Sutton ASD/Neurodevelopmental Pathway

Coproduction Meeting 2

Introduction

- The purpose of this workshop was to build on the discussion from the first co production meeting.
- The key partners working on this pathway are Sutton Parents Forum, the Voluntary sector, Parents and Carers, Children and Young People, Local Authority representatives from Education and Social Care, GPs, Schools, Elected Councillor who sit on some of the Children and Young People's Partnership Boards and Sutton CCG who are leading this work.
- The meeting focused on the redesign of the pathway in four areas namely pre- diagnosis, diagnosis, post diagnosis and transition. The notes below reflect the discussion.
- We would like to involve you in the discussion so that our co production is inclusive and involves as many partners, parent/carers and young people as possible in Sutton.
- The Sutton Parents' Forum (SPF) has agreed to develop a Survey Monkey questionnaire and share the outputs of the event on their Facebook page and website www.suttonparentsforum.org.uk
- There is partnership working with parents, CCG and Local Authority in the administration of this co production process.

Pre-Diagnosis

The perfect service would be

- Role of Health Visitors having more awareness of ASD and asking questions around ASD at two year check ASQ.
- A checklist being available pre diagnosis for parents and for use in schools and pre-schools on Local Offer website.
- More GP awareness of ASD and associated conditions
- Better awareness of ASD in nurseries and preschools.
- Clear pathway and information on what resources area available e.g. Portage.
- Skilled staff in all schools (currently variable) and a checklist for schools.
- Clearly defined pathway (currently varied route) into diagnosis (school, GP, parents)
- Access to diagnosis will not be too reliant on parents' expertise and being pro-active.
- A separate person e.g. Keyworker to support pre-diagnosis.
- Spread of skills within schools to develop a better understanding.
- Opportunities for parents to talk to schools.
- Concern that access to future support is dependent on diagnosis therefore making the diagnostic route very important.
- Playgroups, children's centres and preschool will provide a referral route.

- There will be clear access to the diagnostic pathway at all ages (currently big cut off at reception and infants).
- Won't need a diagnosis to get support.
- Diagnostic route is clear and therefore less emotional impact of chasing a diagnosis which is currently very draining.
- Value of family support workers.
- Support pathway for parents who are not ready for a diagnosis.
- Underlying budget pressure affecting access to diagnosis.
- Alternative route to EP – Health visitors, pre-school, schools.
- Diagnostic tools will be relevant to girls and teams will have a better awareness of signs in girls. (Girls being missed.)
- Research projects can be used as a help to diagnosis (and appropriate support afterwards).
- Ensure timely diagnosis of ADHD.
- Diagnostic overshadowing – not accepting additional diagnosis.
- Should be able to take diagnosis and notes with you to a new Local Authority area.
- Improve diagnosis/awareness in private schools.
- Resolve current problems caused if school or CP are in another borough.

Solutions

- Use of a checklist
    - Older children diagnostic tool
    - Early on
    - ASQ
    - Parents, schools professionals on Local Offer
- A professional to talk to re: pre-diagnosis or to observe. Someone in the building when the service takes place.
- Staff awareness in different settings – pre-school, schools.
- Parent support networks and information on how to find them (e.g. coffee mornings with professionals there).
- Cross-borough co-operation.
- Raise or remove the cut off age for therapies.
- Parental assessment for some services.

Diagnosis

- Health visitor should pick up on things that are important developmentally at 2/2½ check.
- ASQ check list should be used by health visitor who should also have specialist skills.
- Timeline for diagnosis needs to be clear and there needs to be a point of contact if timescales not met.

- Early referral to paediatrician/speech and language therapy.
- Multidisciplinary assessment – community paediatrician, SLT, OT, Education, children and young people and/or parents.
- Early Years assessment unit should extend to age 11, led by paediatrician.
- Refer to specialise assessment unit specialist team triage, formal assessment /early help.
- At the end of the assessments parents and child should leave with a plan/pathway.
- Develop Secondary age 12+ assessment unit, Clinical psychology led/child psychiatry, educational psychology, OT, SLT, school nurse in central place.
- Think about practicality of workforce, space, IT system, education of workforce/staff.
- Key worker needs to sit in assessment and guide parents to next stage of support.
- Universal services (GPs, school nursing, schools, Health Visitors) need key worker to identify issues. Early Help Assessment Tool/Multi Disciplinary Team checklist.
- Need for diagnostic team and specialist team triage for early help and formal assessment.
- CYP, parent or school identify the issue. Check list/EHAT completed.
- Self-referral or professional referral can also happen, perhaps via school office 11+.
- Multi-professional assessment centre triage needed.
- First assessment in school or nursery setting. Second assessment in health or social setting through play set up. Enablers for this include space, staffing, training and education, agreed timelines to complete assessment, communication then diagnosis made.
- Individual plan and/or pathway and introduction to key worker.

See Appendix 1 for proposed pathway

Post Diagnosis

- Strategies need to be in place for home and school.
- Different strategies/needed for children and young people depending on age of diagnosis
- EHCP/resources are currently dependent on diagnosis
    - Golden key – assumptions, plan resources
    - Shouldn't need EHCP to get support
- Can't get funding without EHCP - 2 tier service.
- Therapy needs to be embedded into the curriculum in schools and colleges
- Having team around CYP in schools improves outcomes
- Improve support and awareness in mainstream/colleges
- Personal budgets must cover the therapies needed and additional support required, where not part of the curriculum offer
- Support/key worker needed especially post diagnosis

- Information packs do not give answers and they go out of date quickly, services currently change so quickly – improve and ensure current web based information
- Equivalent of follow up services e.g. those provided for hearing impaired
- Ensure someone for support at school meetings etc - key worker.
    - Vol sector is not always accepted at schools – SEN Team Special Educational Needs staff are
    - Professionals have to accept voluntary sector as equal partners
- Post diagnosis requires support for how the condition affects the individual
- Ensure diagnosis remains relevant eg initial GDD may then be ASD
- Ensure LA holds schools and colleges accountable to ensure they meet needs
- Improved social engagement with informed key workers
- Appropriate Apps etc. for age group
- Ensure CYP are supported in current provision appropriately and reduce referrals to STARS, Limes, Wandle Valley and stop illegal exclusions; improve inclusion rates in Sutton schools and neighbouring colleges
- Ensure good practice in educational provisions eg TA attends therapies with the cyp
- Accessible website with key, up to date information
- ASD/ADHD experts available to help and support quickly (good practice such as teacher of deaf provided post diagnosis)
- Better communication – schools, SEN Team, social care respond to emails
- Meeting attendees from LA have authority to make decisions
- Better support/training for GPs to understand conditions
- Improved commissioning/feedback
- Panel decisions made quickly and reported back to families expeditiously

Transition

- CAMHS start and complete referral to adult services
- Key workers regardless of age of CYP, EHCPlan
- CCG to provide clear criteria for accessing services (LD/Recovery and Support Team)
- When transferring between educational provisions: current provider arranges meeting with new provider to explain and ensure strategies, support and adaptations to environment are in place and new LSA integrated over timely period. When 14+, should be included in EHCPlan/Year 9 review to ensure accountability
- Multi agency solution should include all relevant people; this system is best practice
- Improved and more timely communication
- Provide therapies post 18
- Signposting to appropriate services if don't meet criteria
- Ensure all levels of need are supported, not only higher level

Appendix 1 Proposed Diagnosis Pathway