

Making the Council more autism-friendly



A review by the Social Care, Housing and Public Health Policy Overview Committee

Councillors on the Committee:

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Contents

| | Pages |
|---|----------------|
| 1. Chairman's Foreword | 3 |
| 2. Summary of recommendations to Cabinet | 4 - 5 |
| 3. Background to the review | 6 - 7 |
| 4. Evidence and Witness Testimony | 8 - 16 |
| 5. Findings and Conclusions | 17 - 20 |
| 6. Terms of Reference | 21 |
| 7. Witness and Committee Activity | 22 - 23 |
| 8. References | 24 |
| 9. Appendix A LBH Checklist for Autism-Friendly Public Facing Service Environments | 25 - 28 |

Chairman's Foreword

Making the Council more autism-friendly



On behalf of the Social Care, Housing and Public Health Policy Overview Committee, I am delighted to present the outputs and recommendations of this review, which has sought to examine Hillingdon's front-line services and what opportunities may exist to create a more "autism friendly" service experience for our residents.

The Committee heard from Children's Services, Transitions and Preparation for Adulthood, and about wider Council service provision, including SEND and Inclusion Services, as well as from Hillingdon Autistic Care and Support. The Committee's discussions were also informed by the results of the internal Making the Council More Autism Friendly questionnaire. We were impressed by the candour of the officer team and the evident commitment to build on and apply existing good practice consistently across the range of relevant services.

The Committee noted opportunities to improve in terms of ease of access to services generally and creating a more autism friendly experience, but were pleased to note progress including the appointment of an Approved Social Work Practitioner with a focus on Autism, and on officer training and development. We also welcome the commitment of officers to a culture of continuous improvement. However, it is clear that impending changes to legislation and the publication of the National Autism Strategy, mean this by no means the end of the story, rather a staging post on the road to the evolving improvement of services in Hillingdon for people with autism. As such the Committee will need to revisit progress in these areas at an appropriate juncture.

The review has taken place against the backdrop of the most extraordinary set of circumstances, with the pandemic impacting on meeting schedules, not to mention changes of personnel on the Committee. For me, becoming involved at the tail end of the review fresh from Cabinet, has helped reinforce my own long held view of the value of the POCs, and the potential to contribute meaningfully to the scrutiny of service performance and standards, and the development of supporting recommendations to Cabinet. My thanks to my colleagues on the Committee for their contributions, not least to my two immediate predecessors, Councillors Jane Palmer and Ian Edwards.

I would also like to take this opportunity to thank those officers and witnesses who have given up their time to assist the Committee, and commend them for their continued hard work in providing support, advice and delivering services to the residents of the Borough in our name.

Councillor Philip Corthorne

Chairman of the Social Care, Housing and Public Health Policy Overview Committee

Summary of recommendations to Cabinet

Through the witness sessions and evidence received during the detailed review by the Committee, Members have agreed the following recommendations to Cabinet:

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| 1 | That the Council's public facing service environments adopt a practical corporate standard (checklist) to ensure a consistent approach to making these areas more autism friendly; |
| 2 | That Cabinet notes the rollout of training for front-line staff thus far and recommend that this becomes embedded in the new starter induction and ongoing learning and development targets for key front-line staff in reception-based areas; |
| 3 | That Cabinet explore the feasibility of improving online accessibility for residents with autism by providing further access to, and information about, Council autism services on the Council's website; |
| 4 | That Cabinet consider the merits of seeking Autism Accreditation for eligible Council services through the National Autistic Society; |
| 5 | That Cabinet welcome the culture of continuing improvement and such improvements as the appointment of Advanced Social Work Practitioners with a focus on autism, the development of e-learning training, and clear Council-wide guidance on reasonable adjustments under the Equality Act 2010; |
| 6 | Note the impending publication of the National Autism Strategy review and forthcoming changes to legislation with a report back to the POC at an appropriate juncture covering progress on the recommendations and Hillingdon's approach to meeting these requirements; |
| 7 | That appropriate front-line managers review their service's procedures whereby in formal contact environments, should a resident with autism unexpectedly remove themselves from a meeting or proceeding, it should not be taken as a withdrawal from the process in question, and |

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| | that steps are taken to continue such formalities in a more appropriate or suitable matter; and |
| 8 | That Cabinet recognises all the Council's strong partnership relationships with organisations and providers supporting people with autism in Hillingdon. |

Background to the review

Aim of the review

In scoping and agreeing the review's Terms of Reference, which are set out in section six of the report, the Committee sought to gain an understanding of how residents with autism accessed day to day Council services and to establish ways in which to make the Council more autism-friendly. The aim of the review was to consider how the Council could improve its customer service and key services to support its residents with autism. The Committee has subsequently formed practical, feasible and supportive recommendations to promote inclusion for residents with autism when accessing our universal services.

Setting the scene

"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." (Department of Health and Social Care 2010: 'Fulfilling and Rewarding Lives: the strategy for adults with autism in England')

At the Social Care, Housing and Public Health Policy Overview Committee's meeting on 23 October 2019, it was unanimously agreed that a review into the way in which autistic residents interact with Council services be undertaken with the view that, it is the Council's responsibility to be autism-friendly.

Autism Spectrum Disorder (ASD) is being increasingly recognised within our society, with many organisations now being obliged to have proper awareness and support in place. A steady cultural shift has been taking place to help transform people's attitudes, understanding and perceptions of autism; this shift has been facilitated by the introduction of the Autism Act 2009 and the subsequent National Autism Strategy 2010. By increasing understanding and acceptance of autism, progress can be made to reduce health, education and socio-economic inequalities and improve positive life outcomes for autistic people.

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. One in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK. Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses. Barriers to inclusion can include:

- Social communication and social interaction challenges
- Repetitive and restrictive behaviour

- Over, or under, sensitivity to light, sound, taste or touch
- Highly focused interests or hobbies
- Extreme anxiety
- Meltdowns or shutdowns

ASD awareness has grown year on year, with the public and private sector steadily adapting to accommodating the needs of those with autism. The number of trials and initiatives designed specifically for those with ASD represents positive societal change; think autism-friendly cinema screenings, shopping hours and libraries, all environments which can cause problems for people with ASD who struggles with sensory overload, queues, crowds, displays, lighting and music.

To highlight the pertinence of this review, a 2019 report from the Local Government and Social Care Ombudsman found the Council to be at fault for not providing the reasonable adjustments required for a resident with autism when accessing a Council service. This specific case was heard by the Cabinet and steps were taken to address the incident and avoid recurrence of similar issues. Fortunately, incidents such as this are rare, but it represents the significance of taking positive actions to enable straightforward access to Council services for residents with hidden disabilities, such as ASD.

It is of the utmost importance that the Council remains accessible and approachable for all residents. By adopting a variety of scrutiny techniques, the Social Care, Housing and Public Health Policy Overview Committee have considered whether the Council facilitates a supportive culture for autistic residents and to that end, have offered a set of supportive recommendations to Cabinet.

Evidence & Witness Testimony

It should be noted that progress of the review was hindered by the onset of the Coronavirus Pandemic and nationwide lockdown in March 2020. When the Social Care, Housing and Public Health Policy Overview Committee resumed meetings in September 2020, Members embraced new methods of investigation through virtual means. As a result of the review's hiatus, the timeframe for completion of the review was pushed to Spring 2021.

Through a range of information gathering sessions, the Committee sought to understand the views of expert witnesses by exploring the current work being done with regard to autism in the Borough and how further initiatives could enhance the way the Council works to become autism friendly.

The following sections outline the evidence received and the witness testimony.

The Current National Autism Strategy

The Autism Act 2009 committed the Government to having a strategy for meeting the needs of adults in England with autistic spectrum conditions by ensuring that the local authority and NHS services they need are accessible for them.

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).

The strategy for adults with autism in England sets 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."

In December 2018, the Government announced plans to introduce an updated National Autism Strategy which is set to cover people of all ages in England for the first time. Publication of the updated autism strategy is anticipated in 2021. The National Autism Strategy underpins the Committee's review and lay the foundation for exploring avenues to make the Council more autism-friendly in its service delivery.

'Fulfilling and rewarding lives' 2010 set out the need for better:

- Autism awareness training
- Access to a diagnosis
- Assessments of people with autism

- Service and support
- Local leadership and planning.

'Think autism' 2014 retained these commitments and built on them, with key aims to:

- Increase awareness and understanding of autism
- Develop clear, consistent pathways for the diagnosis of autism
- Improve access for adults with autism to services and support
- Help adults with autism into work
- Enable local partners to develop relevant services.

The 15 Priority Challenges

'Think autism' outlined 15 'priority challenges' established through a consultation with autistic people, families, carers and professionals. These are laid out from the perspective of an individual with autism.

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| 1) | I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism. |
| 2) | I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others. |
| 3) | I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low-level support. |
| 4) | I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism. |
| 5) | I want to be safe in my community and free from the risk of discrimination, hate crime and abuse. |
| 6) | I want to be seen as me and for my gender, sexual orientation and race to be taken into account. |
| 7) | I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process. |
| 8) | I want autism to be included in local strategic needs assessments so that person-centred local health, care and support services, based on good information about local needs, are available for people with autism. |
| 9) | I want staff in health and social care services to understand that I have autism and how this affects me. |
| 10) | I want to know that my family can get help and support when they need it. |

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| 11) | I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies. |
| 12) | I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging. |
| 13) | If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services. |
| 14) | I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible. |
| 15) | I want support to get a job and support from my employer to help me keep it. |

The 15 priority challenges were used to frame statutory guidance issued in 2015 for practitioners in England and Wales. The guidance clearly stated what local authorities and NHS bodies should and/or must do in relation to:

- Training of staff who provide services to adults with autism.
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services.
- Planning in relation to the provision of services for people with autism as they move from being children to adults.
- Local planning and leadership in relation to the provision of services for adults with autism.
- Preventative support and safeguarding in line with the Care Act 2014 from April 2015.
- Reasonable Adjustments and Equality.
- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity.
- Employment for adults with autism.
- Working with the criminal justice system.
- The guidance allows for local discretion in how the strategy is implemented, however health and wellbeing boards, formed through the Health and Social Care Act 2012, are expected to play a part in planning local services.

Hillingdon Adult Autism Partnership Board

The Committee heard how Hillingdon had an established Autism Partnership Board (APB), whose function was to improve outcomes for people with autism and their families. In 2019, the APB was reviewed and it was agreed by all stakeholders that the format would change to better support

participation of adults with autism. The revised Adult APB was launched in September 2019.

The following groups were regularly invited to attend the Adult APB: Adults with autism; CAAS (Centre for ADHD and Autism Support); the CCG Clinical Lead for Learning Disabilities (LD) and Autism; CCG Commissioners (Adults); CNWL Clinical Services; CNWL LD Health Team Lead; CNWL Lead for LD and Autism; DASH (Disablement Association Hillingdon); HACS (Hillingdon Autistic Care and Support); Hillingdon Healthwatch; Hillingdon Parent Carers Forum; LBH Adult Social Care; LBH Positive Behaviour Support; LBH Principal Educational Psychologist; Police representatives; Probation and the Hillingdon Hospital Learning Disability Liaison Nurse.

The Committee heard that the Adult Autism Partnership Board met quarterly and was now well attended by adults with autism and had a co-chairing arrangement. One co-chair being a person with autism or a parent/carer of someone with autism. The other being a representative from a statutory or third sector organisation. Members had sight of the Adult APB's Local Action Plan 2019/20 which demonstrated various workstreams and initiatives undertaken by the Council.

Members Site Visit to Uxbridge and Eastcote Libraries



Before the arrival of the nationwide lockdown and strict social distancing measures, Members conducted a site visit to Uxbridge and Eastcote Libraries to review the types of services available to residents with autism. Members met with the library managers and the following points were noted:

Uxbridge library engaged with a diverse range of people as it was located in the centre of the Borough, including people with autism and carers. Good practice was usually shared amongst different organisations. Uxbridge was the flagship library and its interaction with residents often identified areas where service improvements might be made.

Members were introduced to the Tovertafel Magic Table, an interactive projector and table set up designed for people with dementia. Although the Tovertafel had been introduced for dementia friendly purposes, it was found to be a good resource and worked really well for people with autism. Advertising for the service had increased and schools came in regularly to use the Tovertafel. It was noted that the service was not available without staff supervising and that its location in the library did not lend itself to informal supervision. Members heard how the library

service was exploring the employment of autistic staff to run dementia sessions on Tovertafel with Hillingdon Autistic Care and Support (HACS).

Lego therapy was another good service in place which was thoroughly enjoyed by children with autism. It currently ran well in Harefield as the only specialist trained member of staff was located at that library. An example case study was provided of a mother being pleased with her child's progress, as her child who did not talk often was really enthusiastic about the service. The ambition was to cascade the training to allow Lego therapy sessions at Uxbridge, Botwell and Ruislip Manor libraries.

Access to work for people with autism was being explored collaboratively with HACS. Members were encouraged to hear that there were already work experiences in place and there was work in the pipeline to make a more structured programme. It was noted that work experience, including for autistic children, was largely reactive to requests of schools and was considered on a case by case basis. An example case study was provided of a person who did work experience at the library, a significant difference could be seen in the development of their communication skills. This work was paid and made a significant contribution to the running of the library.

Staff recruitment procedures were explained to Members and what reasonable adjustments were made at interviews for people with autism. This included removing clocks and rephrasing questions, elements which had been known to cause anxiety for people with autism.

It was highlighted that support groups would regularly approach the library to run specific groups/sessions to meet needs e.g. craft, Tovertafel, IT. Library staff were always willing to support new groups but this was dependent on interest and the level of skills required as some activities required professional input. If there was a demand for services they usually started small and then became more established with time.

The library was also keen to develop partnership working with third sector organisations such as HACS, MIND and other different groups to consider how further support could be provided to service users. It was noted that there was not an equivalent group to the Dementia Action Alliance for people with autism.

Members Site Visit to the Centre for ADHD and Autism Support

Members met with the Director of Autism Services at the Centre for ADHD and Autism Support and were encouraged to hear that the centre's experience of working with both Hillingdon and Harrow Councils was positive. It was noted that the Centre helped people from diverse backgrounds and social demographics did not impact on the provision of autism services. It was highlighted that the Centre received funding from the London of Borough of Hillingdon to support residents but was commissioned by, and delivered the majority of its services to, the London Borough of Harrow to deliver health and social care services.

In 2019, the Centre supported 2000 people and delivered over 37 services. Some of the services provided by the Centre included drop-in sessions for support groups and three different parenting courses. Members heard how many parents were not aware of the support that schools and the centre could offer to support children with autism, this often led to miscommunications and complaints. It was, however, acknowledged that some peoples' expectations were unmanageable. Interestingly, it was noted that 70% of autism groups were male dominated and it was usually easier to recognise the signs in men. It was easier to mask symptoms with women.

Suggestions from the Centre on how publicly accessible service environments could be improved for individuals with autism included:

- Staff training that recognised triggers and general awareness.
- Communication and making it easier for people with autism to access services such as the Civic Centre. An example was given from Harrow Council where they had adopted a separate waiting area for residents who may experience distress in public places.

Hillingdon Parent Carer Forum (HPCF)

Expert witnesses representing Hillingdon Parent Carer Forum (HPCF) were invited to address the Committee and outline their experiences as carers for children with a diagnosis of ASD for the purposes of the review. The HPCF is a small statutory steering group in Hillingdon which aims to be the voice of parents of children with special educational needs and disabilities, and to offer information and advice for local residents.

The Committee heard that some of the statutory services for children and young people with autism, such as the Educational Psychology Service, Schools' Advisory Service and support in special schools for children with ASD was very good in the Borough. However, the Committee was advised that, when 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 some of the statutory autism services, to ensure that they did not miss out.

Young People with ASD and Transitioning to Adulthood

The Committee also heard how the LBH SEND & Inclusion service had been active partners in local supported Internships since 2015. These internships have been provided to young people aged 17 -24 with an Education, Health and Care Plan who have a diagnosis of ASD or learning disability. The Supported Internship model was a pathway supported within the context of the Preparing for Adulthood agenda which promotes; employment, independent living, good health and community inclusion for young people with SEND.

Based on the information held for five cohorts of interns, approximately 50% of participants had

a diagnosis of ASD.

These programmes have provided daily structure and routine within a supportive host business environment, specifically aiming to provide young adults with the skills they need to achieve employment. Task analysis, job coaching, and performance of repetitive, familiar tasks helps to improve confidence and work skills. Employability Skills lessons explain the appropriate behaviours required in the workplace and encourage interns to transfer their learning into their everyday practice. Being fully immersed in a workforce on a full-time basis assists interns' understanding of what is required in the world of work and improves their self-confidence.

These supported internships facilitated a smooth and gradual transition from education into work, which would otherwise not be possible for many young adults with ASD. An indicative study by the National Autistic Society indicated that only 16% of adults with ASD are in full time employment. This figure can be compared to the approximately 80% in full time employment who had graduated from the supported internships that the SEND & Inclusion service in Hillingdon were partners to.

As part of its further commitment to providing employment opportunities for young people with ASD, the Committee heard how the Council had become the host business to a Project Search transition to work programme, partnering with local organisation Hillingdon Autistic Care and Support (HACS) who provide the job coaching element of the programme.

Where a young person's needs were not eligible for adult services, families were provided with information and advice about how those needs may be met and the provision and support that young people could access in their local area. Guidance for 'Think autism' suggested that, even where young people with autism are not entitled to adult social care services, under the Care Act 2014 they should be signposted to other sources of guidance and support in the community.

Hillingdon Autistic Care and Support (HACS)

HACS is a charity founded in 1997 by a group of parents and carers in Hillingdon with an autistic family member. HACS have a Resource Centre in Hayes and facilities there include an administration suite, secure outdoor space, sensory room, conference/training room and two classrooms. The charity currently supports more than 1100 people and have developed a highly respected and professional reputation. They are committed to raising awareness, knowledge and understanding of autism and their mission is to improve quality of life by minimising disability and maximising ability.

Having been the Mayor's charity in 2019, services offered include 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 ranges from 2 years 8 months to 59 years and grant funding from Hillingdon had been received over a number of years for the charity. HACS is one of the only autism specific short breaks providers in the Borough providing weekend

respite services for those aged 5 – 25 years. The Committee found the work of HACS to be of incredible value to residents of the Borough and that the charity had played a significant role in the progress made with regard to awareness of ASD in Hillingdon.

The representatives from HACS confirmed that greater clarity was needed regarding the services provided by the Council 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.

In terms of physically navigating the Borough, the Committee was advised that this was extremely challenging for people with autism. Difficulties were encountered when accessing transport services and publicly accessible facilities, including venues such as the Civic Centre, high streets, libraries and parks.

Autism Training for Council Staff

The Committee sought to understand the methods and levels of training that Council staff received with regard to interacting with autistic residents. Through investigations, 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 also confirmed that all staff in the Learning Disabilities and Autism Service had completed the 2-day training course.

During the review, Members were invited to complete a basic autism awareness training module. The Committee felt that a number of front-line staff could benefit from the autism awareness training; e-learning Autism Awareness training had been developed and had been launched in February 2020. This training was available to all Council staff, but further work was planned to promote uptake.

LBH Manager's Autism Survey

Part of the Committee's review was to establish the level to which the Council's public facing service environments, e.g. receptions, facilities, venues etc., are made accessible for residents with autism. A questionnaire was distributed to the managers responsible for the Council's service areas with a public facing environment. Managers were asked to respond in a manner that reflected the delivery of their service area before the onset of the coronavirus pandemic i.e. before March 2020, unless they deemed the response specifically relevant. 13 responses were received.

Summary of responses

Respondents managed a variety of the Council's public facing service environments and engaged

with residents on a regular basis.

Pre coronavirus pandemic, face to face interaction with residents took place in a variety of settings; including publicly accessible areas such as reception areas and leisure centres as well as private settings such as schools, young people's centres and interview rooms. Telephone and email contact with residents were also a primary means of communication. It was noted that there was no uniform guidance or checklist from the Council ensuring that public facing environments were autism-friendly; however, there were instances of public spaces being reviewed by a Speech and Language Therapist.

Respondents were asked about the considerations taken to ensure their public facing service environments were accessible for residents with autism spectrum disorder (ASD), specifically in relation to potential levels of sensory stimulation i.e. noise levels, harsh lighting, strong smells and colour schemes. Although responses varied, it was noted that where there was an element of control over the aesthetics of the space, surroundings were tailored to facilitate muted colours and natural light where possible; this was found to foster a calming environment. There were several environments where responsibility for aesthetics lay with other departments, namely Facilities Management.

There was promising engagement with regard to considering the extent to which public information boards, notices, signage etc. were supported by the use of easily understood symbols, pictures, photos or objects. There were examples of managers and specialists reviewing correspondence templates, literature and signage with a wide range of service user needs in mind, including autism; however, this was an area where some managers requested further support and advice. Furthermore, there were few instances where a formal procedure was in place should a person with autism need to leave an environment unexpectedly.

There was a willingness to engage staff with the Council's latest Autism Awareness Training, some service areas had already taken the training and even expressed an interest in refresher training in future. Some respondents noted that simply by taking the survey, their attention had been drawn to areas where they could improve an autistic person's experience with their service. It was also noted that where reception areas were open to all residents, consideration should be given to ensure the safety of officers and offer a professional and welcoming area for visitors.

Multiple respondents expressed a readiness to receive ideas and recommendations for improving public facing service areas in an effort to become more autism friendly, particularly as many avenues of physical interaction were closed off currently due to the coronavirus pandemic.

Findings & Conclusions

Having considered a range of evidence from a variety of appropriate sources, the Committee has offered the following practical, feasible and supportive recommendations to promote inclusion for residents with autism when accessing Council services.

The Committee were mindful that a primary recommendation from the review would need to focus on the environment within which residents with autism may access services. Members concluded that there was a need for the Council's public facing service environments to adopt a practical corporate standard, or checklist, to ensure a consistent approach in making those areas more autism friendly. Having autism friendly signage in publicly accessible areas was highlighted as an important measure to take. Members were in agreement that this would give uniformity to the places in which residents with autism access day to day Council services. A practical standard forms Appendix A to this report. Many people with Autism can experience severe difficulties with 'unfriendly' environments and an autistic person may have problems with sensory input from the world around them.

Therefore, the Committee is pleased to present the following recommendation:

1

That the Council's public facing service environments adopt a practical corporate standard (checklist) to ensure a consistent approach to making these areas more autism friendly.

Further to this, the Committee expressed particular interest in ensuring front-line staff were well equipped to provide Council services with a healthy understanding of the unique needs of residents with autism. Throughout the review, Members heard how autism training had started being delivered to some key public facing service areas; this led Members to recommend expanding the training offer to a wider range of staff. To this end, the Committee recommend the following:

2

That Cabinet notes the rollout of training for front-line staff thus far and recommend that this becomes embedded in the new starter induction and ongoing learning and development targets for key front-line staff in reception-based areas.

The Committee highlighted the importance of having one centrally located point for residents with

autism to learn about what kind of support is available to them. Further to this, Members were minded to improve the ease of access to services online by including information on referral pathways, not only to services provided by the Council, but for support offered by other bodies such as the NHS and local charities. On that basis, the Committee recommends the following:

3

That Cabinet explore the feasibility of improving online accessibility for residents with autism by providing further access to, and information about, Council autism services on the Council's website.

As a way of assuring quality in the way the Council delivers its services, and to bolster confidence in accessing Council services for residents living with autism, as well as the family and friends of those with autism, the Committee sought to explore the advantages of obtaining autism accreditation through the National Autistic Society. The Committee were minded to make the following recommendation to Cabinet:

4

That Cabinet consider the merits of seeking Autism Accreditation for eligible Council services through the National Autistic Society.

From the outset of the review, the Committee were ardent about helping to facilitate a culture of continuous improvement. Hearing from officers about different initiatives and workstreams such as the Local Autism Action Plan 2019/20 and the Autism Partnership Board have been particularly welcomed by the Committee. Through the review's findings, the Committee encourage Cabinet to acknowledge the progress made in universally making the Council more autism-friendly:

5

That Cabinet welcome the culture of continuing improvement and such improvements as the appointment of Advanced Social Work Practitioners with a focus on autism, the development of e-learning training, and clear Council-wide guidance on reasonable adjustments under the Equality Act 2010.

The Autism Act (2009) 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). In December 2018, the Government announced plans to review and 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 delayed but is due in 2021. The Committee are therefore making the following

recommendation to Cabinet:

6

Note the impending publication of the National Autism Strategy review and forthcoming changes to legislation with a report back to the POC at an appropriate juncture covering progress on the recommendations and Hillingdon's approach to meeting these requirements.

It is important to facilitate an environment whereby residents with autism can engage with day to day Council services. In unfamiliar and often formal environments, individuals with autism may be more sensitive to encountering difficulties. This may affect them in a variety of different ways, from being distracted, unable to concentrate and having mild discomfort, to symptoms of acute pain and deterioration in functioning. If the environment is distressing for the person, this may stop them from accessing it. The result could be that an individual may abruptly remove themselves from a formal situation, thereby limiting their opportunity to effectively take part in formal proceedings as well as Social, Health, Education and Leisure services. As a way of addressing this, the Committee propose the following recommendation:

7

That appropriate front-line managers review their service's procedures whereby in formal contact environments, should a resident with autism unexpectedly remove themselves from a meeting or proceeding, it should not be taken as a withdrawal from the process in question, and that steps are taken to continue such formalities in a more appropriate or suitable matter.

During the review, the Committee heard from representatives of Hillingdon Autistic Care and Support, a charity raising awareness, knowledge and an understanding of autism in the local community. HACS have been improving the quality of life for residents with autism for over two decades; the Committee felt it absolutely necessary to recognise this work and to also recognise the role that all organisations and providers play in supporting residents with autism:

8

That Cabinet recognises all the Council's strong partnership relationships with organisations and providers supporting people with autism in Hillingdon.

Although it is noted that the scope of the review's recommendations are targeted primarily towards the way in which residents with autism access the Council's day to day services and not necessarily the statutory care services and packages offered to residents with autism, Members

felt strongly that reliable support needed to be offered to parents and carers of children with autism, specifically those who may fall short of the criteria for having an Education, Health and Care Plan (EHCP). During the review, Members heard from the SEND Advisory Service which offers training and workshops to parents and carers through their 'Early Bird' and 'Signet' programmes; the Signet programme was not only accessible to families with children with a diagnosis of autism but also children who presented social communication needs without a formal autism diagnosis. Further to this, the Committee noted that delivery of these programmes was scheduled to increase over the coming months and wished to highlight the importance of this work.

Terms of Reference of the review

The following Terms of Reference were agreed by the Committee from the outset of the review:

1. To understand the different types of autism and how residents' lives can be impacted by autism, including the direct views of local residents with autism;
2. To understand national legislation and guidance about autism and consider how the Council is currently complying with this;
3. To assess the work already taken across front-line services and other all-age Council services areas, to be aware of and support autistic people when they access our services;
4. To review autism friendly actions and initiatives across the voluntary, private and public sector to improve customer experience when accessing services;
5. To consider feasible, practical ways the Council could, going forward, make its front-line services more autism friendly;
6. To influence or propose any emerging Council plans, guidance or policies with respect to autism;
7. Subject to the Committee's findings, to make any conclusions, propose actions, service and policy recommendations to the decision-making Cabinet.

Witnesses and Committee activity

It should be noted that this review was initiated in late 2019 under the chairmanship of Cllr Jane Palmer and then in 2020 continued under the chairmanship of Cllr Ian Edwards until Cllr Philip Corthorne's appointment as Chairman of the Committee in January 2021.

The Committee received evidence from the following sources and witnesses:

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| <p>Witness Session 1</p> | <p>Kate Kelly-Talbot LBH Assistant Director of Adult Social Work</p> <p>Hazel Ashworth LBH Head of Service – Learning Disability and Mental Health</p> |
| <p>Member Site Visits</p> | <p>25 February 2020 The Committee conducted a site visit to Uxbridge Library and Eastcote Library to review the types of services available for people with autism.</p> <p>09 March 2020 The Committee visited the Centre for ADHD and Autism Support and met with the centre's Director of Autism Services.</p> |
| <p>Online Training</p> | <p>Members were invited to complete an online Basic Autism Awareness training module.</p> |
| <p>Witness Session 2</p> | <p>Poppy Reddy LBH Head of Service – Court and Children with Disabilities</p> <p>Georgie Bhad Leanne Williams Aisha Richardson-Long Hillingdon Parent Carer Forum</p> |
| <p>Witness Session 3</p> | <p>Toni Mullally Stephanie Mullally Hillingdon Autistic Care and Support</p> |

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| | Kate Kelly-Talbot LBH Assistant Director of Adult Social Work |
| LBH Manager Survey | To establish the level to which the Council's public facing service environments, e.g. receptions, facilities, venues etc., were made accessible for residents with autism. A questionnaire was distributed to the managers of relevant service areas. |

References

The following information is provided in order to signpost readers to useful contextual information to this review:

[Autism Act 2009](#)

['Fulfilling and Rewarding Lives: the strategy for adults with autism in England' – Department of Health and Social Care 2010](#)

['Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: and update' – Department of Health and Social Care 2014](#)

[Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#)

['The Autism Employment Gap: Too Much Information in the Workplace' – National Autistic Society 2016](#)

[Autism Spectrum Disorder in Adults: diagnosis and management – NICE Guidance 2016](#)

[Local Government and Social Care Ombudsman Investigation Report April 2019 – The London Borough of Hillingdon](#)

Appendix A - LBH Checklist for Autism-Friendly Public Facing Service Environments

Many people with Autism can experience severe difficulties with ‘unfriendly’ environments. This can mean that a person may have problems with sensory input from the world around them. This can be simplistically hyper, hypo or perception sensitivity.

This may affect them in a variety of different ways, from being distracted, unable to concentrate and having mild discomfort, to symptoms of acute ‘pain’ and deterioration in functioning.’ If the environment is distressing for the person this may stop them from accessing it. The result could be that Social, Health, Education and Leisure opportunities become limited.

Other difficulties in the environment include unclear communication and a lack of awareness or understanding of autism. If environments become too stressful it is also important to have the option to escape from any situation. This corporate standard seeks to raise this as a factor to be considered within Council departments.

Everyone with autism is, of course, unique and they have their own specific ways and needs to be considered.

This document was developed for services (or individuals) to review whether they could make environments friendlier and raise awareness of how they might be able to make changes.

| | Awareness questions-Core | ANSWER |
|----------|--|---------------------------|
| | It is important that everyone in an organisation has some basic knowledge of autism and is up to date with their training needs. To be aware of the barriers to change can also be a catalyst for effective problem solving and solutions. | Yes No N/A |
| 1 | Are you able to make changes to the Core sensory environment? (E.g. are there practical or financial restraints – changes can include simple or free changes such as changing a room layout). | |
| 2 | Have you considered to what extent is the environment primarily ‘safe’ for people with Autism? | |

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| 3 | Are you up to date with Autism Awareness training to support this checklist? | |
| <p>Communication questions</p> <p>In all walks of life effective communication is vital. For people on the autism spectrum this is perhaps essential. Clear unambiguous indicators in all forms can prevent stress. Like much of the general population there is a definite preference for sameness, for appropriate language and for an absence of sudden change.</p> | | <p>ANSWER</p> <p>Yes No N/A</p> |
| 1 | <p>Does the environment have clear signs to indicate the use of each room? Many with ASC may require pictures as well as written words. Are direction arrows pointing in the correct direction? (Does the layout off the room and present equipment also give some suggestion as to what is expected such as where to sit etc.)</p> | |
| 2 | <p>Are there photographs used to aid recognition of people (Staff/unfamiliar) if needed? (These need to be kept up to date)</p> | |
| 3 | <p>Have you considered to what extent are communication systems supported by the use of symbols, pictures, photos or objects? (This should include any guides about how to externally access services or what to expect for e.g. when waiting in reception for housing – roughly how long it will take? What paperwork they might need? Who will they see? What questions might they be asked? Are there easy read versions of documents available? Have literal descriptions been used?)</p> | |
| <p>Sight / Visual questions</p> <p>Some people who have autism can struggle with visual stimulus that can be offensive. This could be at best distracting causing a lack of focus and concentration. At worse this could cause a person to avoid environments completely. One case example was where a young lady on the spectrum could not speak</p> | | <p>ANSWER</p> <p>Yes No N/A</p> |

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| | at a conference because the carpet leading to the stage was too patterned and she could not walk on it. (The definition of High Arousal relates to a high level of stimulus to the senses such as the above-mentioned carpet. Low Arousal would be the opposite, so some pattern but limited. No Arousal would involve no stimulus, i.e. bland in colour and no pattern) | |
| 1 | Have you considered the sensory needs when accessing the service e.g. it is a high/low arousal environment including decor? (Consider walls, carpets, notice boards, paintings, soft and hard furniture patterns etc) | |
| 2 | How well are the facilities of the service organised/signposted to make the purpose of each part obvious e.g. toilets, waiting area etc? Does the service have a break out area that can be used if needed? | |
| 3 | Have you considered if the environment has fluorescent or harsh lighting? (Is it possible to vary this easily? Does it change at different times of day? Are any surfaces in the area reflective?) | |
| Smell / Olfactory questions If you have ever walked through a perfume department in a store, then you may have experienced the effect on your senses. It can be offensive if you are hypersensitive to smell and can have significant physical responses such as headache and nausea. It is therefore important to minimize this distress. | | ANSWER Yes No N/A |
| 1 | Have you considered the smells of cleaning materials used? (E.g. polish, air fresheners, bleach). Or are facilities near rooms that generate smells (e.g kitchen) | |
| 2 | Have you considered the smells of individuals (including pets) using the environment? (E.g. Deodorants, perfumes and aftershaves) | |
| 3 | Do 'offensive' smells drift around the building from room to room and have you considered how you might isolate them? | |

| | Hearing / Auditory questions Many people with autism seem to be hypersensitive to acute or high-pitched noise that they cannot control. This can feel like sharp pain and people either cover their ears with fingers or earphones/defenders. The other alternative is to hide the offensive sound by masking it with 'white noise'. Sometimes the slightest inconspicuous sound can be irritating and distracting such as a 'hum' or a 'ticking' | ANSWER Yes No N/A |
|---|---|--|
| 1 | Have you considered the general noise level in the environment? (Think about clocks, Squeaky doors and floorboards; squeaky chairs; printers; phones; lights etc.) | |
| 2 | Have you considered hypersensitive hearing and looked at specific noises that may irritate such as clocks ticking, water coolers; humming from lights, road noises or building/gardening work in the distance? | |
| 3 | Have you any specific quiet and louder areas that people can choose from? Have you considered the pitch of noises? Have you checked when any building alarm tests are due? | |

London Borough of Hillingdon Corporate Checklist for Autism-Friendly Environments shortened version from NICE guidelines on Autism spectrum disorder in adults and Autism spectrum disorder.