

Assessment and provision for people with ASD in the UK

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Setting the scene

- At least **1% of the population have an autism spectrum condition** (Baird *et al.*, 2006; Baron-Cohen *et al.*, 2009a, Brugha et al 2011)
- High levels of additional needs:
 - **70% of individuals with autism have at least one other mental or behavioural disorder,**
 - **40 % have at least two disorders,** mainly anxiety, ADHD and ODD
 - (Hofvander, 2009 Simonoff, 2008).
- **Challenging behaviours are more common** in autism than in other conditions with similar levels of intellectual impairment
 - (McClintock, K., Hall, S. and Oliver, C. 2003).
- **Outcomes in adult life,** i.e. employment, relationships, independent living and community participation, **are often poor** (Eaves, 2008; Howlin, 2004).
- **25 to 30%** of individuals with **good intellectual skills** are able to achieve well academically and **find employment as adults** (Howlin, Rutter et al., submitted).
- **A child or sibling with autism** has a significant, often **deleterious impact on family members** (Davis, 2008; Estes, 2009),

Financial context: children

Knapp and colleagues (2009) based on 1% prevalence of autism estimated **annual** cost of supporting children with autism reaches £2.7 billion

- The mean annual total cost per child with autism in the UK reaches £25,400,

Barrett and colleagues (2012)

- In a study on 152 children (aged 2-5 years) the mean total service cost over 6 months was £2,581 (range £317 to £6,698), equivalent to £450 per month and over £5,000 per year.
 - Almost half the costs (45%) were for education and childcare,
 - 41% were for community health and social services
 - 12% for hospital services.

Financial context: adults

- For adults with autism estimated **annual** costs amounts to £25 billion (2006 prices)
 - costs associated health and social care, respite care, special education and day services, accommodation, voluntary organisation help
 - productivity losses (lost employment) of parents and adults with autism
 - **not including** cost estimates on benefit payments or informal care.
- The annual total cost per adult with autism,
 - £32,500 per person for adults with autism without intellectual disability living in private accommodation,
 - £98,000 for adults with autism with intellectual disability living in hospital.

Context of assessment

- Universal free health service
 - **No screening** program for autism or other neurodevelopmental disorders.
 - Approach is for **universal surveillance** by Health Visitors
 - pick up parental or professional concerns leading to rapid assessment and referral to appropriate assessment pathway.
- 3-4 tiers of health provision
 - Primary – General practitioners, nurses and Health visitors
 - Secondary – local district hospitals, community therapy services
 - Tertiary – regional hospital and specialist services providing second opinion and advanced clinical interventions
 - Fourth tier – national specialist resources
- **'Care pathways'** across age ranges permit smooth transition between levels

Diagnosis

- National Autism Plan for Children (NAP-C) and Scotland (Assessment, Diagnosis and Clinical Interventions for Children and Young People with Autism Spectrum Disorders SIGN) Published by The National Autistic Society (NAS) 2003
- Since NAP-C,
 - increase in the number of **local teams** who have a formal autism assessment protocol: (32% in 2001 rising to 54% in 2007);
 - more services are using a **multidisciplinary/multi agency team approach** (48% in 2001 vs. 93% in 2007),
 - more teams have **joint clinics with child mental health services** (34% in 2001 vs. 57% in 2007).
- Still a **wide variation** in access to and quality of diagnostic and intervention services; **especially poor for adults**
- There is good awareness in many areas of **key diagnostic tools** e.g. autism specific interviews (ADI, 3Di and DISCO) and assessment measures (ADOS, PEP-R etc)
- The current estimated **prevalence rates** of autism have major resource implications and continue to place a **considerable strain on local diagnostic services.**
- Some **diagnostic services** are being provided by **education professionals and private sector teams**

Therapy and teaching

- Early years:
 - **Initially provision** may be through **health services** e.g. speech and language therapy, occupational therapy and psychology
 - **Education** services become involved in provision of **early learning skills** possibly home based visiting e.g. Portage, and providing placements in either **mainstream or specialist nursery provision** that can include therapy input

- School age years 5-19*

New Education and Health care legislation

- will provide **education to 25yrs** for individuals with special educational needs
- **One single assessment process** and education, health and care plan to give children all the help they need.
- Education, health and social **services must work together** to give families **one single package of support**, tailored to their individual needs.

Therapy and teaching

- All children attend either **mainstream (70%) or special school (30%)**.
 - In mainstream settings staff are required to make **'reasonable adjustments'** to ensure that a child can achieve their potential (Department for Education, 2006).
 - The government-led **Inclusion Development Programme (IDP)** helps **teachers** address the needs of children with ASD (Department for Children, Schools and Families, 2009a)
 - The aim is for **collaboration of universal and specialist services** (health and education)
 - Individuals with statements of SEN are **assessed in school at the age of 14** years to provide a **Transition Plan** aims to collate
 - Information from as many sources as possible to **plan for the young person's transition to adult life.**
 - It is tied in to legislation from education, health and social government departments.



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Vision:

The AET believes that all children and young people with autism should receive an education which enables them to reach their individual potential to engage in society as active citizens (and that individuals, families and professionals are informed, supported and equipped to enable this to be achieved).



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Therapy and teaching cont

Post 16 years:

- Most young people are expected to go to a college or post 16 provision.
- Depending on intellectual development and degree of autism this can range from a **university degree to skills based or vocational training**.

Adulthood

- Only **12%** of individuals with ASD without intellectual disability have full-time jobs, whilst across the **whole spectrum** the figure is **6%**. (Barnard et al. 2001)
- **Lower** levels of employment than those with **other disabilities**.
- **NAS Prospects Employment Consultancy** assisted **67%** of their clients to **find work** with a job **retention rate of 68%** (Howlin, Alcock & Burkin, 2005).
- For some individuals with learning disabilities and autism the main priorities are access to opportunities for **purposeful occupation and social inclusion** as a priority (Clegg, Murphy, Almack & Harvey, 2008).

Legislation

- **2004 Early Support Programme** (established the DFES/DH) produced **professional and parent *guides on ASD***.
- **2009 Autism Bill** which became the Autism Act - Secretary of State for Health is required to develop a **strategy for adults with autism regardless of their level of intellectual ability or disability**.
 - Set out several legal requirements for local authorities and/or NHS bodies
 - These include specialist training for key professionals
 - A requirement for a clear diagnostic pathway;
- **2010** - Statutory guidance asserts the requirement for services to recognise that **individuals with autism with an IQ of 70 or over** may **require support**, not just those with intellectual disability .

Legislation

- **2010 ‘Getting it right for Children’** review of services: Kennedy report.
 - Achieving Equity and Excellence for Children and Young People Government **proposals for the NHS as applied to children.**
 - **Shared decision making** between families, young people and professionals
 - ‘outcomes framework’ for services emphasising **enhanced quality of life,**
 - ensuring a **positive experience of health care,**
 - **Children’s National Service Framework,** ‘Care will be provided in an **appropriate environment** that is **safe and well suited to the age and development** of the child or young person’.

Legislation cont

- **2012** The Report of the Children and young Peoples Health Outcomes Forum **for children and young people**
- Included a **subgroup for children with disability**, SEN and long term conditions such as autism.

Main outcomes:

- Reduction of time from first presentation to diagnosis or the start of treatment;
- A quality assessment
- Key working approach
- Need for integrated care;
- Effective transition from children's to adult services
- Age appropriate care.

National Institute for Health and Clinical Excellence

- Management of individuals with Autism is covered by 3 guidelines
 - Autism diagnosis in children and young people
 - Recognition, referral and diagnosis of children and young people on the autism spectrum
 - Published: September 2011
 - Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum
 - Published June 2012
 - Autism - Management of autism in children and young people
 - To be published August 2013

Key recommendations - diagnosis

- Local autism strategy and management groups
- Aims of group
 - **improving early recognition** of autism by raising awareness of the signs and symptoms of autism through multi-agency training
 - making sure the **relevant professionals** (healthcare, social care, education and voluntary sector) are **aware of the local autism pathway** and how to access diagnostic services
 - supporting the **smooth transition to adult services** for young people going through the diagnostic pathway
 - ensuring data collection and audit of the pathway takes place.

Key recommendations - diagnosis

- Team should include
 - paediatrician and/or child and adolescent psychiatrist
 - speech and language therapist
 - clinical and/or educational psychologist
 - and others as necessary e.g. gastro, neurology, OT etc
- Provide a **single point of referral** for access to the autism team.
- A **case coordinator** in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.

Key recommendations - intervention

- **Local autism strategy group** with responsibility to **deliver and coordinate intervention across age range** (i.e. into adulthood)
 - via local MDT teams and services
 - Case coordinator for all families
- Unrestricted **access to** all forms of care including **CAMHS**
- Access to tertiary services if necessary
- Some recommendations for specific treatments

