

# Autism

The experience of children and young people in Croydon



March 2016

# “Hello, I am autistic”

“Autism is a lifelong condition that affects my social and communication skills. I don’t understand language and social situations the same as you so I may behave differently to other people.

New situations can make me feel very anxious and I may also have an over sensitivity to sound, light, smells and touch.

Please help me by being patient and understanding.

To me the world can be a mass of people, places and events which I struggle to make sense of, and which can cause me considerable anxiety.

Thank you very much.” [1]

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## Foreword

Healthwatch is the official ‘patient voice’ across England. Established as part of the Health and Social Care Act 2012, we champion the views and experiences of health and social care service users.

Day in, day out, we gather feedback from local people about their experiences and use their collective voice to influence the delivery and design of local services, whether it’s improving them today or helping to shape them for tomorrow.

We are attentive listeners, with a presence across Croydon - at health and social care services, community venues and online.

Whatever the setting, one thing we have heard much about is children’s mental health services, in particular those for Autism. People have told us about waiting lists in excess of a year and express feelings of isolation - often despair. There are many children, parents and carers who feel that the system has not met their needs, and having listened to their experiences, Healthwatch Croydon has issued this report to bring their views fully into public view.

While acknowledging Croydon’s unique challenges, in terms of demography and population, and welcoming plans for improvement that are now underway - we must not lose sight of what people have experienced, and continue to tell us.

We believe that as a borough, we should endeavour to provide children’s mental health services that are fit for purpose, intuitive (not responsive), with a service level that is not too different from other London boroughs.

Recently there has been much movement on this, with Croydon Clinical Commissioning Group conducting a complete redesign of the service, and the service itself under the spotlight of the Health and Wellbeing Board.

There is a real sense of determination that ‘the job will get done’ and it is the role of Healthwatch, through continuous engagement with children, their families and carers, to gauge the improvements that are anticipated, certainly expected. It is easy to calculate figures for waiting lists, but how do we calculate the impact on children’s development, and knock-on effect for wider society?

This report outlines the scale of the challenge, the experience of local people and the plans that are underway to bring about change.

....and service users have clearly indicated that they believe change is needed.

*Healthwatch Croydon Team*

## Executive Summary

### Context

Healthwatch Croydon, the 'official patient voice' of local health and social care service users has received feedback from residents to suggest that children's mental health services are not meeting their needs, and point to 'substantially better services' offered in comparative boroughs such as Lewisham and Bromley.

This is particularly so for Autism services, where children can expect to wait 18 months to access the services they are entitled to. As you can imagine, waits of such length can have a detrimental impact on the child's development, with consequences for family, carers, and indeed society as a whole.

### Listening Events

To find out more, we conducted a series of 'listening events' in the Autumn of 2015 to gauge the issues, and in doing so, offer suggestions for improvement. Engaging with community groups Inaspectrum, Parents in Partnership and the Burgess Autistic Trust, we recorded both casual feedback and more detailed case studies, and although we encouraged both positive and negative views, the shortcomings of the system were laid bare, with only glimmers of positivity forthcoming.

### What Children and Parents Said...

- Comparative services are much more accessible in Lewisham, Bromley and Surrey, which local residents resent.
- The referral process can be lengthy, with paperwork 'often on somebody's desk' and families having to prompt action.
- Services can be insensitive, for example, referring children to the 'Personality Disorder Clinic' will not help their self-esteem.
- Parents encounter 'constant barriers', needing 'official permission' time after time.
- Delays can be counterproductive and 'cost more', should conditions and circumstances deteriorate.
- Parents do not feel supported and some struggle under the burden.
- Services are not integrated, particularly social services and GP's.
- Specialist nurses and appointed 'key workers' are crucial in providing support and their contribution is highly valued.
- Services drop away in transition, which can be detrimental to long term development.
- Parents have to 'fight' to get their child's condition recognised, particularly at schools.
- Assessments can be too complicated, leaving people incorrectly assessed and feeling insecure.
- The fragmentation of services (multi-provider environment) makes the system difficult to navigate.
- It is felt that people with 'hidden conditions' are ignored.
- Lack of support can lead to decline of physical and mental health, with children self-harming, binge-eating and experimenting with alcohol and drugs.
- It can be difficult to access a social worker when needed, with one family calling 10 times in a day, and not managing to make contact.
- If support is lacking, children can become reliant on medication as there is 'little else'.

- Diagnosis is an essential pre-requisite to support and GP's need to refer to the correct pathways sooner.
- Some parents feel that funding is becoming more of an issue.
- One parent felt that the treatment 'destroyed' his child's creativity, so generic programmes may not be suitable for all.
- Children and their parents can feel 'totally isolated' within society.

### **Our Recommendations in Brief...**

Having analysed the feedback, our full report makes 'key recommendations', including:

- Experiences at different GP Practices vary considerably, with children and parents stating 'there appears to be no consistency of process.' GP's may benefit from refreshers on the pathway, plus wider training, including communication and how to involve children better in decisions about them.
- Families say 'there is a lack of information on the diagnosis process and time frame', this is perhaps due to the long waiting lists and multi-agency arrangement. If possible, families should be kept up-to-date and given relevant information. A lot of families say they are 'often in the dark' with support lacking.
- Children on the waiting list may be 'jumped' at any time by those who become acutely unwell. Is there a system in place to ensure that this does not happen 'time and again'?
- Parents are frustrated and not confident that their children will get the support they need. Lack of trust is an issue, so constructive dialogue is needed to offer reassurance. If clinical services are full, is there scope to utilise supplementary services or treatments?
- Many families are confused about services and support options, and would like much more information, particularly on which services exist, eligibility criteria and how to gain access. A one-stop-shop for information, in accessible formats and widely publicised, would provide much needed clarity.
- Access to Social Workers and other social care services such as behaviour management can be difficult, leaving families with little or no support, when they need it most. Telephone access in particular needs to be improved, with the ability to leave messages, should staff not be immediately available.

### **Local Transformation Plan**

Croydon Clinical Commissioning Group (CCG) has conducted a complete redesign of the service, and the service itself is under the spotlight of the Health and Wellbeing Board. Many of the issues, including on waiting lists, are being addressed by the plan, and an additional 20% in funding has been secured to augment Children and Adolescent Mental Health Services (CAMHS) as a whole.

The plan will be welcomed by children, their families and carers, but we must not lose sight of what people have experienced, and continue to tell us. We believe that as a borough, we should endeavour to provide children's mental health services that are fit for purpose, intuitive (not responsive), with a service level that is not too different from other London boroughs.

## 1. About Autism

The Autism Spectrum Disorder (ASD) is a condition that affects communication, social interaction, interests and behaviour. It includes Asperger syndrome and childhood autism. The signs of ASD typically start to develop in childhood. More boys are diagnosed with it than girls. There's no "cure" for ASD, but a range of educational and behavioural support programmes can help people with the condition. [2]

### 1.1 Signs and Symptoms

People with ASD tend to have problems with social interaction and communication. They can find it hard to understand other people's emotions and feelings, and have difficulty starting conversations or taking part in them properly. Language development may be delayed. Those with the condition are often only interested in certain things, have repetitive behaviours, and like to stick to a set routine. They tend to get upset if these routines are disrupted. [2]

Children and young people with ASD frequently experience a range of cognitive (thinking), learning, emotional and behavioural problems. For example, they may also have attention deficit hyperactivity disorder (ADHD), anxiety, or depression. About half of those with ASD have some degree of learning difficulty. However, many people are able to be independent with appropriate support. [2]

### 1.2 Diagnosis

The main features of ASD - problems with communication and social interaction - can often be recognised during early childhood. Some features of ASD may not become noticeable until a change of situation or environment, such as when the child starts nursery or school. [2]

## 2. Increasing Awareness of Autism

Estimates on the prevalence of autism amongst the population vary. The National Autistic Society estimates that approximately 1 in 100 of the population could be diagnosed as being on the spectrum but in reality it could be as high as 1 in 50. [3]

One factor which is likely to have impacted on the potentially increased prevalence could be greater awareness of the condition. Over recent years teachers, nursery workers and teaching support staff have benefited from greater awareness of autism. Where once a child may have been thought of as "fidgety" or "disruptive" staff have now been trained to look beyond the negative behaviour and consider other traits and behaviours. [3]

In addition, greater understanding and awareness among parents has also contributed to this especially with the plethora of resources and information available on line. As such, the increase in awareness amongst early years staff and parents. [3]

**“Even after admission, funding was not in place.”**

Case Study 4.2.5



### 3. Children and Young People with Autism in Croydon

Croydon faces very clear demographic pressures. The borough has the largest resident population in London, and the largest number of 0-16 and 0-19 year olds. The child population in Croydon is growing rapidly. An analysis of local authority school places planning returns shows that Croydon has the highest percentage growth of school aged population of any authority in the country. Given the growth of the child population it has been estimated that this figure will rise to approximately 24,000 by 2021. [4]

The number of children with ASD is set to rise significantly by 2021, with the number of children with autism (diagnosed) amongst 0-18 year olds expected to increase from 881 in 2012 to 1414 in 2021. Currently it is expected that 360 children will be on the ASD diagnostic pathway a year; this number has increased year on year. [4]

#### 3.1 Service Capacity Issues

Despite the size of its population, Croydon has a comparatively smaller core of specialist mental health services than other London boroughs which share its population features. Tier 3 investment in Croydon in 2013-14 amounted to £44 per child compared to £64 in Lewisham, one of the borough's statistical neighbours. In the face of difficulties in accessing Tier 3 services, it is estimated that children's services professionals are referring fewer children to the service, with a total of 1,345 referrals in 2014-15. This is a similar number to each of Lambeth, Southwark and Lewisham - despite Croydon's child population being approximately 50% larger than the population of any of these boroughs. Fewer numbers of referrals were accepted in Croydon in 2014-15, and waiting lists have developed into these services. [4]

For mental health conditions such as anxiety or depression, the waiting time from referral to assessment for the specialist Child and Adolescent Mental Health Services (CAMHS) service is 13.1 weeks. Waiting times for the Children Looked After and Youth Offending services provided by South London and Maudsley NHS Foundation Trust (SLaM) respectively are 6.3 and 1.6 weeks. For children requiring ASD diagnosis, without mental health comorbidities, the wait has been considerably longer, currently between 65 and 80 weeks. Recent figures state that 247 children under 5 and 239 over 5 are awaiting diagnosis. [4]

#### 3.2 Multi-Agency Landscape

CAMHS provision in Croydon is complex. As in other boroughs, it is commissioned at a local and national level and has multiple funding streams including Croydon Clinical Commissioning Group (CCG), London Borough of Croydon, Schools and NHS England. In addition to this, there are multiple relationships and interfaces with a large number of public and third sector agencies. These include Off The Record, Croydon Drop In, mainstream school provision via Head Start, Children Looked After and Youth Offending Teams in SLaM, Children's Centres, Primary Care General Practitioners, secondary and tertiary health care providers including Adult Mental Health Services for children in transition. [4]

**“ Our referral was sat on someone's desk. ”**

Case Study 4.2.2

## 4. The Experience of Local People

The challenges of capacity and pathway are well documented. For each statistic there is a child, parent or carer with a story to tell and Healthwatch Croydon held a number of listening events during the Summer and Autumn of 2015 to get a clearer sense of the local issues, visiting local groups Inaspectrum (19<sup>th</sup> August), Parents in Partnership (15<sup>th</sup> September) and Burgess Autistic Trust (16<sup>th</sup> November), engaging with around 40 people.

### 4.1 About the Groups

#### Parents in Partnership (PIP)

Parents in Partnership Croydon (PIP) is registered charity established in 1992, whose aims are to relieve parent/carers of children and young people with disabilities and special needs in Croydon by providing appropriate support, information and signposting. PIP also represents parent/carers views by working closely with those partners who cater and shape services to meet the needs of families. The charity strives to enable parents to be involved with each other to reduce the isolation that can be part of having a disabled child; supports parents to access appropriate services for their child; provides opportunity for information sharing among parents through events, training and online; empowers parents and develops their skills to be more involved in shaping services, providing representation on particular topics or areas of disability and being part of the developing Croydon Parent Forum; voices parents' views into strategic settings and works towards the improvement of services in the borough, facilitating parent representation for consultations on existing or new services, initiatives and on panels.

It was the experience of PIP members that inspired Healthwatch Croydon to research Autism from the outset. [5]

#### Inaspectrum

Inaspectrum is a voluntary, small (non-registered) charity. Their aim is to gather together an inclusive association of people affected by Autism, so that members 'contribute to the world around them'. [6]

#### Burgess Autistic Trust

Burgess Autistic Trust is a specialist independent charity, working with people in Bromley since 1981 and now working in several other South East London boroughs. They offer a wide range of services supporting children, young people and adults with differing needs. Their Family Service supports families with children with a diagnosis of ASD up to the age of 18. [7]

Working across boroughs, the Trust has noted differences in service level with one person commenting:

### 4.2 Case Studies

#### Case Study 4.2.1 'Croydon, the Poor Neighbour'.

"We are fortunate that we live in Sanderstead and our GP Practice is on the Limpsfield Road, just over the border in Surrey. Our GP was great and very supportive for our son's depression. So our son was referred to the Community Mental Health Team in Oxted, where he saw a brilliant psychiatrist."

“When he self-harmed 3 times was sent to Langley Green Hospital, Crawley where there was an excellent team, and was referred to SLaM for assessments for Aspergers and Attention Deficit Hyperactivity Disorder (ADHD) in 2011 & 2012 funded by Surrey NHS. We eventually got a Croydon Social Worker allocated, she was forced by the Hospital Psychiatrist to place him in a care home in Tandridge/Godstone where he was helped enormously.”

“She told us never to change our GP as we would never get similar services in Croydon. Our Parents Group children have not received similar support from their GPs, Croydon Community Mental Health Team (CMHT), or Croydon Social Services, and cannot even get referral for assessments, so are in real messes, with no support from Croydon Social Services either.”

A number of other case studies follow, illustrating the challenges faced by children, their families, and carers. Access to mental health, primary and social care services is a common thread, but we also found wider issues, such as under-achievement at school, diminished quality of life and social isolation. We seek to emphasize positive as well as negative experiences, however, during our listening events, where attendees were able to talk freely, the shortcomings of the service have been laid out bare.

#### **Case Study 4.2.2 ‘Our Referral Was Sat on Someone’s Desk’.**

It’s taken a long time for our son to get services. He dropped out of education - we went to the GP and asked for a referral to the national service at Bethlam. It had to be funded through the CCG (who make assessments) so we put a referral in. A couple of months later we’d heard nothing, so chased it up - the panel came back and said ‘sorry, you gave us insufficient information’, turning the referral down, but why were we not told this, or given an opportunity to resubmit with all the required information? A lot of things about the referral process were not followed up. The GP said he would ‘fight the decision’ but in the end did not, as he was ‘busy’. I’ve heard people say it might be because this type of service is ‘expensive and difficult’.

#### **Case Study 4.2.3 ‘Let’s be Sensitive About This’.**

My child does have a personality disorder, but it doesn’t help her self-esteem when she’s referred to the ‘Personality Disorder Clinic’. Couldn’t we use a kinder service name?

#### **Case Study 4.2.4 ‘Barriers, Barriers, Barriers’.**

A year on and we’re in the same boat - things are getting worse and worse. We have to get official permission just to get an appointment. It’s all ‘barriers, barriers, barriers’.

#### **Case Study 4.2.5 ‘Delays are Counterproductive’.**

The diagnostic pathway is ‘retracted’. Our son needed to be sectioned for hospital treatment and it finally happened after 3 - 4 months. But the real frustrating thing was even after admission, funding was not in place, and it took another 3 - 4 weeks of uncertainty, while he was in his hospital bed. All these delays, apart from the anguish they cause, are ‘counterproductive’ and end up ‘costing the system more’.

**“The doctor has been genuinely concerned.”**

**Case Study 4.2.21**

#### **Case Study 4.2.6 ‘Nobody Supports Us to Support Him’.**

It took 2 years to get our son into inpatients, it’s been ‘really quite difficult’. Over the course of time things have gone ‘right downhill’.... and it’s ‘all avoidable’! Our son self-harms, wonders out at all times of the night. There’s no support. It’s a cry for help and he thinks ‘why isn’t anyone listening to me’ - he bangs on doors and bangs his head. He looks to us as parents to solve the problems but ‘nobody supports us to support him’. It’s a reflection of the ‘inadequacies of mental health services’, there’s a lack of beds and care in communities. The ones missing out are often the ones least able to support themselves and ‘I think that is wicked’. It’s been a full time job for my husband - it could all have been avoided and it’s affected the whole family - the impact is enormous on all of us. It has been very difficult trying to get my son to stop banging his head.

#### **Case Study 4.2.7 ‘We Need and Certainly Deserve More’.**

As parents we are our daughter’s carers and we need support - at the moment the floor is literally giving way and we will be needing temporary respite while work is being done. Our social worker says we’re not eligible for supported living even though our daughter is diagnosed with Asperger’s. The social worker is also critical of GP’s and says ‘they have no knowledge’, so is there an issue of trust between the services? Anyway, we as a family have been given ‘very little knowledge, advice, understanding and professional support’. We need more than that and certainly deserve more than that. A lot of money has been put into areas such as diabetes, understandably, but mental health is also a rising challenge.

#### **Case Study 4.2.8 ‘Having a Key Worker is Vital’.**

Having a key worker, that one place to go is ‘vital’. Our daughter had huge problems at school - the ‘absolutely fab’ ADHD team at SLAM have been brilliant, especially one specialist nurse, ‘a lovely lady who has been a life saver’. Various things have come up and we’ve been able to pick up the phone and email and she’s dealt with things.

#### **Case Study 4.2.9 ‘Back On Square One’.**

Our teenage daughter has a speech and communication disorder as well as ADHD - making her particularly vulnerable. Things got difficult and we feared she may not manage at college, but we did secure therapy sessions and got a care plan. Then, suddenly we were discharged - we wrote a letter of appeal but were sent back to our GP - ‘back on square one’. The key worker stepped in and the therapies were reinstated, but at the age of 16 it’ll stop and we will have issues.

#### **Case Study 4.2.10 ‘Constant Fighting’.**

We lose trust and confidence in the system and become miserable and angry. There’s little or no support in schools and we’ve had to fight all along for what we did get. It’s ‘constant fighting’ - the only way to get acceptance is through people who understand. Our daughter became silent in class and was assessed - the professionals ‘thought she was stupid’ but just the opposite - she has an IQ of 149! She was put in a special unit and lost all her GCSE’s, but she got the highest grade ever in the school for art. If only people would understand.

**“ I feel my GP has little awareness of autism. ”**

**Case Study 4.2.18**

#### **Case Study 4.2.11 ‘The Assessor Was Trying to Undiagnose Me’.**

At my last assessment for services I’m sure the assessor was ‘trying to undiagnosed me - trying to catch me out’. She had written something down I didn’t say - and confused me with a local mental health ‘map’. ‘It was awful’ - she didn’t take my communication difficulties into account. I feel like I will be caught out and undiagnosed. I was left feeling frustrated, anxious and angry - none of my difficulties were put into the report.

#### **Case Study 4.2.12 ‘Not Asking the Right Questions’.**

I need therapy but there’s a ‘focus on alcohol and drugs’ and I have no problems with either. I feel penalised for not having addictions - they’re ‘not asking the right questions.’

#### **Case Study 4.2.13 ‘There Needs to be One Point of Reference’.**

There needs to be one point of reference - without having to go to the GP - somebody who knows us. Our son was having problems with driving tests, they upped his medication and sorted it, but the hassle we endured having to go through the GP!

#### **Case Study 4.2.14 ‘Those with Hidden Conditions are so Often Ignored’.**

Life is really, really hard for us parents - it’s not fair, we need some help. It’s not fair that people with a broken leg get treated, but those with hidden conditions are so often ignored. Mental Health problems do impact on physical health.

#### **Case Study 4.2.15 ‘Vulnerable’.**

Our son is vulnerable - he looks for ways to feel good and there’s nothing out there, so he ends up binge eating. He’s now been diagnosed with diabetes and it’s undermining his health. The annoying thing is, with a little support these people can live decent lives - they just need a cushion. But in many ways our son can ‘outshine people’. Autism is our child’s finest trait - hardworking, honest, full of integrity. If supported properly autistic people would be ‘extremely valuable’.

#### **Case Study 4.2.16 ‘Tried 10 Times Today.... and Nothing!’**

Our son needs support - he has problems eating and going out, amongst other things. We discussed support and referral options with the GP, then went to the transitions team who said ‘sorry, you’ve got to have a social worker’. It took ages. We got an assessment of a sort, but a full financial assessment was needed. We managed to get a meeting with the National Autistic Society (NAS) and a social worker, who agreed our son needs confidence training. Since then we’ve not been able to get hold of a social worker at all - someone picked up the phone and put it down - it was actually ‘really scary’. These are the people who are supposed to help! Eventually we found a way around - we phoned Business Support (not the Social Work Team directly) and they will get the social workers to do something. You can also get onto a manager and ‘pull up social worker’. However, we ‘tried 10 times today and nothing’. So frustrating! There should be some kind of a system.

#### **Case Study 4.2.17 ‘Left to my Own Devices’.**

Once you have a diagnosis, what support is there - what is there at the end of it? I feel that way. If I am ‘left to own devices’ it’s very difficult and I’m dependent on drugs.

**“In many ways our son can outshine people.”**

**Case Study 4.2.15**

#### **Case Study 4.2.18 ‘Diagnosis is an Essential Prerequisite to Support’.**

Diagnosis is an essential prerequisite to support, benefits, and a raft of options. I feel my GP has little awareness of autism - he said ‘what you need to do is go out and socialise’. I’ve had a horrendous time over the last few years, fighting for an official diagnosis. Eventually my GP did recognise depression (at least) and referred me to the Maudsley, who supplied a comprehensive diagnosis, at long last.

#### **Case Study 4.2.18 ‘Funding Issues Have Amplified in Recent Years’.**

Assessments are regular and quite challenging and I feel funding issues have ‘amplified in recent years’.

#### **Case Study 4.2.19 ‘Autism is a Gift’.**

Our son got an 18 page assessment, including a 2 page executive summary which focussed on depression, but really autism ‘is a gift’. Crowd avoidance is the issue - we were offered six months of Cognitive Behavioural Therapy (CBT) but that turned out to be inappropriate. Medication resulted in him putting on 4-5 stone. The treatment didn’t hinder creativity - ‘it destroyed it’! Since coming off the medication he is on the road to recovery. He can now go into nearby shops when quiet, and has just come through a period of clinical depression. He got funding and other benefits including a freedom pass - he’s now ‘ticking over’ is the best I can say. Looking after his best interest is ‘a constant battle’ and we’ve had to fight alone. We’re concerned there is no ‘parallel support’ (safety net) in the borough. We all bump along, on a learning process, but why should we be struggling? We’ve had to do much to get to where we are. There is a common need that we feel is not being met.

#### **Case Study 4.2.20 ‘Totally Isolated’.**

Our son was ‘totally isolated’ - he had no friends, or understanding, whatsoever. The youth clubs didn’t speak to him. The only time he was really understood was at a school for physical disability - not perfect, but at least he was supported.

#### **Case Study 4.2.21 ‘The Doctor Has Been Brilliant’.**

“We have only been registered with this GP for a year, having had to switch surgeries due to NHS funding issues (we live in Croydon but our old surgery was in East Surrey NHS area). The doctor has been brilliant. I have seen them a few times in relation to my son’s social communication and health concerns and the doctor has always treated me as a sensible, intelligent adult, and really taken on board my views and opinions as a mother, something that I am afraid I have not always experienced from my previous surgery. I don’t feel I am being rushed through an appointment and the doctor has been genuinely concerned and helpful. Dealing with getting medical support and assessment for a child with suspected social communication disorder (autism spectrum) is incredibly stressful, but the doctor has been very efficient and really helpful in trying to get us the referrals we needed, and I have really appreciated it.”

**“Those with hidden conditions are ignored.”**

**Case Study 4.2.14**

## 5. Learning from Experience

Based on what we've heard, we have summarised 16 'key' improvements that may be considered to improve the service for children, their families and carers.

It is the role of Healthwatch to influence the commissioning and delivery of services, therefore our recommendations are not prescriptive, but intended to inspire solutions to the issues that clearly exist.

### 5.1 Communication

*Children feel they are not being communicated with effectively, particularly in GP settings, with some commenting 'I feel as if I'm not in the room'.*

#### **Recommendations for GP Providers**

1. All practice staff would benefit from a sound level of awareness in how to recognise, support and communicate with people with neurological conditions, particularly children. This could be achieved by training, including learning from specialist practitioners and nurses.

**Action:** By this time next year, we hope that awareness of neurological conditions (including Autism) is included in staff training plans.

2. When practice staff interact with children and parents, explanations should be clear and concise, with care taken to ensure patients are given enough time to listen to and understand. It would be beneficial if computer systems alerted staff to the condition so that interaction is not expedited and care is taken.

**Action:** By this time next year, we hope that people with neurological conditions are differentiated from other patients in a systematic way (for example, a visual symbol that may be instantly recognisable by all staff).

3. Children with Autism are particularly prone to anxiety. Practice staff and systems could help by being sensitive and flexible, for example, providing an alternative to the electronic calling display, which can cause children to become anxious immediately prior to their appointments.

**Action:** By this time next year, we hope that calling options are more person-centred, with alternatives (such as personal calling) in place.

#### **Recommendations for Mental Health Providers**

4. As well as anxiety, lack of confidence can be common in children with Autism. Services such as the 'Personality Disorder Clinic' will not help their self-esteem - perhaps a more subtle use of terminology could be explored.

**Action:** By this time next year, we hope that alternatives (such as use of acronyms - PDC in this case), have been considered.

## How will we know we have succeeded on communication as a whole?

When consulting with children, families and carers this time next year, we hope to hear that they have been included in discussions and decisions about them, and encouraged to take part. We hope that they understand their journey through the system, at each stage.

### 5.2 Consistency of Process

*Experiences at different GP Practices vary considerably, with children and parents stating 'there appears to be no consistency of process.'*

#### **Recommendations for GP Providers**

5. It is important that GP's ask targeted, relevant questions so that children may be placed on the correct pathway, and sooner. Refreshers on pathway criteria, and access to standard documented guidance, could prompt GP's to make correct assessments and decisions more often.

**Action:** By this time next year, we hope that GP's are fully aware of the pathway, and of which organisations to refer to (CAMHS should not be an automatic default option).

*Families say 'there is a lack of information on the diagnosis process and time frame', this is perhaps due to the long waiting lists and multi-agency arrangement.*

#### **Recommendations for the CCG**

6. 'We need a single point of access' is a phrase that Healthwatch hears regularly. The development of a unified access point, with agencies working together, would reduce inconsistency, confusion and delay, and increase efficiency and effectiveness.

**Action:** By this time next year, we hope that children, families and carers can call a single number to access all services.

7. Lack of information and awareness of the 'process' is a common cause of frustration. Families should be kept up-to-date and given relevant information at every opportunity, whatever their stage in the pathway. A 'shared care' arrangement between agencies would enhance consistency of service and support.

**Action:** By this time next year, we hope that children, families and carers know who to contact (named person) for advice and support.

*It is widely known that comparable services in neighbouring boroughs are more accessible and this is the cause of local resentment.*

#### **Recommendations for the CCG**

8. Given that regional disparity is clear, residents would hope that the CCG is 'fighting for a bigger share' of funding that does exist. The additional £1.2 million for Tiers 2/3 CAMHS services (equating to an extra 25%) is a substantial funding boost, but this is a short-term measure, and will not solve the entrenched problem of capacity.

**Action:** By this time next year, we hope that longer term funding has been explored, with key funders challenged. We hope that the funding disparity with neighbouring boroughs has decreased.



## How will we know we have succeeded on consistency as a whole?

When consulting with children, families and carers this time next year, we hope to hear that trust in the system is restored and that families no longer feel they are 'in the dark', or that the 'referral process is a challenge, with all too often delays'.

### 5.3 Service Access

*Parents often comment that 'nobody supports us to support our children' and many express feelings of frustration, sometimes despair.*

#### **Recommendations for Social Care**

9. It can be difficult at times to access social workers, particularly by telephone, with one family 'calling 10 times in a day, and not managing to make contact.'

**Action:** By this time next year, we hope that telephones will be answered more often, and when not, messages may be left that are responded to.

*Behaviour management, including self-harm, is problematic for some, with one family not able to stop their son 'banging his head'.*

10. There is very little support available for behaviour management, it has been cited that the 'existing service is extremely limited', therefore children and families may go with little, or no support.

**Action:** By this time next year, we hope that an adequate level of support is provided, this may include signposting to organisations that may be able to offer assistance.

*Waiting lists are excessive and it is well documented that children can expect to wait 18 months for a diagnosis. Some families have also said that although therapies have been stated, they may expect to wait a number of years, for example, for speech therapy.*

#### **Recommendations for the CCG**

11. Recruitment of additional psychiatrists, counsellors and therapists would boost capacity and ease pressure on waiting lists.

**Action:** By this next year, we hope that more trained professionals are available, with waiting lists down.

12. If clinical services are full, is there scope to utilise supplementary support services or treatments that have proven benefit in the interim? Greater promotion of peer support groups, for example, would benefit both users, and the group.

**Action:** By this time next year, we hope that attendance at supplementary support groups and services has increased, with greater awareness amongst professionals.

## How will we know we have succeeded on service access as a whole?

When consulting with children, families and carers this time next year, we hope to hear that the waiting list is much shorter (considerably shorter than 18 months), and that the wait for therapies and treatments is reasonable.

We hope that parents do not feel they have to 'fight' to get their child's condition recognised.

### 5.4 General Information and Advice

*Access to advice and information should not be underestimated as a major issue - many families are confused about services and support options.*

#### **Recommendations for the CCG**

13. A one-stop-shop for information, in accessible formats and widely publicised, would provide much needed clarity.

**Action:** By this time next year, we hope that there is a single document (guide) offering comprehensive information, thereby easing confusion and isolation.

14. Children and families increasingly use computers - an online facility providing specialist advice, information and peer support may reduce the need for face-to-face services.

**Action:** By this time next year, we hope that children, families and carers are able to use an online platform (advertised widely at GP's and schools etc) and not having to visit professionals as often, as a result.

15. Extra administrative cover at services and agencies may enhance the general availability of information.

**Action:** By this time next year, we hope that agencies have been better resourced to deal with information requests, and better able to give advice.

## How will we know we have succeeded on information and advice as a whole?

When consulting with children, families and carers this time next year, we hope to hear that families are aware of which services exist, are clear about eligibility criteria and how to gain access.

## 5.5 Environment

*Children, families and carers have commented negatively about the environment at Christopher Wren House - the building itself is 'not the most accessible or welcoming' and lacks parking facilities.*

### **Recommendations for Mental Health Providers**

16. To get to the consulting room requires passing through no fewer than six doors, most with security features. Reassessment of layout will go some way to improving attendance rates.

**Action:** By this time next year, we hope the environment at Christopher Wren House is much more accessible and welcoming, with attendance rates up.

### **How will we know we have succeeded on environment as a whole?**

When consulting with children, families and carers this time next year, we hope to hear that they have kept their appointments at Christopher Wren House.

## **6. Addressing the Issues - The 'Local Transformation Plan'**

In acknowledgement of the issues, a Local Transformation Plan for Children and Young People's Mental Health and Wellbeing has been proposed and sets out Croydon's multi-agency approach to promoting children's emotional wellbeing and mental health, along with an action plan which sets out clearly what will be done. Local Transformation Plans cover the whole spectrum of support for children and young people's mental health and wellbeing from health promotion and prevention work, to interventions for children and young people who have existing or emerging mental health problems, as well as transitions between services. The Plan will be held by the CCG in collaboration with local partners and monitored through NHS England from the second half of 2015-16. [4]

An all-age ASD commissioning group (comprising representatives from children and adult commissioning across the council and CCG) has completed its work to consider the diagnostic and support pathways for children and their families affected by ASD. This incorporates a proposal in development to clear the waiting list backlog for diagnostic assessments, along with other measures. [4]

### **6.1 Improving Pathways into Services through a Single Point of Access**

The Single Point of Access (SPA) will offer one point of contact for a wide range of universal services to access a team of children and young people's mental health professionals for advice, consultation, assessment and onward referral. Services will be better joined up locally across the CCG, Local Authority and other partners, enabling accelerated service transformation. [4]

The aim of the model will be to increase access to services by putting in place a clear, well understood pathway, redesigning service flows and permitting commissioners to better assess flow and demand pressures in a timely way, so that resources can be realigned to meet needs more effectively. [4]

## **6.2 Diagnostic Pathway**

The diagnostic pathway is split between community paediatrics and SLaM. The current waiting time for diagnosis is 19 months for both pathways. To put this in to context, the same number of children and young people enter Croydon's pathways each month as Richmond, Merton, Sutton, Kingston and Wadsworth combined. [4]

Commissioners are working with providers to look at the prevalence rate, as Croydon appears to be an outlier in terms of ASD diagnosis compared to both South West London and the other SLaM boroughs. [4]

Additionally, Croydon is an outlier in asking the CAMHS service to hold the diagnostic pathway for over 5s', where other boroughs employ a multi-agency process sited outside mental health services. This has put significant pressure on the neuro-disability pathway, with young people and their families looking for long term support; increasingly relating to behaviour/conduct disorders and multiple mental health conditions, including depression and anxiety. [4]

Pathways for different areas of need are being explored to ascertain where 'the offer should be strengthened'. The pathways under review are autism and autism with learning disabilities (known as co-morbidity). While many of the children and young people services collectively support have a range of complex needs, there is often a primary need which is significant in determining the type of advice and support offered and the teams which provide it. [4]

## **6.3 Implementing a 'Shared Care' Protocol**

Work continues with GP's and psychiatrists to ensure that children and young people have shared care i.e. that they receive specialist mental health services whilst their GP ensures that their physical health is reviewed appropriately, including any necessary access to medication. This is currently patchy in Croydon, and poses a resource requirement on the SLaM CAMHS service. [4]

A GP telephone helpline is being set up that will allow direct access to SLaM services, in order to discuss patients' physical health and any changes to drug regimes. Managed medicines have reviewed and approved the shared care protocol. [4]

## **7. Welcoming the Plan**

Healthwatch Croydon is encouraged by the proposals set out in the Local Transformation Plan, which address many of the key recommendations outlined in section 5 of this report.

The commitment by Croydon CCG to deliver, through service redesign and additional funding is clear, and will be welcomed by children, their families and carers across the borough. There is an expectation that waiting lists in particular will come down, and we aim to revisit people's experiences, to see if this aspiration becomes a reality.

## **8. Croydon Council on Autism**

Going forward Healthwatch Croydon aims to work with Croydon Council, who have brought Autism provision to the agenda of the Health and Wellbeing Board, and appointed Councillor Andrew Rendle as the 'Autism Champion for the Borough'.

On the Croydon Council website, Andrew says that "Well before the local elections in May 2014 I found out about the Autism Champion role within the council, I saw it as a huge opportunity to raise awareness of ASD in Croydon and make a real difference.

My desire to do this job came initially when my son Luca was diagnosed with autism and enhanced when his younger brother Mika was also diagnosed with ASD. The way the boys see the world and communicate has opened up a new a fascinating world for me and highlighted how children and adults with ASD, along with their parents and carers need all the support we can give.

In these past few months I have spoken to or had correspondents from countless parents pointing out to the good, the bad and the gaps in services. I have also had meetings with council officers, teachers, service providers, NHS professionals and representatives of charities such as the National Autistic Society. All of these meetings have helped me understand what we politicians can do the help and I am going to do just that.

My next step is to hold a large autism forum and re-start the autism steering group where council staff, politicians, commissioners, carers and those with autism can shape the future. I am also working with Cllr Maggie Mansell the chair of the Health and Wellbeing Board to push autism policy in Croydon and make it easier for those on the spectrum to access health care. In addition Cllr Toni Letts our cabinet member for Economic Development is working with me to help autistic adults enter the world of work and show employers what excellent employees they can be.

I am also hoping to boost awareness of autism and help organisations who deal with the public such as the police and the council learn how to communicate with and understand what fears and difficulties autistic adults have.

It's a major challenge but with the support of officers, councillors, charities and most importantly those personally touched by Autism I know we can make things better." [8]

Councillor Tony Newman, Leader of Croydon Council says:

"I am proud as the Leader of the Council, that in Cllr Andrew Rendle, Croydon has a powerful Autism Champion who is committed to ensuring we all work together to maximise the opportunities both in terms of training, employment and life opportunities for those with Autism. Cllr Andrew Rendle I know wants to hear your views on how as a Council we can do more to advise and support those who might need it." [8]

## **9. The Online Community**

Croydon has a thriving online community and the Facebook page 'Autism in Croydon' brings together families, residents, community groups and professionals. [9]

## 10. Glossary of Terms

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorders
CAMHS	Child and Adolescent Mental Health
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Group
CMHT	Community Mental Health Team
NAS	National Autistic Society
SLaM	South London and Maudsley NHS Foundation Trust
SPA	The Single Point of Access

## 11. References

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<https://www.croydon.gov.uk/sites/default/files/articles/downloads/Introduction%20to%20Autism%20-%20English.pdf>
2. **Glossary of Mental Health Services, Teams and Care Pathways**  
<http://www.nhs.uk/conditions/autistic-spectrum-disorder/pages/introduction.aspx>
3. **Local Implementation of the National Autism Strategy**  
[http://www.healthwatchcroydon.co.uk/sites/default/files/local\\_implementation\\_of\\_the\\_national\\_autism\\_strategy.pdf](http://www.healthwatchcroydon.co.uk/sites/default/files/local_implementation_of_the_national_autism_strategy.pdf)
4. **Croydon's Local Transformation Plan for Children and Young People's Mental Health and Wellbeing**  
[http://www.healthwatchcroydon.co.uk/sites/default/files/local\\_transformation\\_plan\\_v0.9\\_071015.docx](http://www.healthwatchcroydon.co.uk/sites/default/files/local_transformation_plan_v0.9_071015.docx)
5. **Parents in Partnership (PIP)**  
<http://www.pipcroydon.com/>
6. **Inaspectrum**  
<http://www.inaspectrum.com/>
7. **Burgess Autistic Trust**  
<http://www.burgessautistictrust.org.uk/>
8. **Croydon Autism Champion, Councillor Rendle**  
<https://www.croydon.gov.uk/healthsocial/adult-care/aschealth/autism-0>
9. **Autism in Croydon (Facebook Page)**  
<https://www.facebook.com/autismcroydon>

“In many ways our son can outshine people.

Autism is our child’s finest trait - hardworking, honest, full of integrity.

If supported properly autistic people would be extremely valuable.”