

# **MINUTES OF CHILDREN AND YOUNG PEOPLE'S SCRUTINY PANEL HELD ON WEDNESDAY, 11TH MARCH, 2020 (JOINT MEETING WITH ADULTS AND HEALTH SCRUTINY PANEL)**

## **PRESENT:**

**Councillors:** Erdal Dogan (Chair), James Chiriyankandath, Mike Hakata, and Tammy Palmer

**Co-opted Members:** Luci Davin (Parent Governor representative) and Yvonne Denny (Church representative)

### **38. FILMING AT MEETINGS**

The Chair referred Members present to agenda Item 1 as shown on the agenda in respect of filming at this meeting, and Members noted the information contained therein'.

### **39. APOLOGIES FOR ABSENCE**

Apologies for lateness were received from Cllr Opoku

### **40. ITEMS OF URGENT BUSINESS**

There were no items of urgent business.

### **41. DECLARATIONS OF INTEREST**

None

### **42. DEPUTATIONS/PETITIONS/PRESENTATIONS/QUESTIONS**

None.

### **43. TRANSITIONS**

At a joint meeting of the Children and Young People's Scrutiny Panel and the Adults & Health Scrutiny Panel, Members received a presentation on a review of priorities for a whole of life autism strategy. Members were asked to note the presentation and provide comments. The presentation set out the policy context, drivers and priorities for young adults with autism who were transitioning from children to adults and the pathways involved in that transition from child-orientated to adult services. It was noted that this was a follow up to a previous look into transitions undertaken by the Adults and Health panel last year. The presentation was introduced by Charlotte Pomery, AD for

Commissioning and Georgie Jones-Conaghan, Joint Lead Commissioner for Adult Learning Disability and Autism.

It was noted that an Autism Strategy Group had been established which included a wide array of partners and parent/carer representatives. The group had met three times and was still developing and expanding.

Members were advised that Autism was a life-long condition for which there is no 'cure'. Autism is a spectrum condition. Which meant there are a wide range of traits associated with autism and different levels of need. Some autistic people also had learning disabilities, mental health issues or other conditions, meaning people needed different levels of support.

Autism causes difficulties with social communication and interactions, as well as a potentially restricted and repetitive range of behaviours, activities or interests. Autistic people are more likely to have environmental sensitivity. This means they may be hypersensitive or under sensitive to pain, temperature or other aspects of their surroundings. This will vary in type and intensity from person to person. The social model of autism is increasingly moving away from seeing autism as a 'disorder' and adopting a 'neurodiverse' understanding that sees autism as being different but not deficient.

Officers set out that a whole of life strategy was being developed, which was partially a response to increased awareness of autism, a recognition of that pathways for autistic people were in some cases inadequate as well as a recognition of the need to listen to the voice of those with autism. Officers also set out that the Council was beginning a process of co-production of services with services users and that this had highlighted a need for change. Further drivers of this work included the Autism Needs Assessment in 2017, a recognition of the need for better early intervention and prevention, as well as the SEND Joint Strategic Needs Assessment completed in March 2020 which showed a growing prevalence of autism in Haringey.

Some key facts and figures:

- There are at least 700,000 autistic people currently living in the UK, which is around 1% of the population.
- Approximately 40% of autistic people have co-occurring learning or intellectual disabilities 80% of autistic people, at some point in their lives, have mental health problems such as anxiety and depression, and the majority rate their anxiety as the number one problem in their lives.
- Autistic people without a learning disability are 9 times more likely to take their own life than the general population.
- There are under reported BAME and equalities issues for autistic people, including a high prevalence of autism amongst trans people and some cultures not recognising autism and having no word for it. Autism is apparently more prevalent in males than females, but this is likely to be due to under-reporting of girls and women and their better ability to mask features and behaviours.
- White Hart Lane, Tottenham Hale and Grove were identified as the wards with the highest number of autistic children in the borough. Officers advised that similar information was not held in relation to adults with autism.

The following was noted in response to the discussion on the policy context and drivers of a Haringey whole of life autism strategy:

- a. In response to a concerns raised about the fact that Tottenham had the highest rate of autism in the Borough and the reasons for this, officers clarified that it was three wards rather than the whole of Tottenham and advised that they were looking to see whether there were any environmental factors that could explain this. Officers advised that they were also working on the Joint Strategic Needs Assessment to identify the issues involved. Members were advised that there was a correlation with a need for speech and language therapy in those areas.
- b. In response to concerns about the Grove and an increasing tendency to concentrate children in specialised schools, officers advised that there were 779 young people with an Education, Health and Care Plan who were identified as being autistic and of these around 530 were in mainstream schools. In contrast, there were around 240 in specialist schools of whom 80 went to the Grove. Officers clarified that these figures related to children who were registered as Haringey residents and could attend educational institutions both inside and outside of the Borough.
- c. In relation to a follow-up question, Officers advised that there were 2282 Education, Health and Care Plans (EHCP) in the borough, which represented an 18% growth from the previous year. One of the key things reflected in an EHCP was autism.
- d. Officers advised that the prevalence of autism within Haringey was broadly on trend with the rest of the UK.
- e. Members sought clarification around what was meant by embedding 'neuro diversity'. In response, officers advised that the language used was crucial with autism as well as the need to adopt an inclusive approach. Overall, the approach involved consulting and listening to patients and providing a person specific response.
- f. Members enquired whether there were home school stats for children with autism. Officers advised that the prevalence of home schooling for children in Haringey was comparatively quite low. Officers agreed to send round the figures for home schooling after the meeting. **(Action: Nathan Jones).**
- g. In response to a question, officers advised that information on adults with autism was much scarcer due to the fact that EHCPs were one of the key means by which autism was identified and pathways/responses were determined. There was no register as such for Haringey adults with autism and Members were advised that only clinical institutions like Maudsley Hospital would hold this information. Officers acknowledged that one of the key outcomes in developing a strategy was to provide better information advice and guidance that our ability to signpost services was improved.
- h. In response to a question, officers set out the importance of self-evaluation and the need to be driven by the data.

Priority one of the Autism Strategy was improving diagnostic services for autistic children, young people and adults. The key elements of this included:

- The development of new pre and post diagnostic support in-borough, run by BEH MHT.
- Children's clinical providers had started to work together on joint clinics across CAMHS/ autism diagnostic services. A review of the current children's diagnostic pathway was underway

- Review and emphasis based on feedback from users on importance of pre & post diagnostic support
- Careful planning to ensure young people transitioning will not be disadvantaged by a children and adult diagnostic service, and agreement locally to ensure a whole of life pathway would underpin this.

The following arose in response to the discussion of priority one of the autism strategy:

- a. Members sought assurances about how much work was being undertaken in relation to hard to reach cases and in particular where English wasn't a first language. In response, officers acknowledged these concerns and agreed that some consideration would be given on how to reach hard to reach communities and what support could be given to help them access services.
- b. In response to a question, officers advised that there was a growing body of research into the causes of autism and that clinical knowledge was developing all of the time. It was noted that autism is something that children could be born with and there were also a range of environmental factors that could have an impact.
- c. In response to a question around the autism hub, officers advised that it was primarily designed for ages 16+, however it was hoped that it would also provide a safe space for parents and carers of autistic children to meet and access a varied of other information and services.
- d. In response to a question around other boroughs that provided a similar autism hub, officers advised that Kensington and Chelsea and Westminster were in the process of implementing something similar and that officers had spoken to their counterparts in those boroughs.
- e. The Chair raised concerns about the transition from children to adult services and the disjointed nature of some of those services. Given that the hub was designed for 16+, the Chair was keen to understand what hub-type services existed for younger children and what those pathways were for preparing for adulthood. In response, officers acknowledged that it was more problematic for children without an Education Health and Care Plan as there was a requirement to be planning for adulthood from 14+ in the EHCP. Officers acknowledged that transitions was an area where outcomes needed to be improved and that a lot of the connection services and career guidance had been passed back to schools which made this more difficult.
- f. In response to officers conceding that there was no equivalent hub service for children, the Chair emphasised the ease of access involved with having a hub as well as people knowing where to go. In response, officers set out that a hub service was not the only source of information, advice and guidance and that the Council also had a local service offer which listed universal services as well as disability specific services across the borough. Officers also set out that schools did a huge amount of work in ensuring people received the correct information and signposting services.
- g. Members requested that further consideration be given to what service offer could be provided for the 14-16-year-old cohort in relation to the autism hub and supporting the transition to adulthood. **(Action: Charlotte Pomery).**

Priority two of the Autism Strategy was increasing complex care services for autistic children, young people and adults in the community. The key elements of this included:

- Working with BEH to improve support for autistic people with mental health needs
- Discharging people from hospital and avoiding admission as per Transforming Care
- Developing Positive Behaviour Support (PBS) local provider market.
- Developing autism supported housing programme e.g. Linden Road, SEN 'halls' in borough
- Developing new PBS LD and Autism day service at Waltheof Gardens to support carers.
- Rolling out PBS training in schools and services in the local area and providing a network for PBS supervisors from April 2020.

The following arose in discussion of priority two of the autism strategy:

- a. In response to a request for clarification in relation to the transforming care accelerator pilot proposal, officers advised that this related to additional funding for children who were discharged from hospital to ensure that they retained the same key worker throughout their treatment in order to reduce instances of readmission. In response to a follow up, Members were advised that this was specifically related to complex care needs such as autism and those in receipt of psychiatric care.
- b. In relation to a question on the nature of SEN 'halls', officers set out that this was a project being developed to provide new supported housing at a site in Linden Road for people with autism or who had been discharged from psychiatric care and who were unable to live at home. The facility would be for the 16-25 age demographic and would facilitate their continued attendance at either school or college.
- c. In relation to a query about what suitable housing entailed, officers advised that needs could vary widely across the autistic cohort but that some level of specialist design was required. In particular, housing design needed to have level of environmental sensitivity as ill-considered lighting and decoration could potentially trigger behaviour.

Priority three of the autism strategy was enhancing crisis planning for autistic children, young people and adults in recognition that autistic people were over-represented in mental health services and that without crisis planning, they could spend a long time in psychiatric hospitals unnecessarily. The key elements of this included:

- Crisis management teams.
- The autism hub aims provide low level mental health support, health and wellbeing support and peer support which can prevent crisis in some instances
- Holding a register of those 'at risk' for both children & adults at risk of admission
- Arrange community (education) treatment reviews (CETR) in the community to prevent admission with family and professionals and independent panel of experts.
- Developing Hazelmere respite service for young people and families at risk of placement breakdown and/or admission

The following arose in discussion of priority three of the autism strategy:

- a. In response to a question around providing a rapid response during a crisis, officers advised that a recovery team provided a rapid response as well as there being a dedicated crisis liaison service through CAMHS.
- b. Members questioned whether there was specific service offer towards looked after children and care leavers to reflect the vulnerable nature of this cohort and the additional duty of care owed to them by Members, as corporate parents. The Chair questioned whether a specific target could be put in place for care leavers to reflect this. In response, officers acknowledged these concerns and agreed to develop this further as part of the ongoing development of the autism strategy work.
- c. Members sought clarification around provision of services for low level mental health and anxiety issues as well as the provision of peer review/support services. In response, officers confirmed that the autism hub would include access to CBT and IAPT services. The Chair commented that this could potentially have a big impact on children and young people in the borough.
- d. In relation to a follow-up question about who was leading on the pathway for these services, officers advised that part of the work being undertaken in developing this strategy was around identifying pathways and capturing where gaps existed. It was noted that the autism strategy group were responsible for leading on the development of the strategy and that its composition was developing with time.
- e. The AD for Commissioning agreed to come back to the Children's Panel with a work plan which included a potential improved offer to care leavers as well as pathways for low level mental health support services for children and young people, once this had been developed. **(Action: Charlotte Pomery).**

Priority four of the autism strategy was developing stronger care and support in the community for autistic children, young people and adults in recognition that people with autism and their families could benefit from a range of targeted community services. The key elements of this included:

- Community services such as Markfield, Kith and Kids.
- The learning disability (LD) and autism day service would provide care for people with LD and autism in the community as well as providing respite for parents and carers.
- The autism hub would provide a place for the community to come together in a safe and accessible environment for people with autism and their support networks.
- The autism Hub would also provide autism awareness training in borough to help make Haringey more autism friendly.

The following arose in discussion of priority four of the autism strategy:

- a. Panel Members were keen to see additional roll out of sensory services such as colour coding of library books and book shelves in libraries to make them more accessible. It was also commented that navigation on the London Underground could be difficult for those autism and that more should be done to lobby TfL to colour code stations in a way that was autism friendly.
- b. In relation to a question around best practice examples on developing sensory approaches, officers acknowledged that there was a significant body of work around best practice on this such as Montessori schools.

Priority five of the autism strategy was improving accessibility for autistic children, young people and adults. In recognition of the limited understanding and awareness of autism in mainstream services including health, education and social care reducing their ability to meet the needs of autistic residents. There was also a recognition by the autism strategy group that autistic residents and their families didn't know where to go for help. The key elements of this included:

- Improved digital accessibility such as through Haricare, but more needed in range of different media; documents such as Preparing for Adulthood Pathway guide very popular.
- Driving the health check scheme to support GP's to identify all patients aged 14 + with learning disabilities, to maintain a register and offer an annual health check, including a health action plan.
- The autism hub aims to provide signposting, training and support in the community to improve access to services and awareness of autism.
- Parent post diagnosis workshops and courses including Signet create vital peer support groups that help families navigate services.

The following arose in discussion of priority five of the autism strategy:

- a. Panel Members sought clarification around the accessibility and availability of information through libraries. Members also commented that Haricare was not well known and sought assurance about how its profile could be raised. In response, officers emphasised the need to provide information consistently and ensure it was widely available. There was a recognition that people often only looked for the information when they needed it and that it was important to make sure that information was available in places that were accessible.
- b. In response to a question about the role of schools, officers advised that there was a lot of information shared with schools but that it was only as effective as the individual schools and the extent to which they passed this information on. It was also recognised that information tended to be increasingly online.
- c. In response to concerns about Haringey being recognised as an autism friendly borough and the obstacles to this, officers recognised that this was a key challenge going forwards and that there was a focus on ensuring that the Council listened to the feedback provided by residents and that what residents wanted was for the information to be available locally.

Priority six of the autism strategy is improving education, employment and training in the community for autistic children, young people and adults. This priority was in recognition that many children and young people faced challenges with the education settings and increased challenges of finding employment or training post 16. The key elements of this included:

- Work was underway in transitions and SEND to improve the offer and pathway during transitions.
- Alternative Provision Review to address the gap in SEMH long term education provision and enabling new approach to exclusions
- SEN commission Project Search and number of supported employment initiatives.
- The autism hub would provide employment and training support for people with autism aged 16+. The hub will also employ people with autism, providing more opportunities in Haringey.

- The borough partnership is prioritising adult supported employment initiatives in adults and health, this was at a scoping stage and the intention was for this to develop at pace and grow significantly.

The following arose in discussion of priority six of the autism strategy:

- a. Panel Members sought clarification around the employment of people with autism within the hub, in response officers advised that funding existed for two roles: One team leader and one administrator role. Officers also outlined that it was envisaged that the hub would also include a volunteering facility for people those with autism.
- b. Members enquired about the issues faced with securing good work experience placements and apprenticeships. It was suggested that the Council should be playing a key role in pushing for good work experience placements. In response, officers advised that there was a real drive around supported employments within Adult Social Services. It was acknowledged that there was a problem with the availability of placements and that the Council had a role in coordinating this.
- c. Members also sought assurance about exclusions and concerns that schools passed difficult children on to other schools. Officers advised that a lot of work was being done around exclusions, which included ensuring that children with undiagnosed autism were not part of an exclusion process. Officers also set out a process of supporting a managed move to another school if a particular child was having problems with their current peer group.
- d. Officers agreed to share figures for the number of apprenticeships and work experience schemes in Haringey. **(Action: Charlotte Pomery).**

Priority seven of the autism strategy is developing stronger community safety for autistic children, young people and adults. This priority was in recognition that evidence suggested that people with autism are over-represented in criminal justice systems both as victims and perpetrators of crimes. There was a lack of specialist support within the criminal justice system.

The key elements of this included:

- Support in schools available –but there were questions about the effectiveness of supporting transition to adulthood.
- Links with community safety needed to be better established –there was crossover with PREVENT and hate crime/ mate crime agendas where autistic people are over-represented in case work
- Implementing the Young People at Risk Strategy with clear focus on supporting those most vulnerable to risk
- Safeguarding in the community and making it everyone's business – was there a campaign needed?

The following arose in discussion of priority seven of the autism strategy:

- a. In response to a question, members were advised that the head of the family courts had suggested that around one third of all of the cases related to individuals with undiagnosed mental health conditions.
- b. Members advocated the involvement of the police within the autism hub to help police officers deal with people with autism and to improve understanding of the condition. It was suggested that there was a key role around training police officers and that the Borough Commander could be invited to attend the autism



hub. Officers acknowledged this suggestion and agree to try and take this forward. **(Action: Charlotte Pomery/Georgie Jones-Conaghan).**

Priority eight of the autism strategy is empowering autistic children, young people and adults. This priority was in recognition that the 2017 Haringey Strategic Needs Assessment highlighted that there was not enough representation of people with autism in the designing and commissioning of services. The following proposals were put forward:

- The autism strategy group includes autistic residents and parent carers to improve representation and ownership and challenge old norms of 'disorder' e.g. neurodiverse.
- The specification for the autism hub was being designed alongside a series of community engagement sessions with autistic residents and community groups.
- The autism hub would work closely with be coproduced with autistic residents, community groups and partners.
- The primary function of the hub would be about facilitating peer support, so autistic people could support each other and find solutions to issues themselves or as part of a wider community.

The following arose in discussion of priority eight of the autism strategy:

- a. Members requested further information around the make-up of the autism strategy group, as well as the framework that would be used to actively engage people and encourage parents, carers and community groups to be part of the coproduction process. **(Action: Charlotte Pomery).**
- b. Members advocated that the Council needed to be as visible and inclusive as possible in terms of its communication activity to ensure that representation of people with autism was central to the designing and commissioning of services.

Priority nine of the autism strategy is improving data collection for autistic children, young people and adults. This priority was in recognition that the 2017 Haringey Strategic Needs Assessment highlighted that there were a number of significant gaps in the data which make it difficult to present a comprehensive picture of the autistic population in Haringey and their needs, which made it harder to commission services for autistic residents in Haringey. The following proposals were put forward:

- Trying to embed better autism data collection in services through the autism strategy e.g. provision of an adult diagnostic service.
- Improve our understanding and awareness of the issues facing the local autistic community, through community engagement.
- Improve data collection around people with autism in Haringey, through the autism hub.

The following arose in discussion of priority nine of the autism strategy:

- a. The Chair set out the importance of being able to evidence how the data collected would inform the next of strategy development. In response officers acknowledged this concern and assured Members that work was being undertaken to look at how information could be shared with primary care providers. In relation to the data gathering process, officers advised that the self-evaluation framework was a key tool that provided annual data on how Haringey was performing as well as the performance of other boroughs.
- b. The Chair requested that officers provide feedback to the Children and Young People as well as the Adult and Health Panel on how they could be involved

further in the autism strategy process as it developed. **(Action: Charlotte Pomery).**

**AGREED:**

1. That statistics be circulated to the Panels on the number of children with autism who are home schooled;
2. That further consideration be given to what service offer could be provided for the 14-16-year-old cohort in relation to the autism hub and supporting the transition to adulthood;
3. That the Assistant Director for Commissioning be requested to report back to the Children and Young People's Panel with a work plan that includes a potential improved offer to care leavers as well as pathways for low level mental health support services for children and young people;
4. That figures for the number of apprenticeships and work experience schemes in Haringey for young people with autism be circulated by the Assistant Director for Commissioning to Members of the Panels;
5. That the Police Borough Commander be invited to attend the autism hub;
6. That further information be circulated to the Panels by the Assistant Director for Commissioning on the make-up of the autism strategy group and the framework that would be used to actively engage people and encourage parents, carers and community groups to be part of the coproduction process;
7. That the Assistant Director for Commissioning provide feedback to the Children and Young People's and Adults and Health Scrutiny Panels on how they could be involved further in the autism strategy process as it developed.

CHAIR: Councillor Erdal Dogan/Pippa Connor

Signed by Chair .....

Date .....