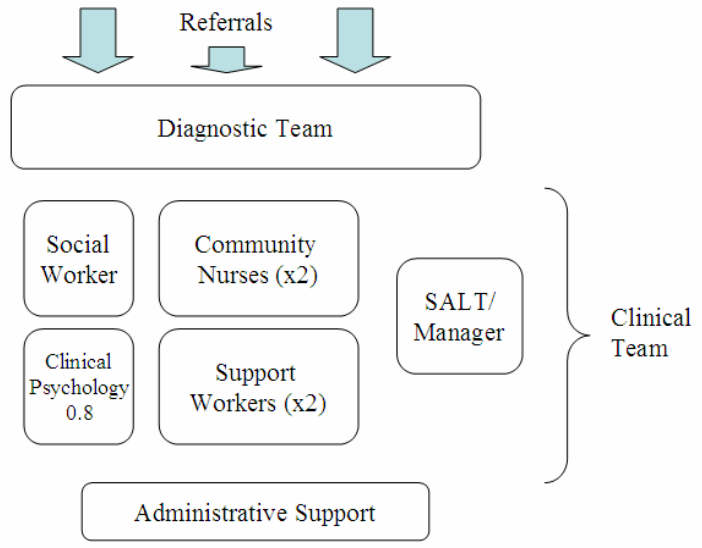
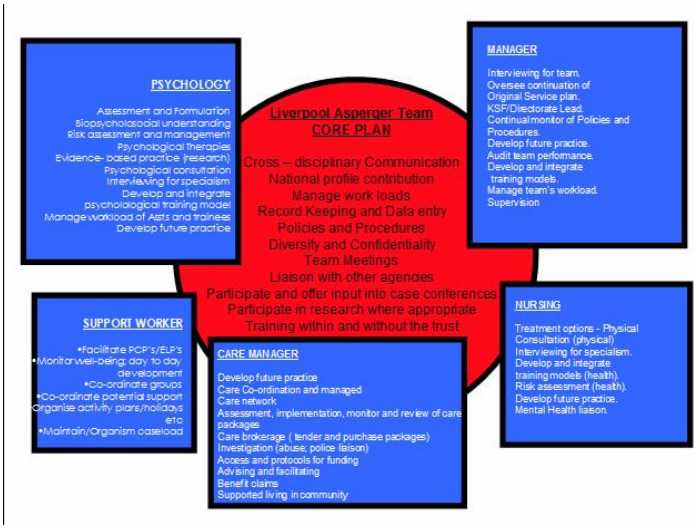


Figure 2: The Roles of the Multidisciplinary Team



Section 5: Who is the Service For?

- The service is for adults who have a diagnosis of Asperger syndrome, who reside in the Liverpool area.

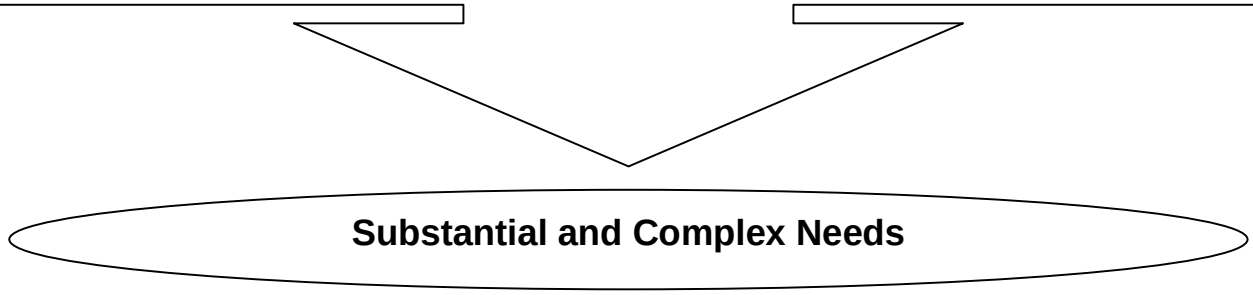
- The service operates an open referral system and offers diagnostic and clinical interventions.

- The team works with service users who may also receive a service from other services in Mersey Care. However, as noted above, the service is specifically designed for individuals who typically "fall between the gaps" of mental health and learning disabilities services (National Autistic Society, 2001).

- As noted above, there is no single treatment for Asperger syndrome and some individuals with a diagnosis of Asperger syndrome can function extremely well in society. For this reason, the service is designed to work with individuals who experience significant social disability (see Figure 3, below).

Figure 3: Social Disability – ***In addition to the clinical presentation, one or more of the following should be present:***

- Significant risk of self-harm, harm to others, risk of harm from others, or serious self-neglect.
- Substantial disability caused by illness, such as inability to self-care, care for dependents, or sustain relationships.
- Recurring crises leading to frequent admissions/interventions.
- Significant risk of homelessness, imprisonment, loss of work or supportive relationships.
- Family support or designated support agency unable to cope with behaviours



The above is not exhaustive. There will be situations which fall outside the scope of this and will require the exercise of clinical judgment.

Eligibility Criteria

To be eligible for the service from the Asperger team, an individual must be 18 years of age and resident in Liverpool, or be registered with a Liverpool GP.

Individuals aged 16-18 may be eligible for a service, dependant on individual need. In these situations, the team may work in association with children's Autistic Spectrum services.

Individuals must have a diagnosis of Asperger Syndrome according to Gillberg's (1991) or ICD-10 classification (See appendix for definitions).

The client group are typically outside the Learning disability client group and often are known to Adult Mental Health services.

WHAT IS ASPERGER SYNDROME?

Asperger syndrome is a developmental condition. It affects the way the brain processes information. This means that people with Asperger syndrome understand people and events in a very different way to others.

People with Asperger syndrome usually have average or above average levels of intelligence and no language problems. These factors place the syndrome at the 'high-functioning' end of the autistic spectrum.

There are groups of symptoms that are common to people with Asperger syndrome. However, people experience these symptoms in very different ways. The affect the symptoms have on their daily life may be quite different to the experiences of others with Asperger syndrome.

Some "Key Facts":

- Asperger syndrome is a lifelong condition. A child with Asperger syndrome will become an adult with Asperger syndrome.
- It has been estimated that 1 in 33,000 people have Asperger syndrome, but there are probably many more.
- Asperger syndrome is four times more common in males than females.
- People in all ethnic groups and social classes can have Asperger syndrome.
- Almost half of people with Asperger syndrome are diagnosed after the age of 16.

Some relatives within the same family may display similar traits to those present in Asperger syndrome, making systemic and family-based interventions a particular feature of this work (e.g. Chapman, Skirrow & Hare in preparation).

The team has received 478 referrals since it was launched in April 2003. There have been a regular flow of referrals with an increase in 2007-8.

Period	No of referrals	OA referrals (total)	OA – funded
To March 2003	34	8	2
April 03-March 04	72	14	5
April 04-March 05	72	20	10
April 05 – March 06	78	16	8
April 06- March 07	82	13	3
April07 –March 08	114	25	10
Date of referral not log	16	4	4

Section 6: Links to other providers

The service operates as a discrete team that works across several services including education, mental health services, learning disabilities provider agencies and employers (see Figure 4, below).

Following the assessment process, a care plan will be written using the Effective Care Co-ordination (ECC) format and a decision made about the most appropriate service(s) to provide these. These may be in the following categories:

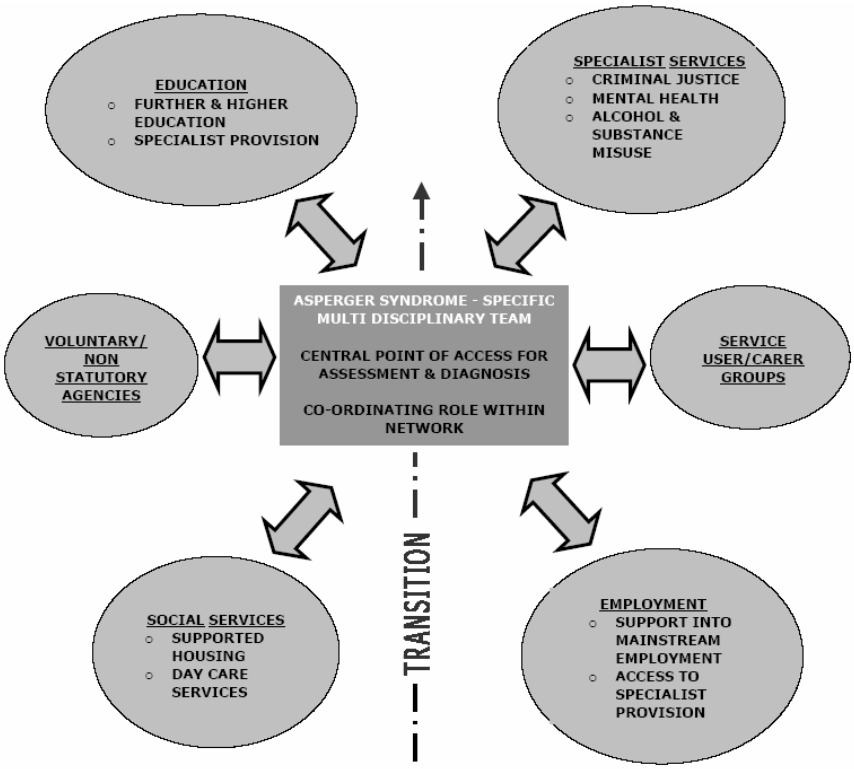
- All the clinical interventions identified are provided by the Team

or

- The clinical interventions are provided within the Managed Care Network.

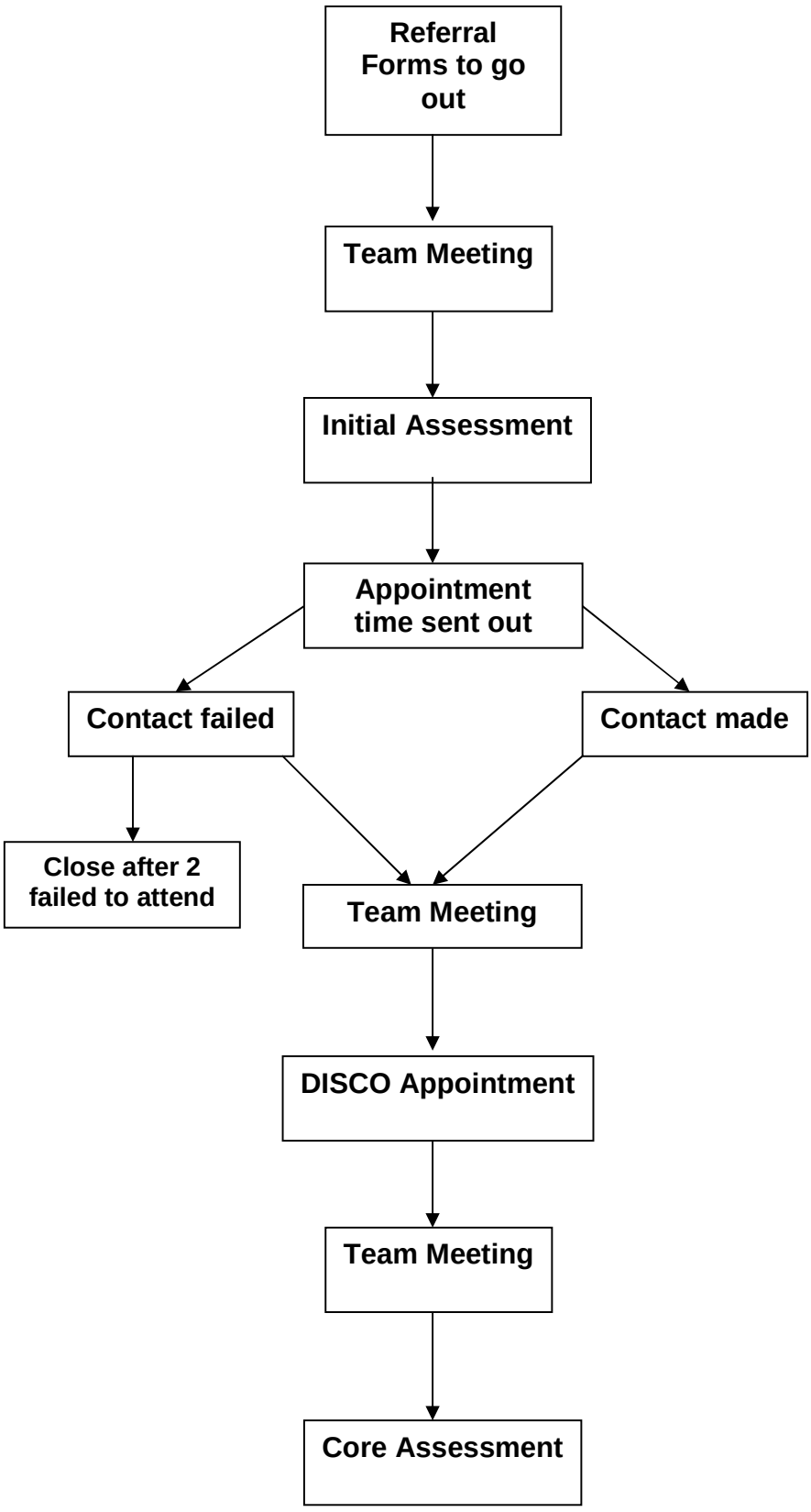
The Managed Care Network consists of services offered elsewhere in Mersey Care, the Local Authority and voluntary organisations. These services may be identified as most appropriate for individuals and may be accessed by the team on their behalf.

Figure 4 - Liverpool's Managed Care Network for Adults with Asperger Syndrome.



Section 7

Integrated Care Pathway for Liverpool Asperger Team



Section 8: High Level Service Specifications for:

Specification	Details
Who is the Service For?	To be eligible for the service from the Asperger team, an individual must be 18 years of age and resident in Liverpool, or be registered with a Liverpool GP. Individuals aged 16-18 may be eligible for a service, dependant on individual need. In these situations, the team may work in association with children's Autistic Spectrum services. Individuals must have a diagnosis of Asperger Syndrome according to Gillberg's (1991) or ICD-10 classification (See appendix for definitions). The team works with service users who may also receive a service from other services in Mersey Care. However, the service is specifically designed for individuals who typically "fall between the gaps" of mental health and learning disabilities services (National Autistic Society, 2001). There is no single treatment for Asperger syndrome and some individuals with a diagnosis of Asperger syndrome can function extremely well in society. For this reason, the service is designed to work specifically with individuals who also experience significant social disability.
What is the service intended to achieve?	As described above, many individuals with Asperger syndrome typically "fall between the gaps" of mental health and learning disabilities services. The Liverpool Asperger Team is specifically designed to meet the needs of this client group. The Team offers a discrete diagnostic service, which is available to adults within the Liverpool Area and also on a commissioned basis to individuals outside the catchment area. This is a significantly unique selling point for the team, where diagnostic services for adults are largely non-existent in the North of England, and this generates considerable income for the trust. The team provides focussed, person-centred clinical interventions for clients who are experiencing difficulties as a result of Asperger syndrome. This is intended to result in significant improvements in mental & physical health, challenging behaviour and 'quality of life' for our service users. The service aims to be a 'beacon' service for adults with Asperger syndrome, developing cutting-edge services and evidence-based interventions for our service users. In this, we have already earned national recognition from the Department of Health (e.g. 2006), the Parliamentary Office of Science & Technology (2008) and the National Autistic Society (2008).

Specification	Details
Principles of Care	The service aims to provide person-centred, needs-based client care in collaboration with statutory and voluntary agencies within the Liverpool Area. Using a 'managed care pathway' model, the Liverpool Asperger team seeks to co-ordinate these services to meet the needs of the individual. The team particularly emphasises a rights-based approach, within a socially inclusive model that supports the empowerment of people to use ordinary services and facilities, with the aim of retaining or regaining a place in local community life. The service aims to work in partnership with service users and carers improve the quality of life and protect the rights of individuals with Asperger syndrome and their families.

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Royal College of Psychiatrists (2006). Psychiatric services for adolescents and adults with Asperger syndrome and other autistic-spectrum disorders. London, RCP.

Skirrow P & Farrington J (2008). Developing Specialist Services for Adults with Asperger Syndrome in Liverpool. *In:* Skirrow P & Hare DJ (Eds). The Clinical Psychology of Autism Spectrum Disorders. Clinical Psychology Forum, 185: 15-20

Appendix A: Diagnostic Criteria for Asperger Syndrome

ICD-10 Criteria For Asperger Syndrome.

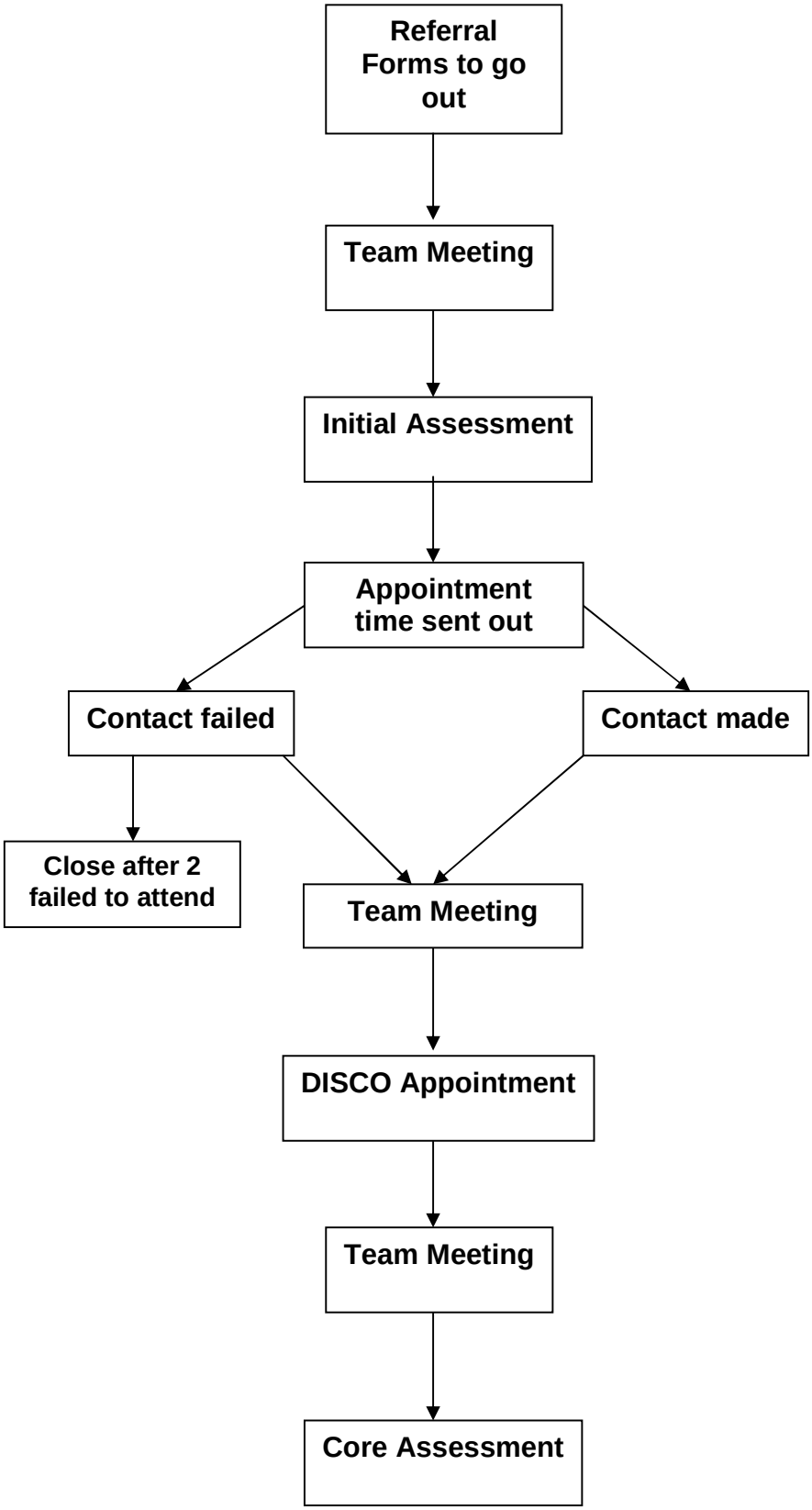
A. A lack of any clinically significant general delay in language or cognitive development. Diagnosis requires that single words should have developed by two years of age or earlier and that communicative phrases be used by three years of age or earlier. Self-help skills, adaptive behavior and curiosity about the environment during the first three years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary feature). Isolated special skills, often related to abnormal preoccupations, are common, but are not required for diagnosis.
B. Qualitative impairments in reciprocal social interaction (criteria as for autism). Diagnosis requires demonstrable abnormalities in at least three out of the following five areas:
    1. failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction;
    2. failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;
    3. rarely seeking and using other people for comfort and affection at times of stress or distress and/or offering comfort and affection to others when they are showing distress or unhappiness;
    4. lack of shared enjoyment in terms of vicarious pleasure in other people's happiness and/or a spontaneous seeking to share their own enjoyment through joint involvement with others;
    5. a lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; and/or lack of modulation of behavior according to social context, and/or a weak integration of social, emotional and communicative behaviors.
C. Restricted, repetitive, and stereotyped patterns of behavior, interests and activities (criteria as for autism; however it would be less usual for these to include either motor mannerisms or preoccupations with part-objects or nonfunctional elements of play materials). Diagnosis requires demonstrable abnormalities in at least two out of the following six areas:
    1. an encompassing preoccupation with stereotyped and restricted patterns of interest;
    2. specific attachments to unusual objects;
    3. apparently compulsive adherence to specific, nonfunctional, routines or rituals;
    4. stereotyped and repetitive motor mannerisms that involve either hand/finger flapping or twisting, or complex whole body movements;
    5. preoccupation with part-objects or nonfunctional elements of play materials (such as their odor, the feel of their surface, or the noise/vibration that they generate);
    6. distress over changes in small, nonfunctional, details of the environment

Gillberg's (e.g. Gillberg 1991) Criteria for Asperger Disorder

1. Severe impairment in reciprocal social interaction
   (at least two of the following)
   a. (a) inability to interact with peers
   b. (b) lack of desire to interact with peers
   c. (c) lack of appreciation of social cues
   d. (d) socially and emotionally inappropriate behavior
2. All-absorbing narrow interest
   (at least one of the following)
   - (a) exclusion of other activities
   - (b) repetitive adherence
   - (c) more rote than meaning
3. Imposition of routines and interests
   (at least one of the following)
   - (a) on self, in aspects of life
   - (b) on others
4. Speech and language problems
   (at least three of the following)
   - (a) delayed development
   - (b) superficially perfect expressive language
   - (c) formal, pedantic language
   - (d) odd prosody, peculiar voice characteristics
   - (e) impairment of comprehension including misinterpretations of literal/implied meanings
5. Non-verbal communication problems
   (at least one of the following)
   - (a) limited use of gestures
   - (b) clumsy/gauche body language
   - (c) limited facial expression
   - (d) inappropriate expression
   - (e) peculiar, stiff gaze
6. Motor clumsiness: poor performance on neurodevelopmental examination

(All six criteria must be met for confirmation of diagnosis

Appendix B: Integrated Care Pathway for Liverpool Asperger Team



Mersey Care NHS
NHS Trust

Integrated Care Pathway for the Liverpool Asperger's Team.

Before writing in this Integrated Care Pathway (ICP) please ensure you have signed your name below. When using this document please complete the date and signature sections against each activity when it has been completed.

If an activity outlined in the ICP has not been completed for whatever reason, then this must be recorded as a variance next to the activity. The variance should also be recorded on the variance recording sheet at the end of the document. This will allow the care pathway to be continually updated.

Please see below for changes in care team.

Start Date:	Title of people involved in your care:	Name:	Signature:	Involvement ended:

Mersey Care NHS
NHS Trust

Integrated Care Pathway for Liverpool Asperger's Team

Personal Details	
Name	
Patient No	
Date of Birth	

Who was the referral form received from?
When was the referral form received?

Date	**Signature**

GP ☐

Consultant ☐

Self/Carer ☐

Social Worker ☐

Careline ☐

Transfer ☐

Other ☐

If other please fill in above:

Please explain

Referral				
Code	**Action**	**Date**	**Signature**	**Comments**
1.1	Letter 1 sent out (within 24 hours,1 working day of receipt of referral form)			
1.2	Logged on database			
1.3	File made up to contain: (within 7 days)			

Date	**Signature**	**Comments**

Essential information ☐

Ethnic monitoring form ☐

Risk Screen ☐

Referral form ☐

Any other information

1.4	Set up on Epex within 7 days			

Team Meeting					
Code	**Action**		**Date**	**Signature**	**Comments**
2.1	Acceptance Criteria				
2.1.1	In Catchment Area	Yes/No			
2.1.2	In Age Range	Yes/No			
2.1.3	Previous diagnosis	Yes/No			
2.1.4	Reason for referral can be established	Yes/No			

	If not accepted:			
2.2	Written to referrer (include process)			
2.2.1	Letter copied to service user			

	If accepted:				
2.3	Risk factors identified (e.g. gender, live alone)				
2.3.1	Identified needs that influence allocation				
2.3.2	Allocated to for initial assessment:				
	Any additional actions: (To also be recorded in Variance sheet at back of Care Pathway)				

Initial assessor actions				
Code	**Action**	**Date**	**Signature**	**Comments**
3.1	Requested relevant documentation from referrer			
3.2	Received relevant documentation from referrer			
3.3	ECC status / documentation identified			
3.4	Date of Appointment			
3.5	Letter sent offering appointment			

If contact made go to 3.14

1st visit unsuccessful				
3.6	Unable to make contact			
3.7	Card left (standard card)			
3.8	Second letter sent offering appointment			
3.9	Copied to referrer			
3.10	Date of 2nd Appointment			

If contact made go to 3.14

2nd visit unsuccessful				
3.11	Unable to make contact			
3.12	Discharge letter sent			
3.13	Copied to referrer			

Visit made				
3.14	Asperger's screen (Social/environmental needs) completed			
3.15	Role of the team explained			
3.16	Process/Care Pathway / DISCO explained			
3.17	Leaflets given on Aspergers syndrome			
3.17	Information given on Team			

	Website			
3.18	Consent given to copy correspondence			

3.19	Identified carers/family members to be involved in DISCO.			
3.20	Availability of carer (preferences times/dates/places)			
3.22	Initial assessment front sheet			
3.21	Any additional actions: (To also be recorded in Variance sheet at back of Care Pathway)			

Team Meeting (within 7 days) of initial visit: Yes/No					
Code	**Action**		**Date**	**Signature**	**Comments**
4.1	Appropriate to continue contact	Yes/No			

4.2	**If no**			
4.3	Letter sent to referrer			
4.4	Copied to service user			
4.5	More appropriate referral advised, if appropriate			

4.6	**If yes:** Allocated to do DISCO Name:			
4.7	Standard letter sent to inform assessor			

DISCO Appointment					
Code	**Action**		**Date**	**Signature**	**Comments**
5.1	Letter sent within 1 week				
5.2	Appointment offered within 4 weeks				
5.3	Date of DISCO Appointment				

If contact made go to 5.13

1st visit unsuccessful				
5.4	Unable to make contact			
5.5	Card left (standard card)			
5.6	Second letter sent offering appointment			
5.7	Copied to referrer			
5.8	Confirmation phone call made			
5.9	Date of Appointment			

If contact made go to 5.13

2nd visit unsuccessful				
5.10	Unable to make contact			
5.11	Discharge letter sent			
5.12	Letter copied to referrer & GP			

DISCO appointment visit made				
5.13	DISCO assessment completed			
5.17	Scored report writing			
5.18	Feedback meeting arranged			

Team Meeting				
Code	**Action**	**Date**	**Signature**	**Comments**
6.1	Outcomes of DISCO Diagnosis: Yes/No			

No Diagnosis of Asperger's				
6.2	Close down file			
6.3	Alternative referrals made to other agencies:			
6.4	Discharge letter sent			
6.5	Copied to referrer			

Diagnosis of Asperger's				
6.2	Recommendations of DISCO have been agreed ☐			
6.3	Allocated key worker:			
6.4	Other input - tick any agreed: ☐ No other input ☐ Health Action Plan ☐ Essential Lifestyle Plan ☐ Psychology Input ☐ Psychiatry Input ☐ Speech language therapy ☐ Risk assessment ☐ Social work Benefits advice / Groups Specify:			

Mersey Care NHS
NHS Trust

Integrated Care Pathway for the Liverpool Asperger's Team

Variance Recording Sheet
This sheet is to be used to complete any variances throughout the care pathway.

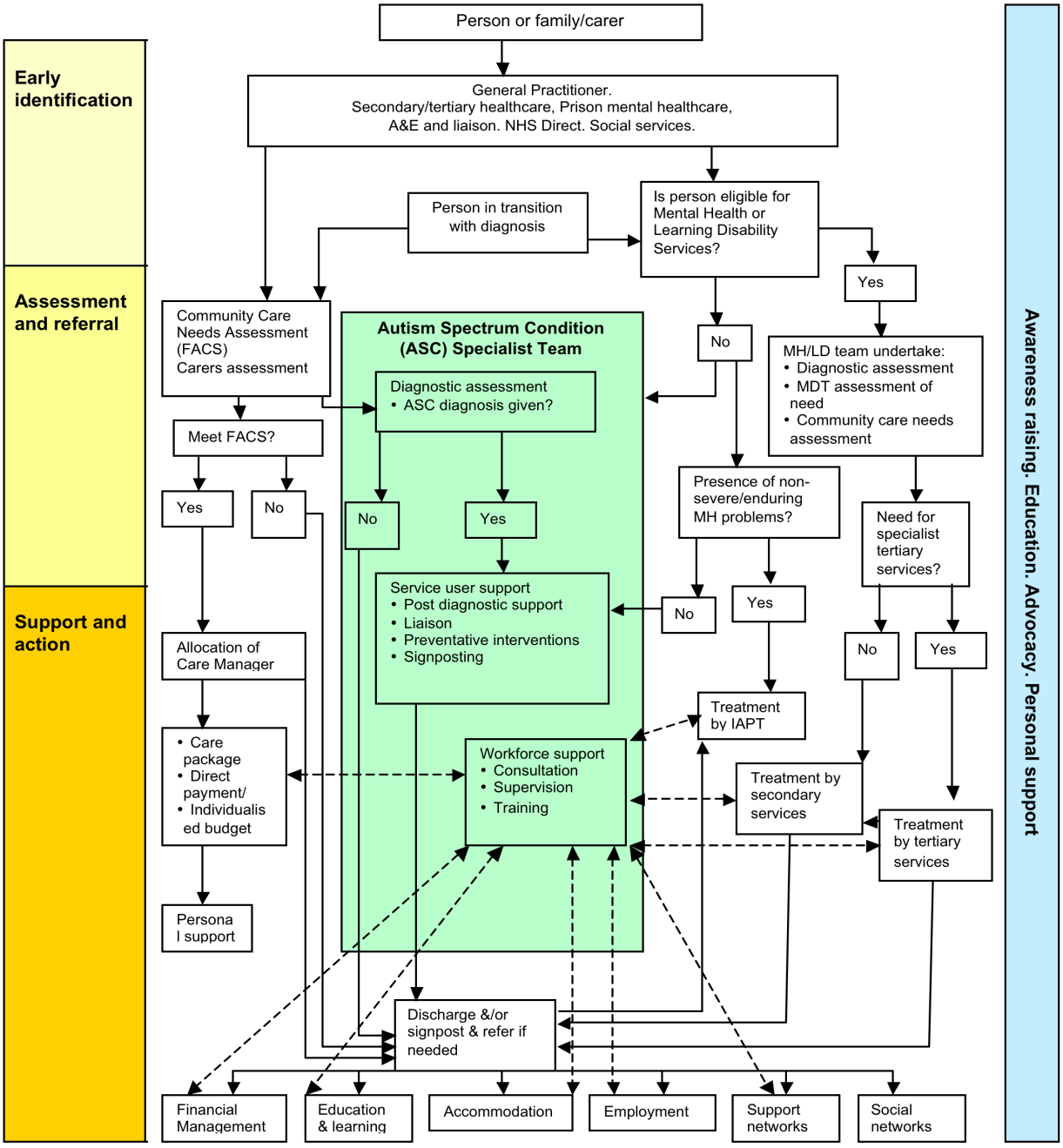
Patient No:-

Code	Variance (Use this column to describe what the variance is and what was done instead if anything)	Date	Sign

Bristol autism spectrum condition adult care pathway

Dr Ian Ensum
Consultant Psychologist
Bristol Autism Spectrum Service

Autism Spectrum Condition Adult Care Pathway



Key points from care pathway

Current Service Issues

- People with Asperger Syndrome without significant psychiatric co-morbidity are currently excluded from accessing mental health/learning disability services. This means that not only are people unable to access diagnostic assessment, if they do experience problems, they are also unable to receive prompt, timely intervention. The consequence being that services are typically only available at the point of crisis, which is both unhelpful and expensive.

- If people with ASC do manage to access mainstream health and social care provision, due to a widespread lack of specialist training and expertise with regard to autism amongst frontline staff, their needs are poorly understood, leading to them receiving services which can be ineffective, inappropriate, and potentially harmful.

- Due to various recent policy initiatives (including the Autism Act, the National Autism Strategy and the statutory guidance), this situation is becoming increasingly untenable.

- However, the lack of additional investment from central Government means that any solution will have to be low-cost and sustainable. This means that for the most part, the needs of adults with ASC should be met within existing services.

- However, two problems remain:

    - Significant competency gap amongst frontline staff with regard to how to work effectively and efficiently with people with autism.
    - Existing services will not be able to offer diagnostic assessment and preventative treatment, accessible from primary care

- This care pathway attempts to solve these problems by recommending the creation of small, multi-agency, jointly commissioned specialist ASC teams, with a remit to provide two broad areas of activity:

i) Workforce support to agencies across the care pathway (including health, social care and voluntary sector organisations) involved in providing services to people with ASC, via:

- **Supervision clinic** to enable professionals in secondary mental health/learning disability services to properly diagnose & manage people with ASC
- Provision of comprehensive, ongoing **programme of training** and awareness-raising to front-line staff across care pathway, targeted to meet the specific training needs of different organisations
- **Consultation/liaison service** to local social care & voluntary sector agencies working with people with ASC, to enable them to obtain:
    - Ongoing, specialist advice about specific cases
    - Support to adapt their services to enable them to be more appropriate and accessible to people with ASC
- **Partnership working** with relevant stakeholders to develop and implement a range of local initiatives to improve the quality of life of people with ASC, and reduce levels of social exclusion.

ii) Direct work with people with ASC who are not able to access existing provision due to the absence of significant psychiatric co-morbidity and/or learning disability, including:

- **Diagnostic service**, accessible from primary care
- Comprehensive package of **post-diagnostic support** for people with ASC and their families/carers

- **Assessment of need** across health, social care, housing, employment, education etc, and **signposting** to agencies who can help with this
- **Range of preventative interventions** to help avoid unnecessary contact with mental health services, and promote social inclusion/independence – i.e. development of self-directed social support networks, "social skills training" etc

- Idea is not to become the people who provide all the services for people with ASC - this would not be sustainable, and would locate all the expertise in a small part of the care pathway
- **The role of the specialist ASC team is therefore essentially a facilitative one – to liaise with mainstream services to help them work better with people with autism, and to offer diagnostic and preventative treatment services to people with ASC who otherwise would not be picked up.**
- In terms of access to diagnosis – if the individual is eligible for mental health or learning disability services, it is the responsibility of these services to diagnose, with support from the specialist team.
- The same applies to social care assessments – each team should include a qualified social worker, whose job is to train and liaise with generic adult social care teams to enable them to provide a better service to adults with ASC.
- Following diagnosis, a full needs assessment should be carried out, the results of which will enable the team to signpost people with ASC towards agencies across the care pathway to facilitate access to appropriate support
- Importantly, all these agencies can access the same level of training & support as mainstream health & social care providers
- Thus if a person with ASC identifies needs around employment, they will be signposted to an employment service, who will have access to ongoing training & liaison from specialist team
- Likewise, if "low-level" mental health needs are identified, the person will be signposted to their local IAPT provider, who will similarly have access to specialist training & supervision

Key challenges

- How to do this with no new investment:
    - Resources allocated to the creation of new teams will inevitably have to come from elsewhere in the care pathway
    - Need for local areas to develop robust business cases, based around QIPP agenda

- How to develop sufficient local expertise:
    - General lack of experienced, skilled clinicians across the UK
    - Need for core training of health and social care professionals to include more emphasis on ASC

- How to guarantee financial sustainability
    - Neighbouring PCTs/Local Authorities to be encouraged to enter into commissioning partnerships to achieve economies of scale
    - Funding to be sought locally from different commissioning budgets, so that resources are pooled, and each stakeholder makes an appropriate contribution.

For further information contact:

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Bristol Autism Spectrum Service

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BS14 9BP

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