Mersey Care NHS
NHS Trust

MERSEY CARE NHS TRUST

LEARNING DISABILITY SERVICE

HIGH LEVEL SERVICE SPECIFICATION

Version Control

This copy - Version

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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

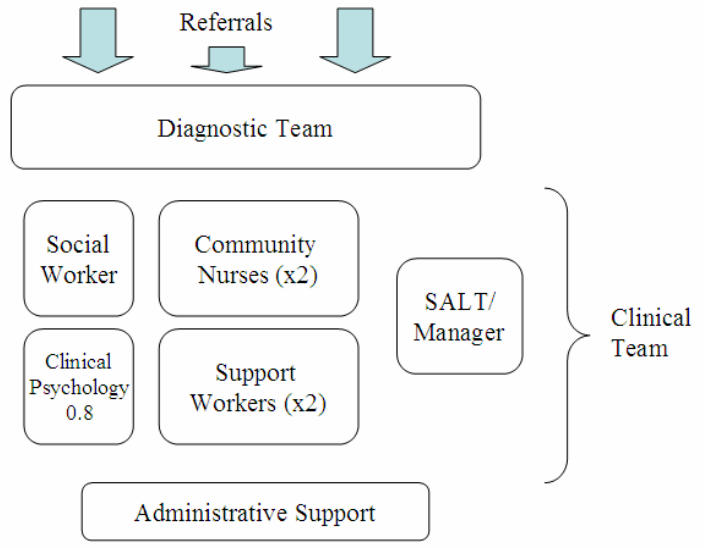
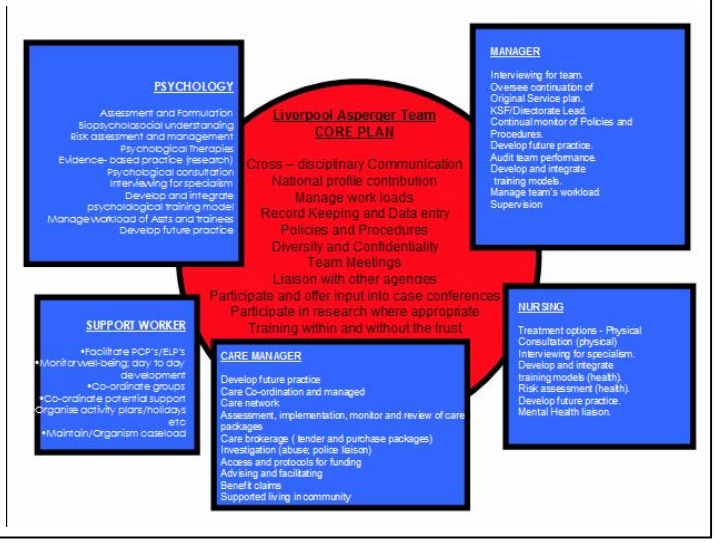


Figure 2: The Roles of the Multidisciplinary Team



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.

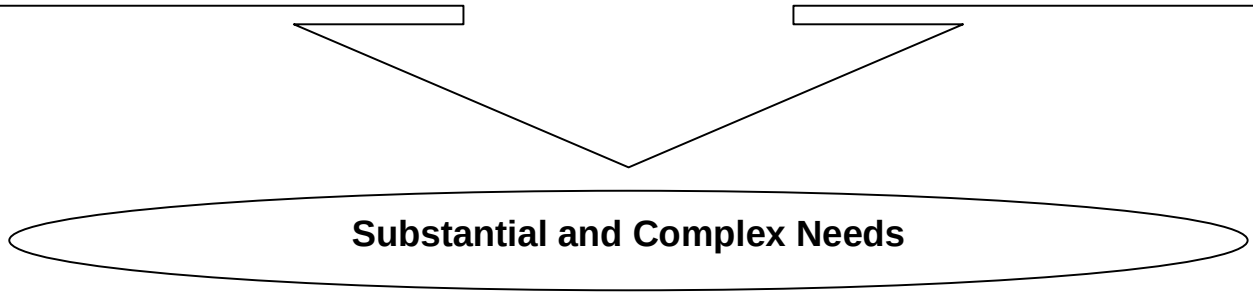
- The service operates an open referral system and offers diagnostic and clinical interventions.

- 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:

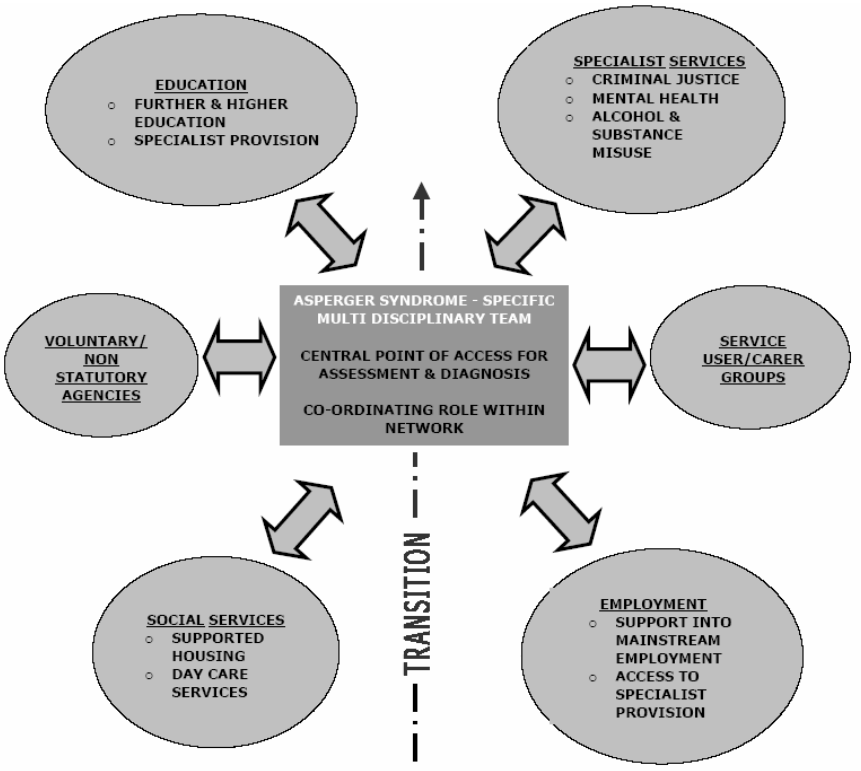
- All the clinical interventions identified are provided by the Team

or

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

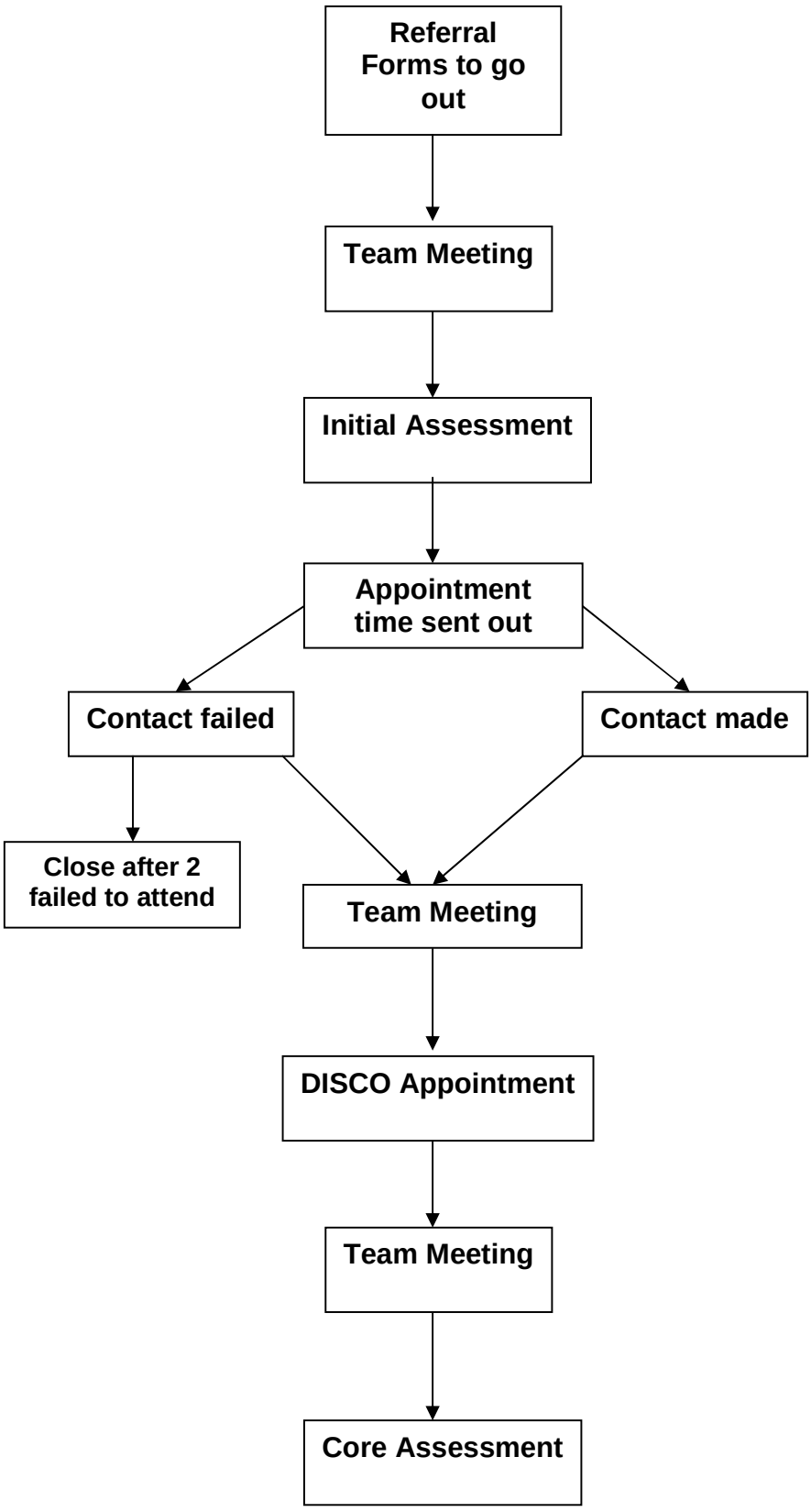
The Managed Care Network consists of services offered elsewhere in Mersey Care, the Local Authority and voluntary organisations. These services may be identified as most appropriate for individuals and may be accessed by the team on their behalf.

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.

References

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Appendix A: Diagnostic Criteria for Asperger Syndrome

ICD-10 Criteria For Asperger Syndrome.

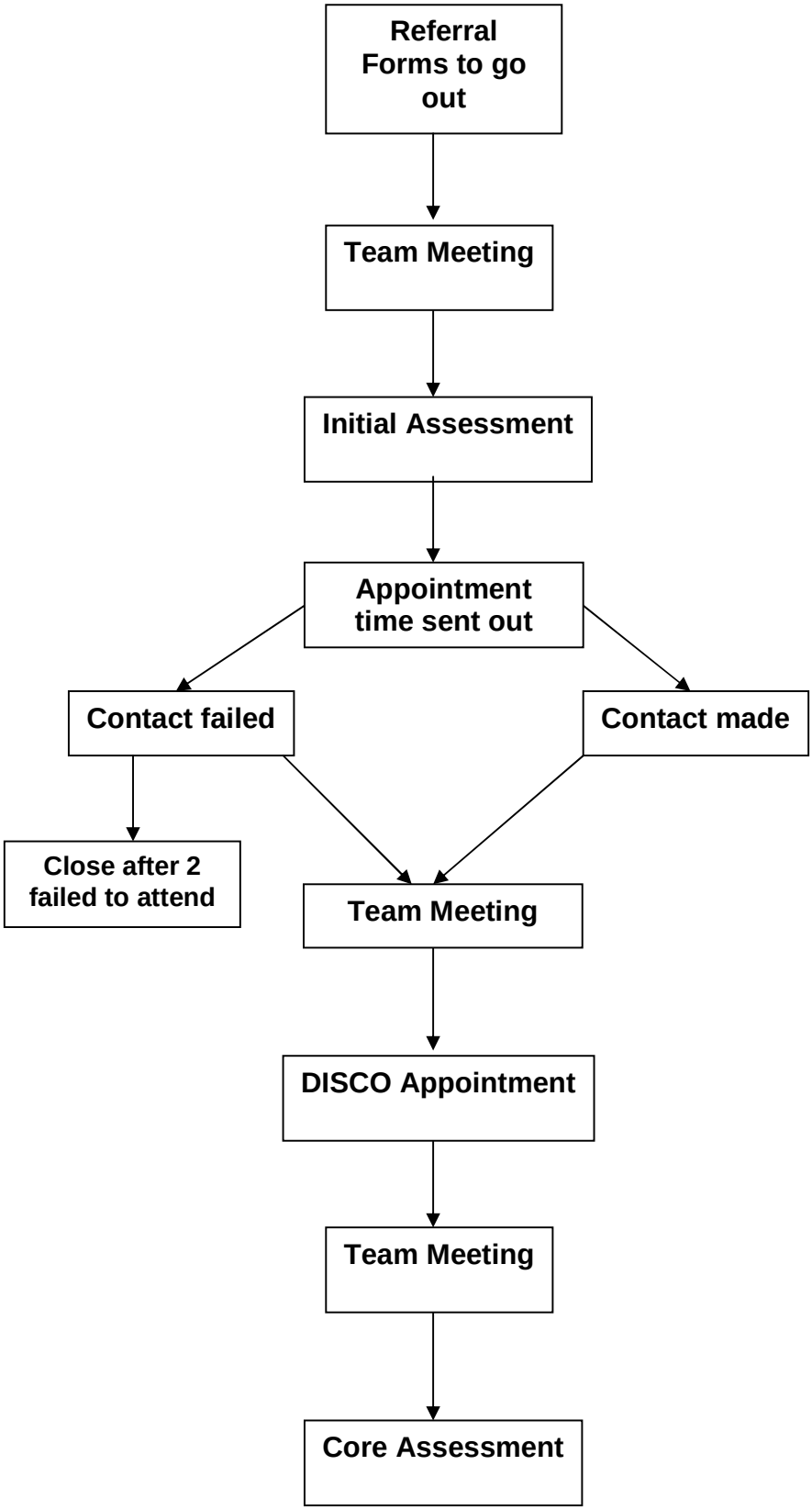
A. A lack of any clinically significant general delay in language or cognitive development. Diagnosis requires that single words should have developed by two years of age or earlier and that communicative phrases be used by three years of age or earlier. Self-help skills, adaptive behavior and curiosity 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



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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:

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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:			

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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