

SOCIAL CARE, HOUSING AND PUBLIC HEALTH POLICY OVERVIEW COMMITTEE
Making the Council more Autism Friendly – Minutes from previous meetings

15/01/20	<p>MAKING THE COUNCIL MORE AUTISM FRIENDLY</p> <p>The Assistant Director – Adult Social Work and Head of Service – Learning Disability and Mental Health were in attendance to present the first witness session on Adult Autism: statutory background and local arrangements.</p> <p>It was reported that the Autism Act 2019 committed the Government to having a strategy for meeting the needs of adults in England with autistic spectrum conditions. Following on from the Autism Act, the government published the first national autism strategy for England, ‘Fulfilling and Rewarding Lives’ (2010), which was then updated with ‘Think Autism’ (2014).</p> <p>It was noted that the strategy for adults with autism in England set out a vision that: "All adults with autism will be able to live their lives within a society that understands and accepts them, they can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents."</p> <p>In December 2018, the Government announced plans to introduce an updated national autism strategy which covered people of all ages in England for the first time. Publication of the updated autism strategy was anticipated shortly in January 2020.</p> <p>It was noted that there were 15 challenges identified in the Think Autism 2014 strategy and this was communicated to local authorities and statutory bodies. The Committee was provided with a local action plan 19/20 demonstrating the different initiatives that had been undertaken by the Council.</p> <p>The Autism Partnership Board had been established to improve outcomes for people with autism and their families. It was confirmed that the Board met quarterly and in order to ensure meaningful engagement there would be a wider range of people attending the Board. The minutes would be reported to the different organisations involved.</p> <p>Members found the report useful and noted the positive work undertaken by the Council particularly in respect of housing. The scoping report established a great framework and formed a good basis for the review.</p> <p>It was emphasised that communication was key and it was important to let residents know about the different services available for both adults with autism and children with autism. Members commented that it would be useful to view the local housing strategy and its reference to autism.</p> <p>RESOLVED: That the Committee considered the information received from officers.</p>
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<p>06/02/20</p>	<p>AUTISM REVIEW - 'MAKING THE COUNCIL MORE AUTISM FRIENDLY'</p> <p>It was noted that a Member site visit would take place on 25 February 2020 to two libraries in the Borough to review the types of services available for people with autism.</p> <p>The scoping report was also updated to read the following:</p> <p><i>The aim of this review is to consider how the Council can improve its customer service and key services to support its local residents with autism.</i></p> <p>The purpose for removing “<i>and key services</i>” was to enable the Committee to focus its review on autism, specifically on the interaction between services and the user.</p> <p>RESOLVED: That the scoping report be updated.</p>
<p>23/09/20</p>	<p>AUTISM REVIEW - 'MAKING THE COUNCIL MORE AUTISM FRIENDLY'</p> <p>Members were informed that the Scoping Report had been updated and the timings revised due to Covid-19. It was confirmed that all Members had been invited to complete an online Basic Autism Awareness training module.</p> <p>In terms of next steps, it was confirmed that the October meeting would focus on Children’s Services, Transitions and Preparation for Adulthood while the meeting in November would cover Wider Council Services. It was hoped that a representative from the Parent Carer Group would attend the October meeting while a member of the Hillingdon Autistic Care Service (HACS) would be in attendance at the November meeting. A survey of Council frontline services would also be conducted to ascertain how autism-friendly they were.</p> <p>Members requested the attendance of a representative from the Benefits Agency at witness session 3 as it was unclear how the system worked in terms of the allocation of benefits to those with autism. This would enable the Committee to understand how autism-friendly the access to benefits was at present.</p> <p>The Committee enquired whether it would be possible to invite a representative of a charity for adults with autism to attend a witness session. It was also noted that it was important to establish the autism-friendliness of establishments (including shops) within Hillingdon both for adults and children. Members were informed that the Centre for ADHD and Autism Support offered help to both adults and children but focused mainly on the London Borough of Harrow.</p> <p>It was suggested that an additional witness session could be required and, if necessary, the work programme would be adjusted accordingly.</p> <p>For the October meeting, the Head of Safeguarding – Children’s and Young People’s Services was informed that it would be useful to understand from parents whether they felt the Council was receptive to the issues regarding which they were seeking help. For older children, it would be beneficial to understand how the Council ensured it listened to them and how it dealt with potential conflict between what the children might want and what their parents might prefer.</p> <p>RESOLVED That the Committee:</p>

- 1) Gave consideration to the updated scoping report and made comments and suggestions on the detail contained therein; and
- 2) Considered the information received from officers.

21/10/20

COMMITTEE REVIEW: MAKING THE COUNCIL MORE AUTISM FRIENDLY: WITNESS SESSION 2

Poppy Reddy, Head of Service – Court and Children with Disabilities, presented the report. Due to unforeseen circumstances, Vikram Hansrani, Assistant Director of SEND & Inclusion, was not in attendance. It was agreed that any questions from the Committee which Poppy was not in a position to answer would be forwarded to Vikram for his response after the meeting.

The report highlighted the services available to residents and local authority support available to adults and children with autism. Members were informed that the Special Educational Needs and Disabilities (SEND) Service and Inclusion Service in Hillingdon consisted of three strands – SEND, SEND Advisory Service and the Educational Psychology (EP) Service. The Committee was advised that the latter was a very popular service. There were two primary referral pathways into the EP Service – statutory and traded.

In terms of Statutory Services, the first point of contact for families was the Early Help Team within the Multi Agency Support Hub (MASH). All staff were appropriately trained to have an understanding of autism and how to help families. Where a child had a disability which met the eligibility criteria for specialist or statutory intervention, the cases were referred to the Children with Disabilities Team (CWD) which consisted of 8 qualified social workers and two family support workers. Following a holistic assessment and identification of need, families were supported via a bespoke Child in Need Plan that was reviewed 6-monthly. A package of support was considered within the Plan which could include:

55. Social Worker support, advice, advocacy and guidance – different communication methods were employed to include play, visual aids, sensory items and electronic devices. During the lockdown period, tablets had been provided to children and families for their use;
56. Direct payments and agency packages to enable families to purchase services directly. A personal budgets policy would soon be launched – this would give families more choice and independence in choosing services;
57. Short breaks to give carers a break and to enable the young person to develop different relationships and learn new skills;
58. From October 2020, Harrow Mencap had been granted the contract to deliver short breaks in Hillingdon – this included holiday and weekend programmes. During lockdown, Harrow Mencap had assisted the local authority by providing virtual activities, art activities, singing etc – these had been popular initially but did not give families the break they really needed;
59. Hillingdon had one excellent in-house respite resource - Merriefield House Resource Centre which offered overnight stays to give families a much-needed break;
60. Referrals to targeted services.

A number of other community resources were tapped into to offer support to families, short breaks or activities including HACS, and CASS. A Home from Home option was being explored whereby foster carers would provide respite care in their own homes.

The CWD team worked with young people until the age of 18 at which time they

would transition into adult services if they met the criteria. A transition panel met on a monthly basis and young people were introduced to the panel from the age of 14 to ensure a smooth transition. Those young people who did not meet the criteria would be signposted to other activities and services. LAC children would have local authority involvement until the age of 25.

Members enquired whether Children's Social Care statutory services were assessed and benchmarked against those of other local authorities. It was confirmed that the service provided by Hillingdon was deemed to be very good - a lot of positive feedback had been received. In terms of costs, it was very difficult to provide accurate figures since the provision was based on individual need and varied hugely – there was no cap on expenditure. There was no waiting list at present – all the young people had an allocated social worker. However, it was noted that not all young people with disabilities fell under the remit of the CWD Team.

The Committee welcomed the report but commented that more data would have been helpful. Clarification regarding the chart on page 12 of the agenda pack was requested as this was somewhat unclear and appeared incomplete. It was agreed that this request would be passed to Vikram Hansrani for further clarification after the meeting. Vikram would also be asked to provide clarification regarding referrals into the Educational Psychology Service – were these being actioned speedily, how many young people were still waiting and how did Hillingdon compare with other local authorities?

Members were pleased to note that approximately 80% of the young people with ASD who had graduated from the supported internships were now in full time employment. It was agreed that, following the meeting, Vikram would be asked to provide further information as to the number / percentage of young people who took up the supported internships initially.

Councillors requested a pie chart or graph to demonstrate the range / different types of autism. It was agreed that this would be explored further by Democratic Services.

In response to questions from the Committee, it was confirmed that, prior to the pandemic, a representative of the benefits service had been co-located in the Civic Centre to provide benefits advice to the leaving care cohort and to assist social workers in supporting families with members with ASD; particularly in relation to accessing benefits which was a complex area.

Members enquired how EHCPs were monitored and tracked. It was confirmed that EHCPs were reviewed annually to ensure they continued to meet the need; they would be updated as required.

In response to further enquiries from the Committee, it was agreed that Vikram would be asked to clarify what additional resource provision within secondary settings to meet the needs of CYP with ASD was currently being explored and who was being consulted on this (as mentioned on page 12 of the agenda pack). Members were informed that Vikram Hansrani chaired a special schools' meeting once a month – one of the issues discussed was how the local authority could support these schools. Vikram would be asked to provide further clarity on this.

The external witnesses (representatives of the Hillingdon Parent Carer Forum - HPCF) were invited to provide further information regarding their own personal

experiences.

Georgie Bhad addressed the Committee confirming that the HPCF was a small steering group in Hillingdon which aimed to be the voice of parents of children with special educational needs and disabilities. Parents were surveyed and asked about their experiences and the information was fed back to the local authority. It was noted that parents were often quiet when things were going well and more vocal when they were having difficulties. Members were informed that parents felt the criteria to access the type of help set out by Poppy in her report were high in Hillingdon – Georgie’s own son attended a special school and had moderate learning difficulties but did not qualify for such support. Short breaks could be accessed but were payable. An EHCP had been in place for her son for many years but it was noted that available services in the Borough were restricted and demand outstripped supply. Waiting lists to be diagnosed with autism were very long and it was often difficult to meet the criteria for an EHCP.

In response to questions from the Committee, it was confirmed that local criteria were based on central Government advice. It was agreed that Democratic Services would attempt to source further information regarding the local criteria to access additional support services and a comparison with those of neighbouring boroughs.

Leanne Williams of HPCF addressed the Committee confirming that an ‘ELSA’ was an Emotional Literacy Support Assistant. Leanne commented that, in Hillingdon, the EP service, Schools’ Advisory Service and support in special schools for children with ASD were very good. It would be useful to have more information regarding the number of ASD students in Hillingdon, the number that access Poppy’s service and the level of students that needed EHCPs. It was felt that many schools did an excellent job in terms of monitoring and reviewing EHCPs; however, this was not the case in all schools. Where problems arose, the systems and processes were in place to escalate these, though they were not always dealt with speedily.

Aisha Richardson-Long addressed the Committee informing Members that she was the mother of two children with special needs and had recently managed to secure an EHCP for her son. It was confirmed that her children attended special schools but did not meet the criteria to access the services outlined by Poppy. Ms Richardson-Long praised the level of support available within the special schools attended by her two children. However, the Committee was advised that, when their children first received a diagnosis of ASD, many parents struggled to cope and needed more guidance and help which was difficult to access. It was felt that more support should be made available to those children who did not meet the criteria for Poppy’s service so they did not miss out. In response to questions from the Committee, Ms Richardson-Long confirmed that she had not initially received the guidance she needed from the local authority. She had found SENDIASS to be excellent and very supportive; however, it had taken her a long time to access the level of support she needed which had been extremely stressful.

Members enquired how the HPCF service linked in with the Council. It was confirmed that HPCF was a statutory service - all local authorities had to offer an information and advice service for local residents.

Members acknowledged that, in terms of special schools, the provision in Hillingdon was excellent. Clarification was sought as to how mainstream schools were managing in terms of those children who did not meet the criteria to attend

special schools, did not qualify for an EHCP and were falling beneath the radar. It was confirmed that mainstream schools were in receipt of SEN support funding to support these young people. It was acknowledged that it was difficult for schools as autism was a very wide spectrum which presented itself in a variety of ways and children with ASD had differing needs. However, if mainstream schools could handle this more effectively, there would be less need for EHCPs. Parents often felt an EHCP would provide some leverage to get the level of support and help their child needed.

In response to further questions from the Committee, it was confirmed that, in her time of need, there had been no support available from the local authority for Aisha as the mother of children with special needs.

The external witnesses from HPCF were thanked for attending the meeting and for their useful contributions to the discussion.

RESOLVED That the Committee:

1. Gave consideration to the information provided in the report; and
2. Sought the views of witnesses and asked any necessary questions in support of the Committee's review.

26/11/20

COMMITTEE REVIEW: MAKING THE COUNCIL MORE AUTISM FRIENDLY: WITNESS SESSION 3

HACS

Two witnesses were in attendance – Toni and Stephanie Mullally – representing Hillingdon Autistic Care and Support (HACS). Members were informed that HACS had been founded in 1997 by parents in of children in Hillingdon affected by autism. It was confirmed that HACS supported over 300 families at present and had a large professional database consisting of teachers, SENCOs, health visitors and mental health professionals.

Councillors heard that services offered included advice and guidance, family support, educational workshops, an employability project started in 2015 and an adult support group. The age range of those supported by HACS ranged from 2 years 8 months to 59 years. Members were advised that HACS was one of the only autism specific short breaks providers in the Borough providing weekend respite services for those aged 5 – 25 years. It was confirmed that autism was not classified as a learning disability or a mental health disorder. The term 'high-functioning' often used when referring to those with autism who did not have a learning disability was particularly unhelpful as it suggested that these individuals had less support needs; this was not necessarily the case therefore HACS avoided using this terminology.

The Committee requested further clarification regarding the effectiveness of the Government's National Strategy on tackling autism. It was confirmed that there was now a clearer focus in terms of central Government legislation and attempts had been made to improve employment opportunities. However, although awareness was increasing, outcomes did not appear to be changing very much. On a localised level there was a more co-ordinated approach with agencies working together. It was noted that the National Strategy focused on adults. However, in Hillingdon, a decision had been taken to focus on children and families too. In response to their enquiries, Members were informed that it was

difficult to access data in relation to autism therefore the tracking of outcomes locally was challenging. On a service level there had been a vast improvement since 2010 in terms of what was available for families to access; however, there was still a long way to go.

In response to questions from the Committee, it was confirmed that greater clarity was needed regarding the services provided by the local authority and how to access said services. It was reported that the information was currently not in a central location and was therefore not easy to locate. HACS received calls from GPs on a weekly basis asking how patients could get an autism diagnosis in Hillingdon. For those who were not eligible for specialist or statutory support, it was confirmed that availability of services was often an issue. It appeared that many Council officers lacked understanding of ASD. It was suggested that one option would be to train up a number of autism ambassadors across the Council (one ambassador per department) who could provide expertise in this area. Should the ambassador be unable to assist, a member of HACS could step in and offer support and expertise. The Committee was informed that Council departments did not appear to offer a joined up approach at present – families were often obliged to repeat themselves again and again when approaching different local authority departments which was exhausting and distressing. Members enquired whether a one front door approach would assist in addressing this issue. HACS felt this would be very welcome; ideally people with autism would be allocated a key worker to help them navigate services. A one front door approach would help to reduce the frustration and distress experienced by those with autism when trying to access support services.

The Committee was informed that very few adult referrals were received by HACS; possibly because their adult services were still being developed and had only been live for approximately one year. There was scope for working much more closely with local authority adult services; particularly to raise awareness of HACS. It was confirmed that the response to a HACS autism awareness day held in 2019 had been excellent with some 500 people in attendance. There had been a number of inspirational speakers– some on the autism spectrum themselves – who had been very well received. An April 2020 version of the event had been planned to engage with adults and shape the development of adult services. Unfortunately, this had been postponed due to the pandemic but would take place in 2021.

Members enquired whether transport facilities, libraries, parks etc within Hillingdon were easily accessible to those with autism. It was confirmed that HACS had been working closely with libraries and young people from the HACS employability project had been offered work there to gain work experience. One young person had been offered a permanent position. Members were advised that, having been trained by HACS, library staff were now very autism aware. In terms of other facilities, it was reported that autism-friendly cinemas in the Borough had been successful and outdoor gyms in local parks were also popular – particularly with younger people with autism. The Rural Activities Garden Centre was another great resource and offered a safe, sensory environment. HACS managed the tea rooms there.

In response to further questions from the Committee, it was confirmed that autism friendly letters would be greatly welcomed as people with autism often struggled to understand letters or were unwilling to open them. An easy read format would be extremely helpful.

In terms of physically navigating the Borough, the Committee was advised that this was extremely challenging for people with autism. It was suggested that autistic adults would welcome the opportunity to be consulted on matters which affected them directly. An example was given of a shopping centre which had introduced autism quiet shopping hours once every three months from 10-11 on Sunday. This was impractical as it was too infrequent and coincided with universal worship time.

In response to further questioning from the Committee, it was confirmed that the nationally recognised incidence rate of autism was approximately one in one hundred. Members were informed that more could be done to support children in care in terms of support networks for foster carers etc. Members were informed that HACS had a strong relationship with the paediatricians on the Looked After Children Board and regularly made recommendations to foster parents and adoption panels. At present HACS were working with the kinship team to ascertain what type of assessments should be considered to assist a young person who was struggling to get an autism diagnosis.

Councillors sought further clarification regarding HACS and their work within schools. It was confirmed that HACS carried out training sessions in schools and supported parents of children with autism at annual reviews, in exclusion cases etc. Members were informed that HACS had a strong partnership with head teachers and SENCOs and worked closely with both mainstream and special schools.

The Chairman thanked HACS for their contribution to the review and congratulated them on their excellent work.

Autism Training within the Council

Kate Kelly-Talbot, Assistant Director – Adult Social Work, updated the Committee on autism training within the Council. Members were informed that, within the Council, two levels of training were available to staff – a General Autism Awareness module and a 2-day specialist training course offered to those carrying out assessments; the latter had been undertaken by approximately 120 Adult Social Care staff members to date. It was confirmed that all staff in the Learning Disabilities and Autism Service had completed the 2-day training course. The Committee heard that a number of frontline staff could benefit from the autism awareness training; e-learning Autism Awareness training had been developed and had been launched in Feb 2020. This training was available to all staff, but further work was planned to promote uptake. A more targeted approach may be required, but this work has been slightly delayed due to the pandemic.

New legislation was being brought in which would be closely monitored to ensure the Council's autism offer was updated and refreshed as necessary.

In response to questions from the Committee, it was confirmed that the e-learning training was ready to be rolled out. There was a need to consider which departments to target first and whether to include it as part of officer induction. Members were keen for this e-learning to be rolled out as quickly as possible to raise awareness among staff and assist in addressing the issues raised by HACS.

Democratic Services informed Committee Members that, as agreed, an autism survey had been circulated to 25 service managers across Council frontline departments. A report would be compiled to appraise the Committee of the results

of the survey in due course.

RESOLVED That the Committee:

1. **Gave consideration to the information provided in the verbal update; and**
2. **Sought the views of the HACS witnesses and asked any necessary questions in support of the Committee's Review.**