

Delivering Better Children's Autism Services in Croydon Event

Tuesday 15 March - 10am to 12pm

Feedback report

Introduction

To mark the publication of the report *Autism: The Experience of Children and Young People in Croydon*, Healthwatch Croydon held on 15 March 2016, to hear further experiences and discuss suggestions from parents, carers, teachers, and support workers.

The event opened with some comments from Linda Townsend, Family Support Worker at the Croydon branch of the National Autistic Society and Cllr Andrew Rendle, Croydon's Autism Champion. Both thanked Healthwatch Croydon for the report and opportunity to discuss ideas for better services. Cllr Rendle specifically emphasising the need to be creative in seeking improvements.

This feedback report shows the depth of the challenges and issues. A single meeting or report could not seek to cover this in detail or comprehensively, but this should be seen as starting point for discussions for improving services so they can effectively meet the community's needs. This is an urgent issue which will not go away. Healthwatch Croydon will continue to raise this issue and research more experiences to support change in services.

Table A: Information about services

Key issues

- Not much for those who have had diagnosis.
- Not much for high functioning.
- Diagnosis is too late.
- Big worries in getting into mainstream schools, not caring when in the schools causing frustrations.
- Clinical diagnosis of mental health with poor medication reaction.
- Big gaps between education, health and social care services. These need integration - there should not be a gap.
- Diagnosis should be by elimination, which would give earlier diagnosis. Start with sound processing, and then look if eyes are working together, but UK policy does not look from here, they don't ever look to see if both eyes work together. Therefore, there is no service, there is a need to look at other countries, but for the moment trials of this kind of diagnosis is being trialled in Sutton schools.
- No consistency of practice.

Suggestions for improvement

- **Early diagnosis is needed/screen all children:** Provide testing of gross motor skills, sound processing, and speech and language testing at young age. The earlier the diagnosis the easier it is to manage and you can more easily meet key developmental goals.
- **Improve delivery of services:** Break down the silos between different services, between education, health and social care services, so ensure consistent service. Also ensure smooth transition onto adult services particularly in occupational health.
- **Deliver services in specialist settings:** Look at ways to deliver in specialist settings either in specialist schools or via alternative services such as online learning, rather than specialist sessions in mainstream schools.
- **Find alternatives to medication:** Anxiety management is the key to managing the worst aspects of autism. Anxiety leads to not sleeping, bad or lack of diet, and can lead to psychosis. It needs to be seen as part of autism, and not be managed by medication, once it becomes a mental health issue.

- **See each autistic child as an individual:** All providers need to see each child in the context of their own specific issues, not just written off as autistic with general perceptions of what the issues are and what is needed.
- **Improve primary services:** Improve special educational needs coordinator (SENCO) and teacher training and behavioural support.

Table B: Consistency of process

Key issues

- Not enough places once diagnosed, and so children are forced back into mainstream schools with significant negative impact for child and parent.
- Cultural behaviour - community leaders need to have languages in autism - so they can have ownership of the issues.
- Then it is the case of getting the ownership to trickle down to schools.
- There needs to be stronger communication both within and across SLAM and community services.
- Teachers could list traits but could not define it as autism (older teachers).
- There needs to be consistency in provision of SENCO and speech therapy.
- There is an allocation that schools need to abide by to observe, train and put in care plans, currently 16 days are delivered from an allocation of 53 days.

Suggestions for improvement

- **Transition:** There is a reference in policy to early intervention, but without a real definition of what it looks like. Therefore a transition plan is needed with teachers trained in autism; and person-centred services - not one size fits all.
- **Training:** SEN reforms policy suggests every teacher by law is a teacher of Special Educational Needs, so each teacher needs to be trained so that needs and care management needs are met by the school, therefore a need for a borough wide inset day on autism.
- **Better planning:** Need for a transition plan with regular meetings.
- **Earlier diagnosis is key** with right diagnosis techniques, sound processing, eyes assessment, occupational therapy and speech therapy are needed.

- **Linked up services needed**, particularly in unspecialised schools.
- **Alternatives to medication**, if anxiety occurs.
- **Alternatives to mainstream schools** such as online learning.
- **Improve SENCO, teacher training** and health professional training.
- **Better behaviour support services.**

Table C: Communication throughout the process

Key issues

- Lack of communication - six month wait.
- People 'talked down to'.
- Autism needs to be an 'openly discussed' condition
- People don't understand 'medical speak'.
- For doctors to use lay terms can be time consuming for them.
- Better footnotes.
- Autism is not always flagged on GP's computers. When not, parents say it's 'like introducing them to an alien'.
- Educational support.
- There's a need for respite and short breaks for family/carers.
- No support after diagnosis.
- More awareness for doctors/training.
- Not enough secondary school support for high functioning children - stuck in mainstream.
- Funding - goes to people on the waiting list - not to those who have been diagnosed.

Suggestions for improvement

- **More support earlier:** The ‘childhood journey is critical’ and the support children receive impact on their whole lives. Systems should not allow families to ‘wait more than six months’ for communication and updates, while on a pathway.
- **Enhanced user and carer involvement:** To avoid children and parents feeling ‘talked down to’, professionals should apply extra care when communicating - with GP’s adhering the autism flag on their computers, or ensuring it does ‘pop up’ if this is not the case. ‘Medical speak’ should be avoided where possible.
- **Clearer notes:** Again, notes should be clear and avoid ‘medical speak’ where possible.
- **Tackling stigma:** Autism is considered a clinical condition, however it is equally a social one. It is also regarded with negativity but children can be extremely gifted and capable. Positive aspects of autism need to be publicised and celebrated, particularly in schools, with autistic children rewarded for ability and incentivised to excel.
- **Behavioural services** don’t currently exist in the borough. This should be addressed as families are stuck without support, many suffering as a result.
- **A single point of access** would go a long way to reducing the confusion that families and children experience. A unified phone number, widely publicised, would make the system much easier to navigate and less daunting.
- **Training for parents** is only available while children are going through the diagnostic process itself. Training outside of the process would be beneficial.
- **Training for Specialist Unit teachers** is essential, if children with autism are to achieve their potential and be treated as equals within education.

Table D: Improving access to services and environment

Key issues

- The private sector has good quality schools, need for this in the public sector.
- Swimming pools are excluding autistic children. There are SEN-related sessions but these are still group activities, and some autistic children need one-to-one sessions. National Autism Society would work with leisure services, but the leisure services are concerned that autistic children are ‘disturbing members’.
- Parents have the right to refuse diagnosis of autism, which they may do for cultural reasons as a diagnosis may affect such as life prospects and marriage, this needs to change.

- Governors and Heads are personally liable for their pupil's care. There is a need for education services to advise heads and schemes to promote them on the agenda.
- Autistic children diagnosed but no follow up in services - unlike other healthcare services

Suggestions for improvement

- **More specialist provision:** There is a new facility at Tollgate in Ashburton, but there is the need for more specialist provision for high functioning individuals.
- **New school needed:** A school for high functioning children at secondary school is needed, but Croydon Council cannot build it, but there could be opportunities through the free school programme.
- **Better support now:** Primary schools in Croydon currently have support, but secondary does not have this. We need to get the skills we have in Croydon out into secondary school support, getting 1-1 support
- **Look at alternative ways of providing provision:** The NISAI Academy <http://www.nisai.com/> is an online school with a routine and safe environment. One parent in Croydon is currently trialling this for her child as a pilot scheme. Croydon Council are paying for this. By being at home and not at school, her child is pushed academically, stimulated, with reduced anxiety and increased confidence.
- **Parents and carer support:** There needs to be 'social provision' for parents and carers.
- **Hospital passports** to take to all services, would help providers prioritise those on the spectrum for certain service, and support a more personal service. These already exist in primary healthcare, but need to be a simple document, so that providers understand quickly the challenges and can provide services accordingly.
- **Autism champions:** The Department of Health has online autism awareness training which they are rolling this out to businesses, with an award - Autism Champions. How about providing a similar scheme for schools, but it needs to be led by a teacher or teaching assistant not a special educational needs coordinator.
- **Ensure teachers have accessibility to training:** encourage school leaders/boards of governors to ensure these are available. Getting it onto their agendas.

Table Notes

Table A: Information About Services

Facilitator and note-taker: Gordon Kay

- A parent summed up the services: “It is just not working between health and social services”.
- Head teacher at St Nicholas School a specialist school which has 80% on autism spectrum said, we have all the services together in one place including community paediatrician, Croydon SEN contact, and a speech and language therapy contract with Croydon child and adolescent mental health services (CAMS) but this is a private arrangement (we pay for it). CAMS is used for diagnosis usually but we use it for support as well.
- Adolescence with autism usually brings mental health issues but tends to be diagnosed by professionals such as GPs as just the symptoms of autism, missing the point that it is a cry for help.
- Different sectors see it differently with different solutions. Education people see it as a learning disability, which needs to be managed, while health providers see it a health or mental health condition which of which medication is considered a key option.
- A lack of resources in Croydon for high functioning children, who are left in mainstream schools, causes their health to deteriorate, and brings on mental health issues.
- Croydon has little mainstream secondary school support for autistic children, Sutton has specialist support.
- High functioning autistic adolescents need a different care in mainstream schools to what is offered, they need to be stimulated, other boroughs have specialist units, Croydon has none. As a result they are being traumatised.
- NISAI is an asset, home schooling within a routine, currently being trialled by child in Croydon (paid for by Croydon Council). It is a real learning environment with set times for lessons and interaction with teachers and other students. Other boroughs are using it as a gap for services. In first few months, anxiety levels have dropped (as a result of not having to be in the school environment), leading to better sleep and health patterns, and child is now integrating more socially. A real solution for some, as you cannot build a new school immediately.
- Croydon Education department wants autistic children in mainstream schools, but this leads down the route of high anxiety, disturbed sleep and eating patterns, and mental health issues which end up with medication which only makes things worse. Parent said “ I was this close to having my child sectioned, all as a result of the insistence that he went to mainstream school. Now NISAI has changed things around”.

- As opposed to being traumatised in school, he gains from vision and music therapy, and it is building his social confidence.
- Anxiety affects diet, sleep and health, to the aim is to focus on interventions that reduce anxiety such as NISAI.
- SLaMs answer is medication. It focused on OCD, but they say is just part of the autism, and don't want to tackle it. Parent said "He was medicated for nine weeks, the worst nine weeks of his life and no-one saw the side-effects. The prefer to prescribe medication without a qualified assessment of the impact anxiety is having on the child, and why he may be underweight etc".
- The whole system is too confusing, the challenges are that this falls between medical/health, education and social care and need to be seen as a whole.
- There needs to be flexible on home schooling.
- Croydon Council is there to advise alternatives but there is nothing available.
- Significant money is spent by the council on transport costs, transporting children by coach or taxi to mainstream schools, to go to services which do not work for them, so it is not to do with costs. If this transport money was used to put into alternative services such as NISAI, children would benefit.
- Providers are not following code of practice- Education psychologists provide assessment to make services better in the school, but were not being approved The parent had to get information, and then give it to the school, it could not be done direct. If Croydon Council want to keep children in mainstream school, they need to put things in place. The mainstream environment has too many children for it to work for specialist needs.

Table B: Consistency of Process

Facilitator and note-taker: Charlie Ladyman

A pertinent quote from a parent with a child with autism: 'Crisis, rejected from mainstream/frustrated, the system is 'setting up to fail'

Theme 1: Leisure activities

- Swimming pools banning disabled children swimming lessons
- Certain spectrum require one to one
- Purley baths will not engage, swimming important for access and healthy living, it is discrimination
- Extra sensory facilities, libraries are excellent
- There needs to be integrated family leisure activity, it is currently segregated
- Going out and eating in a restaurant, it is difficult to be accepted
- Toys R Us has an opening day one day before Christmas for children with autism
- NAS have 2 members of staff, provide social activity
- Additional support, relief/respite

Theme 2: Schools

- Winterbourne School - Enhanced services for Croydon
- Capability questions for mainstream schools - there are no calm down areas/no safe space
- The special needs views joining mainstream classes without forward planning
- Parent of 5 year old (Rainbow) expelled and in specialist provision; still has not been diagnosed
- Short-term he is based unit Bramley
- Highare not managed in mainstream
- 1 to 1 in nursery, primary school
- Schools did not put in support for his issues
- Schools have a legal responsibility to accommodate the needs of a child
- Variable service from schools

Theme 3: Communication

There needs to be better communication that services are available

- Facebook is an effective form of communication
- There is frustration in not knowing that services have changed, and the way services are accessed
- Autism in Croydon Facebook utilised by all services and residents affected by autism, 'one stop shop' for information
- <https://www.facebook.com/autismcroydon/>
- <https://www.croydon.gov.uk/healthsocial/adult-care/aschealth/autism-1>
- Theme 4: Non-English speakers, information about autism and services for autism in the top spoken languages in Croydon
- A school in the North, Winterbourne EAL pupils Sri Lankan family that are not good at English and we are having complex conversations
- Information needs to be in lay terms in Urdu, 8 top spoken languages in Croydon
- First stage explained in all languages
- Cultural behaviour have an impact on diagnosis, some parents do not accept autism in their culture
- Parents are able to challenge a panel of community medical experts regarding their child's condition

Theme 5: NHS services

- Croydon Hospital Services - Sanderstead clinic the OT says do exercise but not how many times for a specific movement or how Sanderstead Clinic

Theme 6: Consistency

- Standard and quality, multi-professional teams are sub-standard. The quality of their reports is atrocious
- Otavao, child in reception, no hand over; no forward-thinking in a child's required adaptations; a child's needs change and evolve over time. Multi-professionals write exactly the same report as 6 month previously on a child's condition.
- The reality is there are too many children for the limited services available
- Not enough places even if diagnosed
- There's so much rhetoric about early intervention - make it real
- Ironically looked after children are more provided for

Theme 7: What good looks like

- Transition meeting at 3 years old, a transition plan through childhood
- Good relationship with the professional from the start
- Autism teacher training is not inclusive, not part of teacher training, mature teachers require training
- Sol services - Joanne Kelly
- SENCO - multi-tasking
- Speech therapy and OT - training is one size fits all training
- EHC plan -statements of special educational needs are a step-forward
- Will not assess unless you can prove spending over 6k
- A solution is a mentor about the spectrum of autism
- Widening awareness through the community
- Special schools (currently very small %)
- Primary school - provision, small group learning
- A child that sees other children pick up a coloured crayon but cannot themselves you can soon identify the condition, good looks like a child starting in a special school and then considered for mainstream
- There are positive Niks is expanding, St Giles expanding

Table C: Communication Throughout the Process

Facilitator and note-taker: Darren Morgan

Issues

- GP's are difficult to access in the first place. Waiting rooms are small and cramped - my son is told to 'keep quiet', which makes him louder.
- My GP is the only person on my side - throughout the whole process. He is as frustrated as we are, as he's made referrals to CAMHS etc.
- We can't do anything without a GP referral.
- I've had to hand-deliver referral letters to the head of CAMHS personally, as I have no confidence in the process.
- My own GP is very helpful - when I get to see him, but the 'others aren't as understanding'. Some GP's tell my son off as he can be disruptive.
- They 'just ignore you'.
- My son has a habit of touching all the stuff in the GP's room.
- I can get a GP appointment straight away - the same day. They gave support while we were waiting for CAMHS - who just 'sit there and say not serious enough'.
- It gets more difficult as children get older.
- There are two waiting lists and a few different pathways - autism and co-morbidity. They also have a high risk pathway.
- It's a fragmented service.
- The children are all different but they run the service 'in a blanket way'.
- CAMHS are sending people out of borough (Camberwell for example), as they can't cope locally.
- Not all the services know where the support networks are. Went from the paediatrician to the GP to the Crystal Centre before I got the information I needed.
- The GP doesn't give us information.
- Pre-diagnosis support network is missing.
- We got a letter, so we waited. A year later and nothing.
- We got an information sheet from CAMHS that was too generalised.

- We have to re-explain things wherever we go - sometimes it feels like they don't know how to communicate with an autistic child. They ignore it and talk normally.
- The 'specialist' dentist isn't that different from the 'normal' one.
- A lot of it is 'down to individuals'.
- You have to 'live it to know it'.
- We have to be careful with labels - what does 'autism' mean?
- We need somewhere to go if our child has a meltdown - somewhere quiet.
- People at the lower end of the spectrum are 'brushed under the carpet'. I have nothing on paper to confirm my child's condition.
- There's 'not a lot of help' from teachers.
- I want my son to meet other people with autism - I want him to have confidence and to make friends.
- Services and support need to be appropriate to children's needs.
- The 'Waggy Tails' group is good for children - they get to train dogs and it builds their self-confidence.
- A lot of things that need improving don't require money - it's (1) acceptance and (2) information sharing.
- A lot of parents have special needs themselves.
- There's not a lot out there for behavioural support - people often have to seek private help (for ADHD etc).
- Nothing happens after diagnosis - no follow up or regular appointments (we need to see what's in the care plan).
- Things have been put in place for our son but it won't happen until we 'provide evidence'.

Priorities

- Lack of communication until you're 'somewhere in the system'.
- The way people talk to you (often feel talked down to).
- Autism needs to be an openly discussed condition.
- There needs to be a single leaflet - we don't know who to communicate with.
- Effective communication is resource and time consuming for clinicians - many seem to ignore the autism and talk normally.
- Some parents said the 'red autism flag' doesn't pop up on GP's computers so they have to explain everything, other parents said it did pop up, so mixed experience.
- When GP's don't understand it's like 'trying to introduce them to an alien'.
- Children are very sensitive and they know when people are trying to get them 'out the door'.
- The quality of booked and emergency appointments should be the same.
- Could hospital passports apply to primary care (GP's, dentists etc).
- The mum of a 6 year old has received no information or support on autism.
- Children get height and weight monitored - 'my son comfort eats and his weight is noted, but not the underlying cause'.

Suggestions

- Education and awareness raising please!
- The condition needs to be treated as a social one, as well as a clinical one.
- In schools they do things like sex education awareness - needs to be more disability awareness. It's schools autism awareness week but how many schools are actually doing anything??
- Professionals need specialist training.

- It's more important that we educate younger people.
- Children need support and input at a young age, the 'childhood journey is crucial'.
- There aren't any behavioural services and 'it's diabolical'.
- Children are being diagnosed with autism when it's not the case - they just have behavioural issues (ADHD etc).
- We need a phone number to call.
- There's no training for us parents - it's only available if you're going through the diagnostic process.
- Teachers in the specialist unit don't have autism training.
- A head teacher confirms that there is online autism awareness training for organisations (ie; hairdressers) and they get an award.

Improving Access to Services and Environment

Facilitator and note-taker: Taryn Thomas

Issues

- One parent tried to access respite and short breaks but was told that these services are for children with more severe needs.
- When the child is diagnosed there is no further support (the child grows and changes, their needs change).
- Diagnosis from CAMHS - again, no further support (nobody checks to 'see how things are going').
- The nursing assistants (present) need help/training.
- Children are unique and the spectrum is wide.
- One parent is confused as to where to seek help - somebody present advised the educational psychologist.
- Children at home are affected by their sibling's condition.
- Long waiting lists for CAMHS and no after support dealing with autism 'behaviours'.

Suggestions

- Better school communication needed.
- Teachers need to be better educated on autism.
- A higher level of support in secondary schools in particular.
- There needs to be a connection of all services.
- The ability to deal with overlap of ADHD, Autism etc.
- Family support services should be better funded and more widely available.
- There needs to be a mentoring service - with more role models.
- Peer support groups and counselling sessions should be widely publicised and signposted to.
- Enhanced training for doctors and medical staff.
- More training for other professionals (one child is fearful of going to the dentist - more support needed there).
- Free travel passes for carers!
- More assessments and support as children get older.
- Autism unit needs to be attached to the school.