



Unmet Need for Adults with Autism Spectrum Disorders

DIRC

5 April 2012



Outline

- Need for skilled interventions
- Cannot be provided reliably by a generic service designing one off responses
- Specific adult autism spectrum disorder team and professionals required
- Access to personal budgets
- Need for a plan across government
- Need to ensure access to mainstream services and standards for this



Autism Spectrum Disorders

- Increasing prevalence – 2003 vs 1998
100% increase in people identified to have autism spectrum disorders
- Major gaps in provision of treatment – one off packages
- Need for skilled intervention – social skills, communication, behaviour and social interaction. Therapy and rehabilitation.



Specific response

- Skilled – therapy and early intervention
- Accumulate knowledge
- Specialisation and efficiency
- Problem with the incorporation of autism services in a generic service
- Limits of case management. Need to redirect resources to specific community teams



An Autism Plan

- Cannot rely on a generic disability response
- Need to consider non disability services – mental health, general health, education and employment
- Further develop assessment and treatment skills
- Need to consider all age groups – adults can miss out twice



Early intervention – children's services. As of 2010.

- Generic – 20 special education units, 16 special schools 110 special classes
- 6 addition special units – two to be autism specific, expansion of big buddy program
- Commonwealth – Helping Children with Autism Program
- Medicare Specific Payment Items – up to 13

?? From first diagnosis



Early intervention gaps

- Need for intensive highly structured intervention
- Low student teacher ratio. Specific teaching and therapy ratio
- Reports – children grouped with other children with different disabilities
- Autism SA – 15 staff to support 3664 children (in early 2011)
- Need for individualised funding



Adults

- Increasing recognition and need to respond
- Asperger' Syndrome – can miss out on childrens services
- Problems accessing - Mental health services – depression and anxiety
- Education and work



ELIZABETH II



Autism Act 2009

- Autism Strategy
- Statutory Guidance by the Secretary of State
- Local Authorities – duty to act under it



All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents (Department of Health, 2010a).

'Fulfilling and rewarding lives'





UK Adult Autism Strategy – Mar 2010

- Increasing awareness and understanding
- Clear and consistent pathway for diagnosis
- Improved access to services and support people
- Local partners to develop relevant services



UK Adult Autism Act 2009

Section 2(1) of the Autism Act further requires that:

“For the purpose of securing the implementation of the autism strategy, the Secretary of State must issue guidance—

**(a) to local authorities about the exercise of their social services functions within the meaning of the Local Authority Social Services Act 1970 (c. 42) (see section 1A of that Act), and
(b) to NHS bodies and NHS foundation trusts about the exercise of their functions concerned with the provision of relevant services.”**



Statutory Guidance Dec 2010

- Training
- Identification and diagnosis of autism in adults, leading to assessment of needs of relevant services
- Planning in relation to the provision of services as people move from children to adults
- Local planning and leadership re adult autism



Training

- General training for everyone in health and social care
- Specialised training – GPs, those who do assessments, people in leadership roles

“That training must lead not only to improved knowledge and understanding but also to changing the behaviour and attitudes of health and social care staff.”⁹



Identification and Diagnosis of Adult Autism

- NICE Guideline July 2012
 - Clinical pathway
- Services have a duty to assess a person who needs community care services
- Diagnosis and assess carer need
- Some people may not want a diagnosis but still get services



Children to Adults

- Planning when people turn 18
- Not a single point “switchover”
- Involve young people and their families



Local Planning and Leadership

“they [adults with autism] can depend on mainstream public services to treat them fairly as individuals”.

- Make reasonable adjustments in service for people with autism
- Access personal budgets and direct payments along with need
- Plan for local need and commission services
- Local teams suggested

Adult Asperger Team

Figure 1: The Structure of the Liverpool Asperger Team

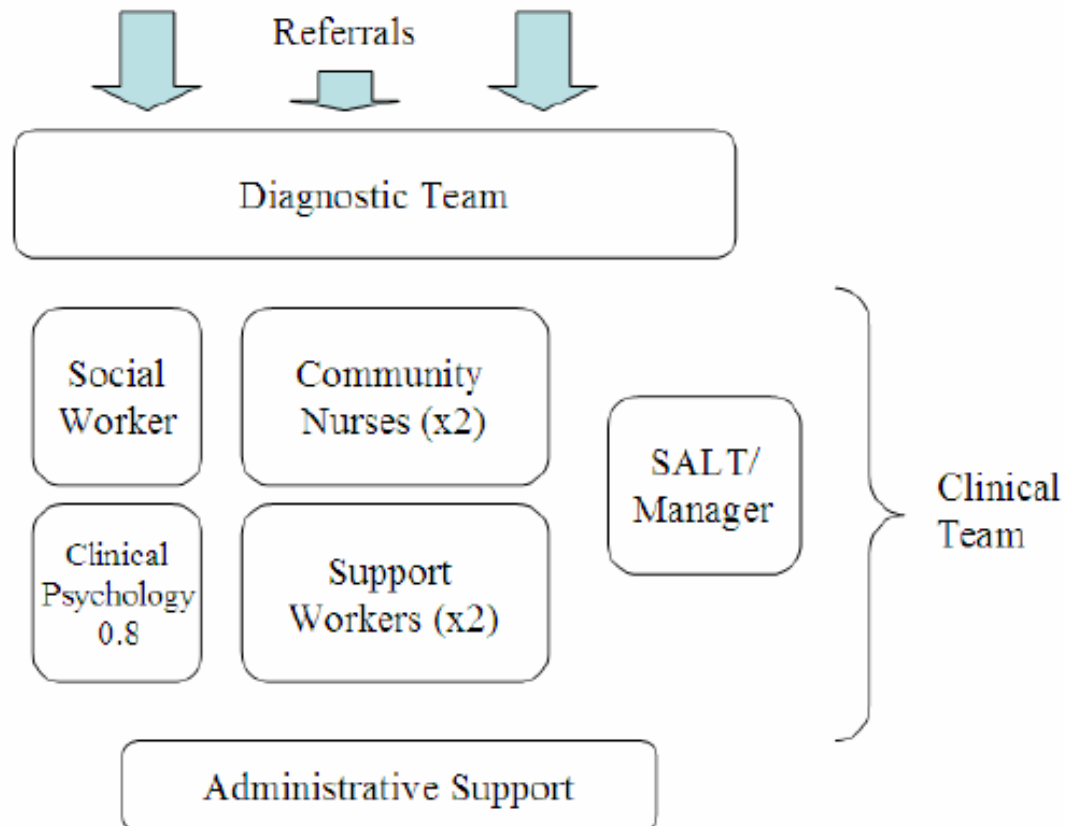


Figure 2: The Roles of the Multidisciplinary Team

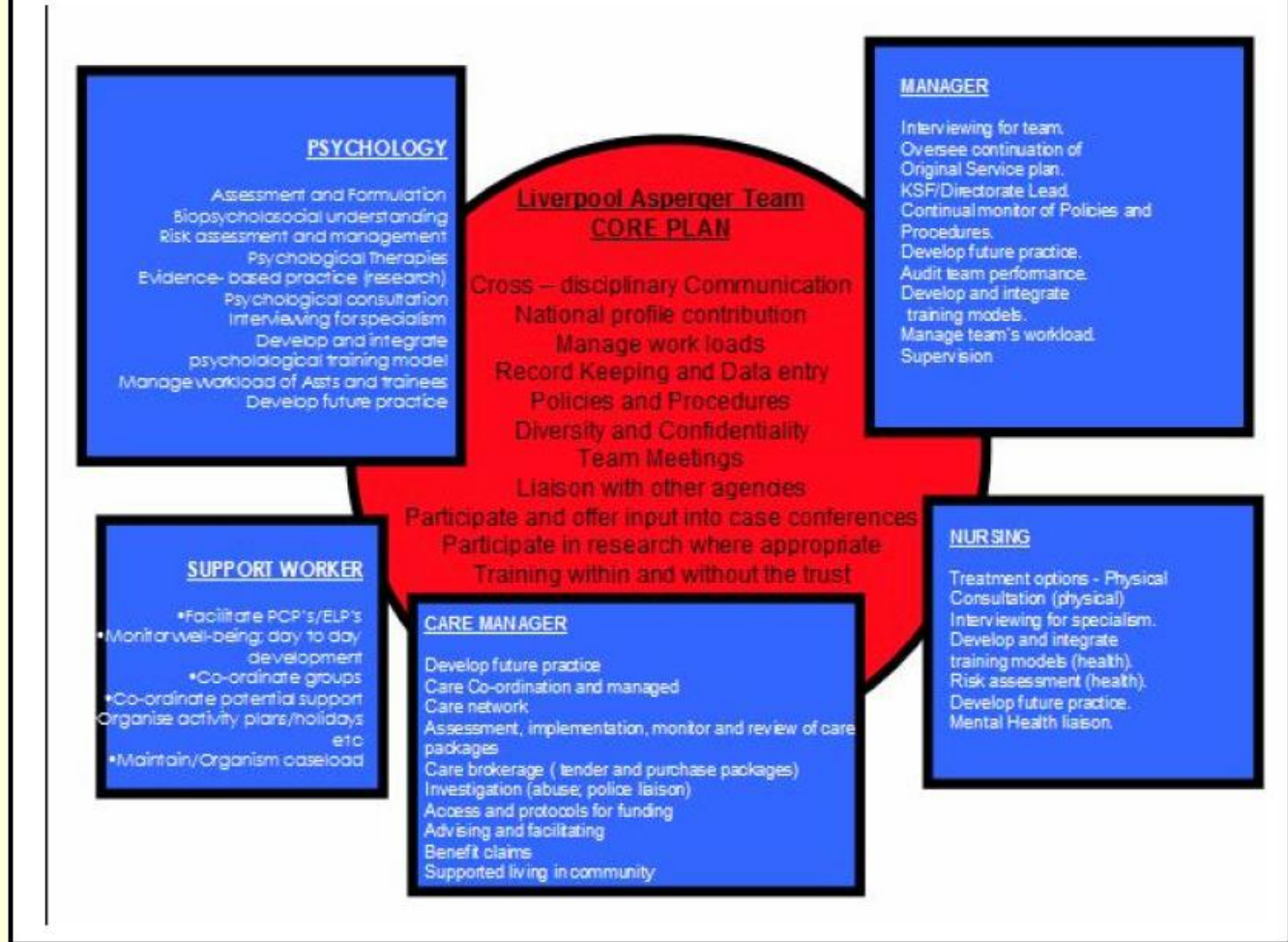
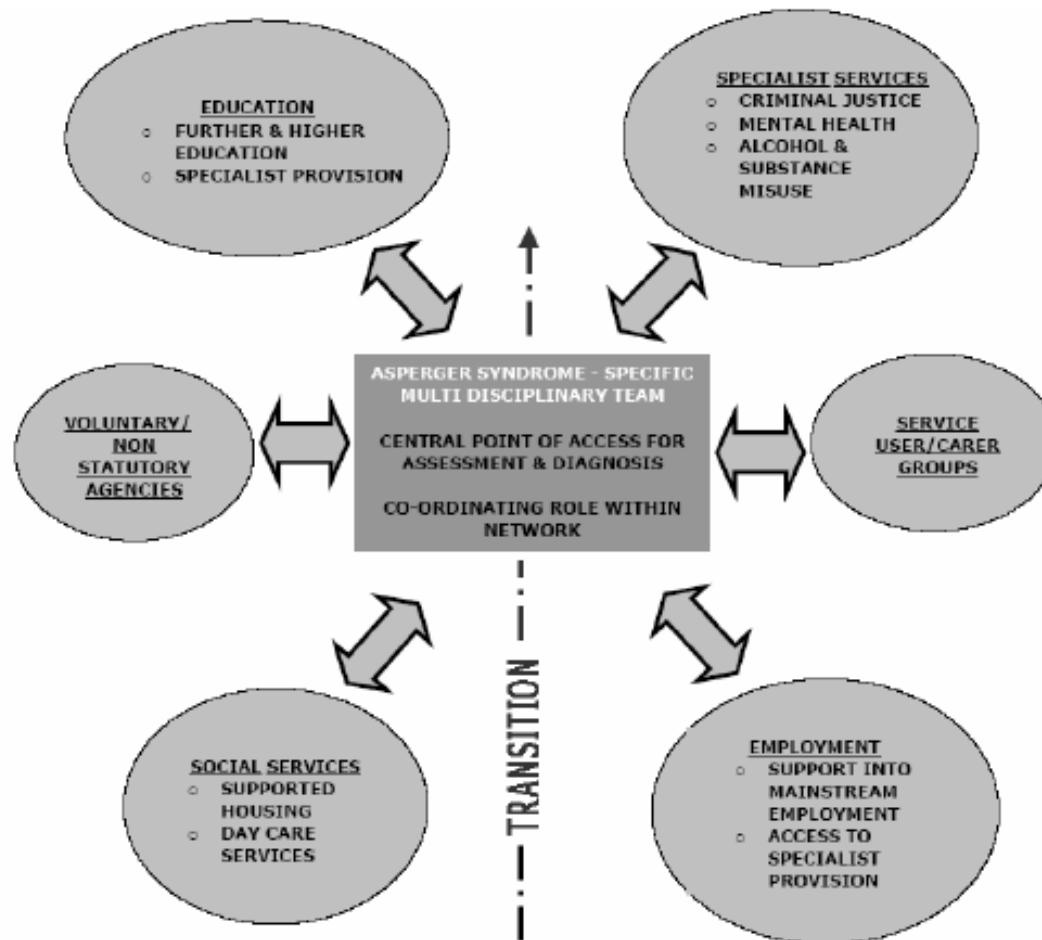


Figure 4 - Liverpool's Managed Care Network for Adults with Asperger Syndrome.





Autism spectrum disorders in children and young people

recognition, referral and diagnosis

Commissioned by the National Institute for
Health and Clinical Excellence



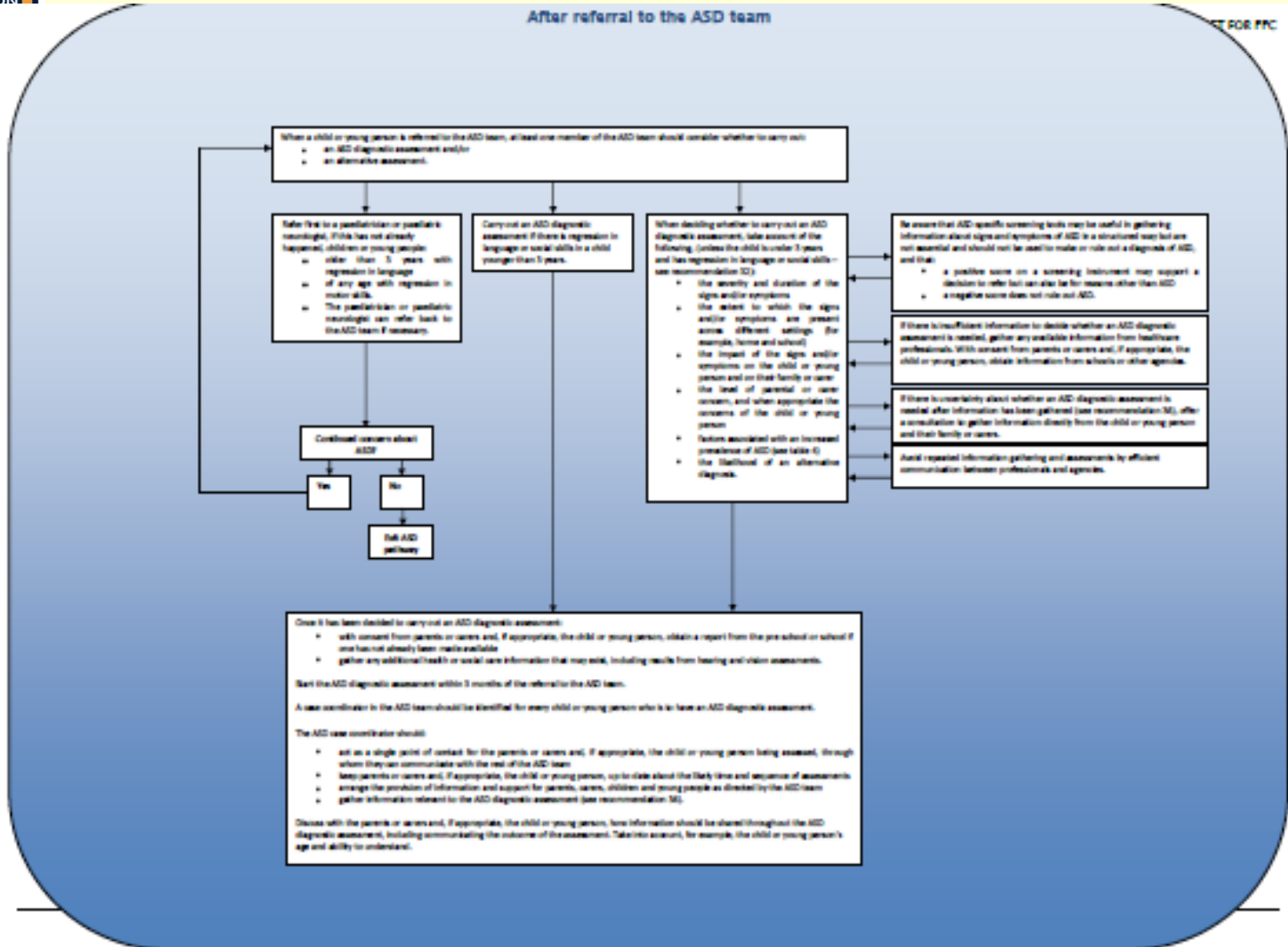
Multidisciplinary ASD Group

- Paediatrician and/or child and adolescent psychiatrist
- Speech and language therapist
- Clinical and/or educational psychologist

Access to

- Neurology
- Occupational therapist

NICE Guidelines





NICE Consultation Dec 2011

3

Autism

4

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6

Recognition, referral, diagnosis and management of adults on the autism spectrum

7

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12

National Clinical Guideline Number X

13



- **Intervention(s)**
 - **Case co-ordination models** (for example, case management; collaborative care; key worker systems)
 - **Advocacy and support services**
 - **Multi-disciplinary team models** (for example, specialist assessment teams; specialist community teams; assertive community treatment teams)
 - **Models of care delivery** (for example, stepped care, clinical care pathways)
 - **Day care services** (including the model and content of services)
 - **Residential care** (including the model and content of services)



Community Autism Team

- Clinical psychologists
- Nurses
- Occupational therapists
- Psychiatrists
- Social Workers
- Speech and language therapists
- Support workers



National Autistic Society Campaign 2 April 2012





National Standards Report



THE NATIONAL STANDARDS PROJECT—
ADDRESSING THE NEED FOR EVIDENCE-
BASED PRACTICE GUIDELINES FOR
AUTISM SPECTRUM DISORDERS



Established treatments

The following interventions are Established Treatments:

- Antecedent Package
- Behavioral Package
- Comprehensive Behavioral Treatment for Young Children
- Joint Attention Intervention
- Modeling
- Naturalistic Teaching Strategies
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Self-management
- Story-based Intervention Package



Behavioral Package {231 studies}

Evidence Level} Established

These interventions are designed to reduce problem behavior and teach functional alternative behaviors or skills through the application of basic principles of behavior change. Treatments falling into this category reflect research representing the fields of applied behavior analysis, behavioral psychology, and positive behavior supports.

Examples include but are not restricted to: behavioral sleep package; behavioral toilet training/dry bed training; chaining; contingency contracting; contingency mapping; delayed contingencies; differential reinforcement strategies; discrete trial teaching; functional communication training; generalization training; mand training; noncontingent escape with instructional fading; progressive relaxation; reinforcement; scheduled awakenings; shaping; stimulus-stimulus pairing with reinforcement; successive approximation; task analysis; and token economy.

Treatments involving a complex combination of behavioral procedures that may be listed elsewhere in this document are also included in the behavioral package category. Examples include but are not restricted to: choice + embedding + functional communication training + reinforcement; task interspersal with differential reinforcement; tokens + reinforcement + choice + contingent exercise + overcorrection; noncontingent reinforcement + differential reinforcement; modeling + contingency management; and schedules + reinforcement + redirection + response prevention. Studies targeting verbal operants also fall into this category.

Skills Increased

Academic	Communication	Higher Cognitive Functions	Interpersonal	Learning Readiness	Motor	Personal Responsibility	Placement	Play	Self-Regulation
X	X		X	X		X		X	X

Behaviors Decreased

Problem Behaviors	RRN	SER	General Symptoms
X	X	X	

Ages

0-2	3-5	6-9	10-14	15-18	19-21
X	X	X	X	X	X

Diagnostic Classification

Autistic Disorder	Asperger's Syndrome	PDD-NOS
X		X

Modeling {50 studies}

Evidence Level} Established

These interventions rely on an adult or peer providing a demonstration of the target behavior that should result in an imitation of the target behavior by the individual with ASD. Modeling can include simple and complex behaviors. This intervention is often combined with other strategies such as prompting and reinforcement. Examples include live modeling and video modeling.

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	X	X	X			X		X	

Behaviors Decreased

Problem Behaviors	RRN	SER	General Symptoms
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Diagnostic Classification

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X	X	X



The following treatments have been identified as falling into the Emerging level of evidence:

- Augmentative and Alternative Communication Device {14 studies}
- Cognitive Behavioral Intervention Package {3 studies}
- Developmental Relationship-based Treatment {7 studies}
- Exercise {4 studies}
- Exposure Package {4 studies}
- Imitation-based Interaction {6 studies}
- Initiation Training {7 studies}
- Language Training (Production) {13 studies}
- Language Training (Production & Understanding) {7 studies}
- Massage/Touch Therapy {2 studies}



Conclusion

- Specific evidence based interventions
- Incorporates into a state autism plan
- Access to personal budgets
- Predictable need for an adults autism spectrum disorder service
- Complemented by training and access to mainstream health and social services



References

OPA Annual Report 2011. Autism Strategy Recommendations page 24-28

http://www.opa.sa.gov.au/documents/09_Publications/Annual_Reports/17_AR%202010-2011.pdf

UK Autism Act <http://www.legislation.gov.uk/ukpga/2009/15/contents>

UK Adult Autism Strategy

<http://www.dh.gov.uk/health/2011/08/autism-strategy/>

UK Statutory Guidance on Adult Autism

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847

National Institute for Clinical Excellence (UK) Guideline Autism in Children and Young People

<http://www.nice.org.uk/guidance/index.jsp?action=download&o=55240>

National Institute for Clinical Excellence (UK) Guideline Consultation Autism in Adults

<http://www.nice.org.uk/guidance/index.jsp?action=folder&o=57391>

National Autism Centre (US) National Standards Report

<http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf>