



Proposed ASD Unified Diagnostic Pathway

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Background

- Initially considered a rare disorder, numbers of children recognised to have an ASD have increased significantly year by year
- Current best estimates suggest prevalence of just over 1%
- Using figures provided by Children with Disabilities Needs Assessment: estimated 1160 children with ASD in NHS Berkshire West.
- Increases in prevalence combined with complex range of needs for children and families pose a significant challenge for health, education and social care

ASD Services

- Services have developed over time in a piecemeal fashion in Berkshire
- Recent Dingley review highlighted very considerable issues for ASD in Berkshire; mirrors UK-wide NAS 'You Need to Know' report. Both refer to problems with:
 - ❖ Screening, diagnosis, intervention (eg mental health, speech and language, occupational therapy), education, support (including respite, leisure), training

Diagnostic pathway

- To make manageable the huge task of improving services across the board, we are tackling the diagnostic pathway as a first step, because its manageable and (relatively) quick to implement
- ❖ To develop a high quality diagnostic service in Berkshire, with screening and onward referral as appropriate

Diagnostic shortfalls: why?

- Significant increase in the demand for assessment, leading to large increase in referrals
- ❖ DLC records show **97** children were referred for diagnostic assessment in 2004 and **300** in 2009

Diagnostic shortfalls: why

- Age criteria for access is arbitrary and confusing across Berkshire
- No standardized assessment procedure (process, tools, involvement of other pros)
- Lack of protocol about what is offered immediately post diagnosis
- Lack of training about ASD (recognition, referral, diagnosis)

Proposed diagnostic pathway

- Planned new unified pathway where all children under 18 are seen by 1 service, in clinics that meet their particular needs, with a single point of access and following a standardised process

Principles of new system

- All children to be offered the same assessment process, with timely diversion to CAMHS Choice or Paeds appointment if ASD looks unlikely at any stage
- Assessment to follow National Autism Plan for Children, and NICE guidelines.

Referral process

- Online information will include downloadable referral form, clinic information, info about ASD, links, Photos to help prepare children?
- Referral – to one centre using standardised referral forms. Referral by GP, schools, HV

Referral process

- Following receipt of referral, we will ring referrer or parent for more information or to clarify their understanding of the referral if needed
- May also of course come to CAMHS or paed's for other reasons and be referred across
- Similarly, if need for assessment is not clear, children can have a 'choice' appointment in CAMHS or Paeds

Screening process

- We will send out standardised screening questionnaires (home and school/nursery), a form asking parents to describe their concerns, and to give us information about the professionals involved with their child
- We will include some information about the purpose of the assessment and the process with this pack

Screening and triage

- Once all forms returned, telephone call to parents if additional information needed or for clarification
- Allocate to appropriate clinic. Clinics might include 'straightforward' assessment (1 specialist and 1 non-specialist), complex/second opinion (2 or 3 specialist ASD clinicians)
- Assessment will not proceed till all forms are back including those from school (we will chase!)

Assessment Clinic

- Appointment letter plus leaflet about the process, including information about what to say to young people and a leaflet for children
- Assessment. Single clinic lasting about 2 hours for developmental history and ADOS, brief feedback
- Staffed by experienced and trained clinicians

School and other information

- Additional school /nursery information collected by observation or interview (assistant psych) in most cases
- May be omitted if sufficient information already available
- Reports from SLT, EP etc as appropriate

Feedback appointment

- Aiming to offer feedback in a month
- Appointment with parents, finalise report, screen for onward referrals (OT, SLT, medical conditions, mental health)
- Information pack for parents including local services, information about ASD

Post feedback

- Multi-professional meeting if required
- Parents invited to psycho-education group (PAWS, Moving on, etc)
- Close to diagnostic pathway (but with onward referrals where appropriate)

Benefits

- Primary benefit: pathway is clear; families will have a speedy and organised journey with feedback and onward referral built in
- Follows NICE guidelines using high quality assessments and trained staff
- Many other benefits eg training, research, service development