

All Age Autism and ADHD strategy priorities

Phase 1 Engagement Report *July 2024*



This graphic is a visual representation of the most frequently used words across all responses to questions about the draft priorities. The size of the word corresponds to how often it appeared in people's responses to the engagement.

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1. Introduction

The Royal Borough of Kingston upon Thames (RBK) undertook an engagement exercise over a six week period during May and June 2024. The purpose of this engagement was to get views from Experts by Experience¹ and professionals on draft priorities for a new Kingston All Age Autism and ADHD Strategy. It also asked people to share views on what is working well, what is not working well and suggestions for improvements. This has provided rich content that will inform the draft strategy and an action plan following the publication of the new strategy.

This document looks at the responses from an online survey, focus groups and other feedback received. This analysis informs the 'You Said, We Will' section which sets out how the feedback will influence the strategy and action planning.

2. Executive Summary

The objective of this report was to collect information relating to the draft priorities being developed for Kingston's All Age Autism and ADHD strategy 2025-2030 including 'what is working well and what could be improved'.

Feedback was received from people with experience of services, residents (children, young people and adults), community, health and care organisations and other professionals such as colleagues in the education sector. It has given valuable insight into what is important for autistic people and people with attention deficit hyperactivity disorder (ADHD) in Kingston.

The report provides recommendations for developing Kingston's All Age Autism and ADHD Strategy 2025-2030. It highlights the need for prioritising accessibility, raising awareness of neurodiversity, and providing the right type of support services in the borough. A focus on timely access to diagnosis and treatment, sharing best practice across educational settings, boosting employment support and simplifying administrative processes will need to be reflected through both the strategy and subsequent action plans.

There is a clear mandate for collaboration across healthcare providers, schools, community organisations, and policymakers.

¹ Experts by Experience - For this survey, an expert by experience is an autistic person and/or someone who has ADHD. It also includes someone who might give support, like a family member.

3. Overview of the engagement process

Feedback was gathered via:

- Survey (hosted on RBK's Let's Talk engagement platform)
- Focus Groups
- Emails
- Phone calls

Overall people engaged: around 140 (including focus group participants)

Survey

- The survey ran from 01/05/2024 to 13/06/2024
- Total number of responses to the surveys: 92
- Survey format: online on the Council Let's Talk Portal, written in plain English and supported by images
- Co-produced with feedback from members of the Autism and ADHD Partnership Board
- Promoted through a variety of channels by Kingston Council and partners, e.g. virtual newsletters, mailing lists/ clients/ contacts, via networks and Boards, partner Facebook posts, partner websites and posters with QR codes.

Focus Groups

- Number of focus groups: 6
- The groups were:
 1. Fastminds (*"Fastminds is a user-led group run entirely by volunteers. [They] provide support, friendship and understanding to adults in our community living with ADHD and comorbid disorders regardless of diagnoses."*²)
 2. Kingston Council's Staff Disability & Wellbeing Network/ Neurodiversity Champions
 3. Kingston Council's Community Safety Team
 4. Experts by Experience from the Autism and ADHD Partnership Board
 5. Achieving for Children (AfC) - young people in the Recruits Crew³
 6. Achieving for Children - held a focus group at a local school at which they spoke to a group of learners with autism/ADHD

Limitations of engagement:

- A General Election was called while the survey was live. As a result, there were some limitations around certain promotional channels, nevertheless, the overall response rate was good.
- The engagement period fell during school/ college exam season. This is an all-age strategy and we must hear directly from young people. To mitigate this barrier, we gave AfC additional time to hold focus groups with this cohort in July.

² <https://adhdkingston.org.uk/>

³ Where young people who have previously used the Emotional Health Service/Mental Health Support Team have a say in new clinicians.

- Unforeseen circumstances meant that some of the partners who had committed to delivering a focus group were unable to do so. We aim to support these partners to hold focus groups in the second phase of engagement instead.

4. Method

The survey was hosted online on the Council Let's Talk engagement portal and structured as four different versions depending on the respondent's status:

1. I am a resident and/or expert by experience
2. I am a focus group leader and want to provide feedback from my group
3. I attended a focus group and have extra feedback
4. I am from an organisation

The resident survey was co-produced with members of the board. Following feedback around supporting neurodiverse residents to fully engage in this work, an option of an additional question was included where people who attended a focus group could add any feedback that they forgot to share in the meeting or thought about after.

The Autism and ADHD Board members were involved in the engagement planning process during brainstorming sessions at board meetings and via email. A high-level engagement plan was shared with the group for feedback and input. Partners suggested stakeholders and channels for engagement.

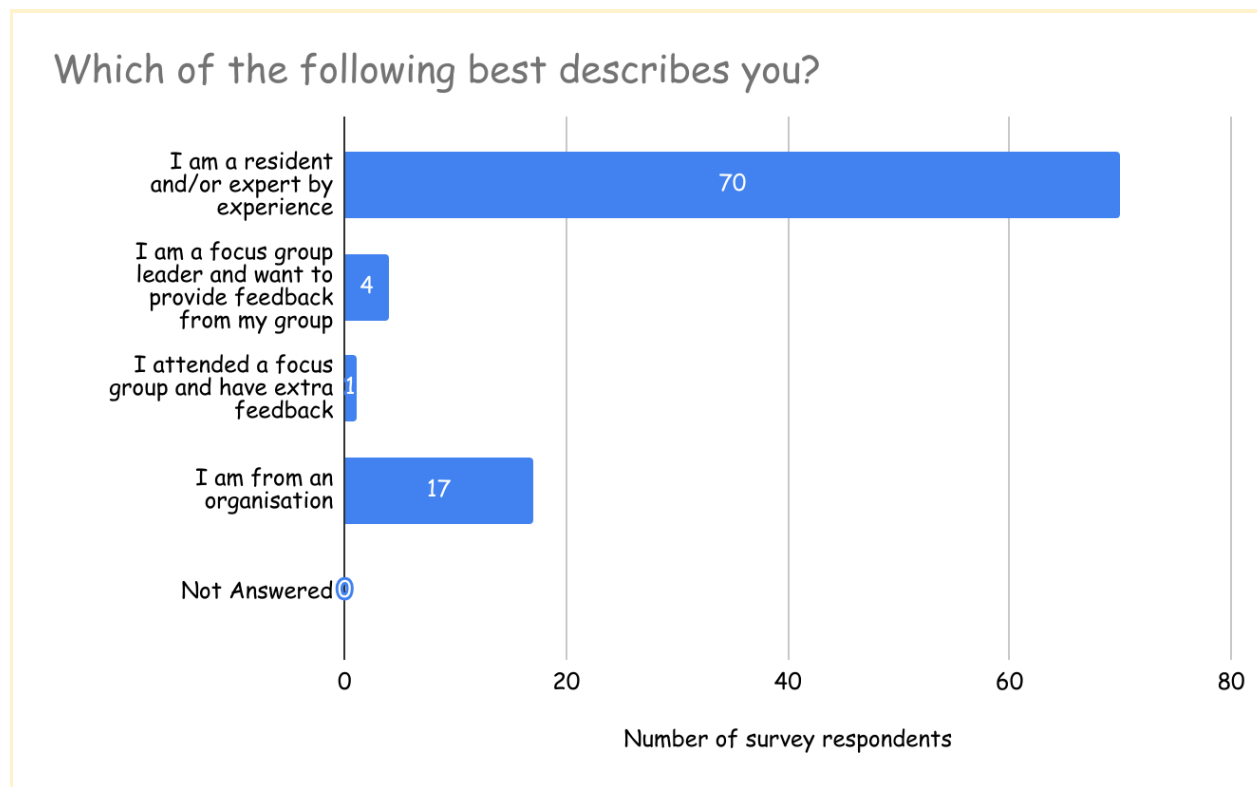
A partnership approach to the engagement delivery was used, with board members sharing links to the survey and supporting its promotion. Organisations discussed the engagement in their internal meetings and directly supported people to complete the online survey. Some partners also held focus groups within their existing communities which offered a method other than the survey for targeted groups to share their ideas on the same questions. By using the expertise of our partners we were able to support residents to engage in a way that met their needs.

4.1 Who engaged with the survey?

There were 92 online respondents to the surveys. This included 4 responses on behalf of focus groups. Overall, 47 people engaged across 6 focus groups (this includes the addition of 2 focus groups with young people that were not reported in the main survey). The total number of people directly engaged was **139**.

Some organisations also shared insight from previous conversations/engagement exercises over the past few years. The majority of survey responses (76%) were from residents / Experts by Experience (see Fig 1).

Fig. 1 Number of people completing the survey by experience



- 70 people who responded described themselves as a resident/and or expert by experience.
- Four people stated they were focus group leaders providing feedback from a group.
- One person attended a focus group and had additional feedback
- 17 people responded from an organisation that works with young people or adults with autism or ADHD.
- Organisations: 59% said they were from the voluntary sector/ CIC⁴ (more than one option could be selected). There were also responses from day opportunities, supported living, care home/ homecare, NHS and health, education and a statutory service.

Disability

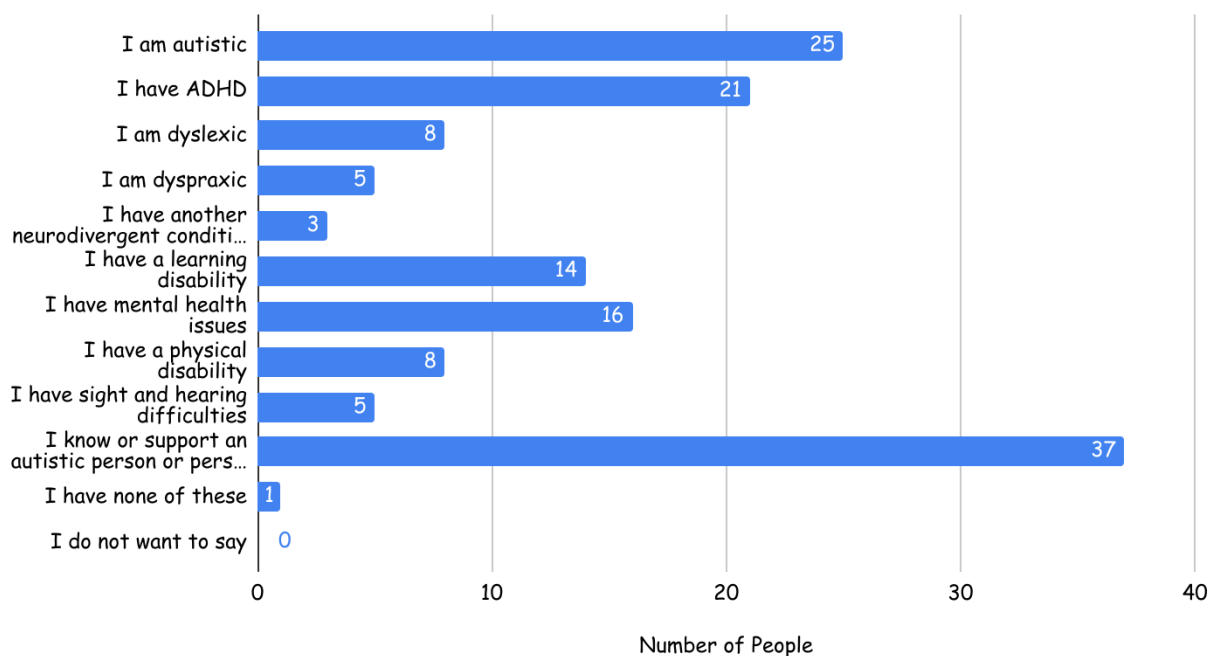
- Organisations Survey

⁴ CIC – Community Interest Company; A Community Interest Company (CIC) is a limited company, with special additional features, created for the use of people who want to conduct a business or other activity for community benefit, and not purely for private advantage.
(<https://www.gov.uk/government/publications/community-interest-companies-business-activities>)

- 2 people responding on behalf of organisations told us they were neurodivergent.
- Experts by Experience Survey (all 70 people responded to this question. They were able to select multiple answers.)
 - 53% of people said they know or support an autistic person or person with ADHD.
 - 50% of people said they were Autistic/ had ADHD or both. There was fairly even representation from people who identified as being Autistic (25 people) or having ADHD (21 people) themselves. 10 of these people identified as having both Autism and ADHD (14% of overall EbE survey people).
 - 23% identified as having another neurodivergent condition.
 - 20% said they had a learning disability and 23% said they had a mental health condition.
 - Many people selected multiple options.

Fig. 2 Experts by experience data from the online survey

Experts by Experience: Do any of the following apply to you?

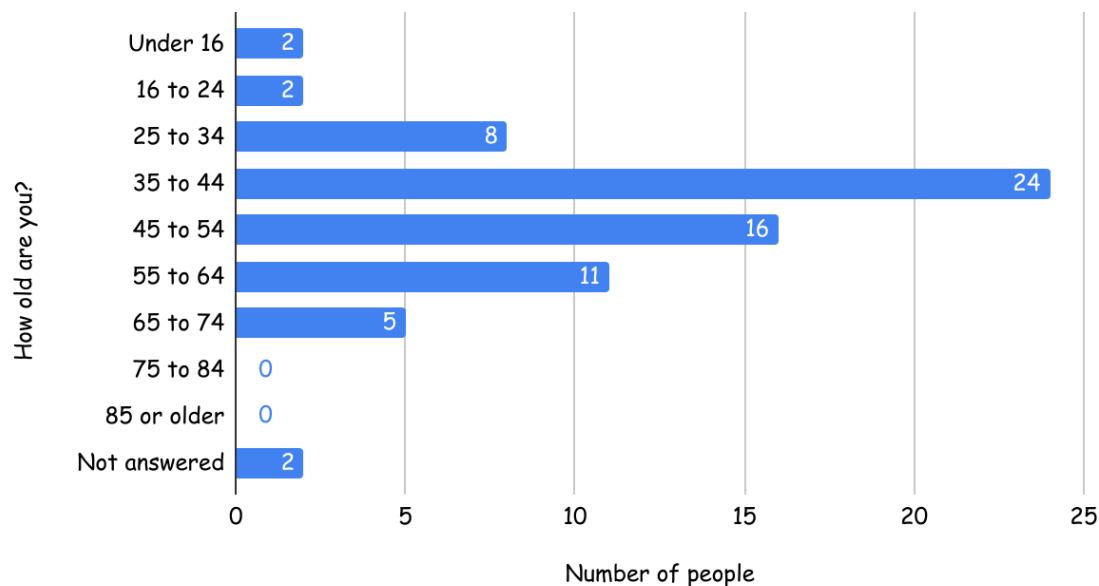


- Focus Groups with Children and Young People
 - 4 people identified as having a learning disability in addition to Autism/ADHD.
 - 8 Autistic, 4 ADHD, 3 another neurodivergent condition, 1 Dyspraxia (not all participants chose to respond to this question).
- Focus group with Adults
 - There was a mixture of Autistic people, people with ADHD and some people with physical disabilities.

Age

Fig. 3 Age of Residents and Experts by Experience who responded to the survey

Age of Resident/ EbE Survey Respondents

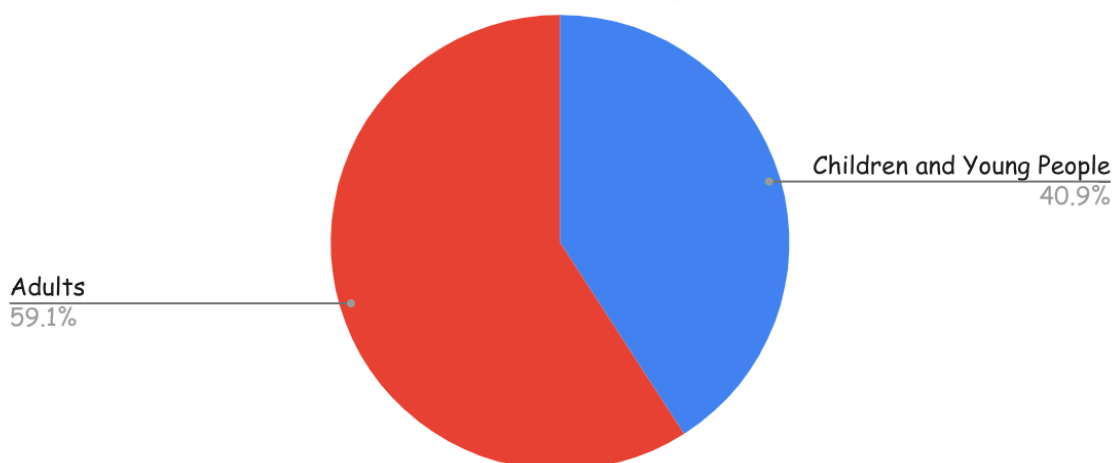


- There were four survey responses from young people aged 24 and under. There were no EbE survey responses from residents aged 75+. Therefore, the voices of residents at either end of the age spectrum are underrepresented in this survey data (the general age distribution in Kingston is 30.6% under 24s and 6.5% over 75s)⁵
- Over half of the people responding to the resident/ EbE survey were between the ages of 35–54.
- Four focus group leaders reported speaking to adults and two groups spoke to children/ young people.
 - 10 children under 16 and 1 young person aged 16–24 attended the focus groups led by Achieving for Children.

⁵ Census 2021, <https://www.ons.gov.uk/visualisations/censusareachanges/E09000021/>

Fig. 4 Organisations by working with Adults or Children and Young People

Organisations: What age group do you work with?

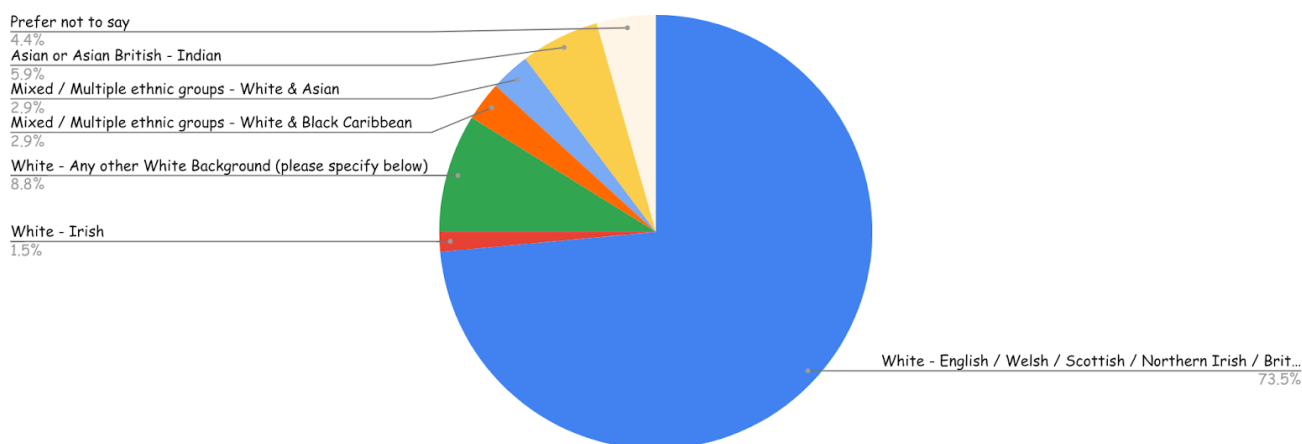


- 59% of the organisations who responded worked with adults, and 41% of the organisations worked with children and young people.

Ethnicity

Fig.5 Ethnicity of Experts by Experience survey

Ethnicity of Experts by Experience (online survey respondents)



- All 17 people from organisations completed this survey question (see fig.7). 1 person who identified as 'any other ethnic group' added additional information in the text box: 'Middle Eastern'.

- 67 of 70 EbEs responded to this question (see fig. 5). 4 people who identified as 'white' added additional information in the text box: 'mix with Israeli Jewish', 'East European', 'British', 'half white British/Irish, half Ukrainian Jew'.
- A full cohort of demographic data was not collected by the adult focus groups as leaders found it challenging to gather it in this setting. 2 groups provided a summary of ethnicity and they reported speaking to people who were: White British, Indian, Pakistani, Bengali, Caribbean, White and Black Caribbean, White other.
- The 2 AfC led focus groups with children and young people collated About You Easy Read Survey responses from all 11 participants. (see fig.6)
- The biggest difference between the ethnicity selected and the general population of Kingston was Asian or Asian British (5.9%), in comparison with 17.8% in the 2021 Census.

Fig. 6 Ethnicity of Children/Young People from the focus groups

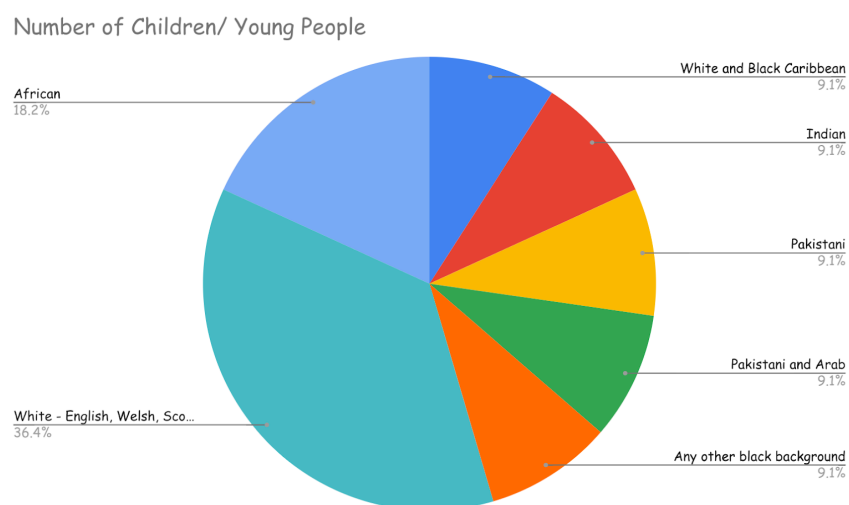
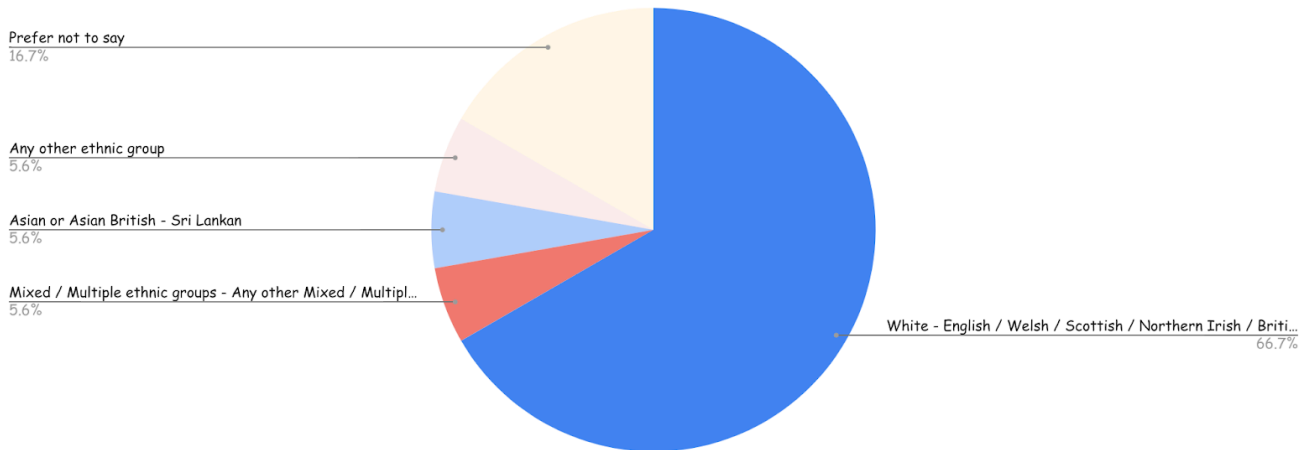


Fig. 7 Survey people from Organisations

Survey Respondents from Organisations



4.2 Supporting accessible engagement

- Different options were available for completing the survey such as providing a phone number and email address for further support. Partner organisations also directly supported members to complete the surveys.
- Two people gave feedback on the survey questions by phone.
- Two people shared their thoughts via email.
- Focus groups were offered as an alternative way to contribute.
- Images and pictures were used alongside text to make the survey more accessible.
- Focus group leaders were provided with an easy-read equalities form.

4.3 Considerations for the next phase of engagement

Younger People

We recognise the importance of hearing the voice of young people in an all-age strategy. The engagement period fell during exam time so focus groups led by AfC extended into July 2024. Consideration will be made to how and when young people are best able to give their views going forward.

Accessibility

There needs to be consideration that some people do not have access to a computer or a mobile phone, or may prefer information in written form or have the opportunity to talk to someone in person.

Our plans for the next phase of Engagement

We have identified additional groups and stakeholders to engage with in phase two. This targeted approach will enable us to increase engagement and hear a more diverse range of voices.

- A focus group with Kingston Council's Violence against Women and Girls (VAWG) survivors forum. Some of the members identify as having autism and ADHD.
- Partner-led focus groups
- Children and young people and people
- Wider faith and community groups (including Asian)
- People who have used advocacy services
- Chairs of other, related Boards in Kingston
- CLICK Cafe (many of the members are neurodivergent)
- Mental Health Wellbeing Group or Place Mental Health Group

5. Summary

Feedback was received from people with experience of services, residents and organisations. It has given valuable insight into what is important for autistic people and people with ADHD in Kingston. This summary shares key findings and recommendations from the surveys and focus groups with the following sections providing further detail.

Frequently people mentioned that all the priorities were important and it was hard to choose one. It was suggested that some priorities were similar and linked to others. Some feedback mentioned that it was important that priorities were linked to specific, measurable, achievable, realistic and time-bound (SMART) goals. Overall it was clear that everyone's experience of autism and ADHD is different.

In developing an action plan to address the findings, there is a clear need for collaboration across healthcare providers, schools, community organisations, and policymakers.

6. Findings

The following findings detail feedback on the priorities being developed for Kingston’s All Age Autism and ADHD Strategy 2025–2030 and ‘what is working well’ and ‘what could be improved’.

6.1 Priorities

The priorities were developed by considering national policy⁶, neighbouring boroughs’ strategies (Richmond, Sutton and Merton), previous engagement with the Autism and ADHD board and wider work including the 2022 Pulse Check report⁷.

The feedback collected during the Engagement Phase 1 provided rich content that will inform the draft All Ages Autism and ADHD Strategy, and ultimately an action plan following the publication of the strategy.

People were given a set of draft priorities to provide feedback on, and were asked three key questions:

- 1a. Which priority is most important?
- 1b. Why?
- 2. Is there anything you think should be added or changed?

⁶ Statutory guidance to support implementation of the Adult Autism Strategy (2015); National Strategy for autistic children, young people and adults 2021–2026; DoH Think Autism strategy governance refresh 201

⁷ Pulse Check report: Neurodiversity and health and care services 2022

Image 1: Image of priorities from survey

Autistic people and/or people with ADHD:



Will be involved in planning and developing services



Will be supported into employment



Will easily find information and support



Will feel safe and included in their community



Will be given the right support at the right time, including diagnosis.

Kingston Council and partners:



Will focus on people's strengths to overcome barriers



Will support young people as they move to adulthood



Will increase the awareness of Autism & ADHD

Key highlights from responses

- Lots of people said all the priorities we shared were important and it was hard to just choose one. They also said that many of the priorities were interlinked.
- Some residents felt that no further changes were needed to the current draft priorities.

- It was clear that everyone's experience of Autism and ADHD was different.
- It is important for residents to see action and progress on the priority areas of focus. A number of respondents mentioned that priorities need to be measurable, practical and realistic.
- Mental health challenges came through as a strong theme in the responses around the priorities (particularly the priority: 'Will be given the right support at the right time, including diagnosis'). This feedback was commonly shared by Experts by Experience.
- People told us that support is also needed for people who haven't yet got a diagnosis of Autism or ADHD.
- Increasing awareness of Autism and ADHD was important to people especially young people and young adults, and this was reflected in further feedback. *'It would be nice to see really positive autism and neurodivergence posters - not being referred to as a condition or something with lots of negatives, let's celebrate differences!'*
- Other key themes identified in the feedback about the draft priorities: the need for specialist neurodiverse friendly services/ training/ support/ engagement, the need for practical support (eg. form filling, housing, bills or benefits), issues accessing ADHD medication and support for parents.

Top Priority: Diagnosis/ Support



Will be given the right support at the right time, including diagnosis.

This was selected as the most important priority by over half the organisations and Experts by Experience who responded to the survey. In particular, this was related to long waiting times and the lack of support.

Priorities with the least votes:



Will focus on people's strengths to overcome barriers



Will support young people as they move to adulthood

These priorities were the least selected in the survey. Some people felt that focusing on strengths came under the priority about employment. However, those people who did find these two priorities important were young people. Wider feedback tells us that for young people and their families, moving to adulthood is an important time. **‘Will be supported into employment’** was selected by young people from the focus groups as one of the most important areas.

6.2 What’s working well?

There were examples of things **working well** in Kingston:

- Support from the Community and Voluntary sector
- Great work within Health and some schools/colleges
Eg. examples of good practice by GP's including quick referrals.

6.2.1 Residents and or Experts by Experience responses

We heard that there are examples of good support from their GPs and the Kingston Adult Autism and ADHD team⁸. Collaboration between healthcare providers and community groups is playing an important role.

There are examples of best practice in schools and colleges demonstrating good support systems for students with autism and ADHD, to create inclusive and supportive learning environments. This supports the academic needs of neurodiverse students and helps their social and emotional well-being.

The community and voluntary sector, despite facing resource challenges, are making significant contributions. Organisations like Express CIC⁹, Fast Minds¹⁰, and the Working Well Trust¹¹ were mentioned as offering valuable support, enhanced by resources such as the ‘Neurodiverse Friendly Collection’ on Connected Kingston.¹²

Some people had noticed a positive trend in job and volunteering opportunities for neurodiverse people. Increased awareness and supportive actions across society were felt to reflect a growing

⁸ The Kingston and Richmond Autism Service is a specialist NHS service providing ASD (Autism Spectrum Disorder) assessment for adults living in Kingston and Richmond

⁹ Express CiC is a user led organisation, supporting autistic people and their families and promoting awareness in the community

¹⁰ Fastminds is a volunteer led group in Kingston supporting Adults living with ADHD

¹¹ Working Well Trust is a supported Employment service in Kingston

¹² Connected Kingston is an online Information, Advice and Guidance portal to help residents find services

acceptance and understanding of neurodiversity. The Sunflower lanyard¹³ is increasingly recognised, including on bus transport.

Fig 8. Feedback received on ‘what is working well’

*Great **Kingston GP** made our referral quickly and efficiently,*

*‘The **Kingston adult autism and ADHD team** are great (Your Healthcare), engaging and really positive’*

*‘**Local colleges** seem to be well informed about the needs of autistic people and seem willing to engage actively to make accommodations’*

*‘I feel as though the services do make a good effort to include people with disabilities and (I) have felt **included and heard.**’*

*‘The borough is one of the **safest areas** in London.... My daughter has a travel card that allows her to use public transport without paying and the public transport system in Kingston is good. Bus drivers recognise the Sunflower lanyard which can be useful.*

- **Health and Social Care:** The feedback we received gave some positive individual experiences of the health system with GPs referring patients for ADHD assessments promptly, having a good understanding of neurodivergent needs, enabling prompt access to mental health services, physical therapy, and specialist counselling. This was not the same experience for all people and this area is also included in the ‘what’s not working well section’.

The Adult autism and ADHD team run by Your Healthcare were felt to be providing knowledgeable and positive support. Positive experiences were also shared with medical and emergency services personnel who demonstrate neurodiversity-friendly approaches.

- **Awareness:** We hear that there was a ‘noticeable shift’ towards greater awareness and acceptance of neurodiversity in the community. Supportive environments and the use of reasonable adjustments contribute to greater levels of success in education and employment.
Positive experiences were shared about supportive schools and tailored educational activities. Efforts to increase opportunities for neurodivergent people in the workplace

¹³ Sunflower Scheme – This scheme allows people to discreetly share their hidden disability by the use of a lanyard or a card with a picture of a lanyard. Organisations in the scheme commit to being inclusive, and increasing awareness.

and through volunteering are improving. Initiatives like tailored career fairs and inclusive webinars for employers are making a positive impact.

- **Getting out and about:** Good transport links were highlighted with travel cards and blue badges facilitating easier access to public spaces. Feeling safe in the community came through strongly, with initiatives such as the Hidden Disabilities Sunflower lanyard scheme and having access to quiet, sensory-friendly spaces like libraries and parks which helped reduce anxiety.
- **Community-based support:** Local charities and groups were felt to be providing valuable support including information, navigating healthcare, employment and activities that include practical support with life's daily challenges. There was also positive recognition of local businesses and services implementing neurodiverse-friendly practices (e.g. sensory-friendly shopping times).
- **Information Advice and Guidance:** The availability of resources like Connected Kingston (including the Connected Kingston Neurodiverse Friendly Collection) help to effectively signpost people to support services and activities.
- **Activities:** There are increasing options for activities tailored to neurodivergent children, young people and adults, providing more inclusive opportunities for leisure and social engagement. Various activities like adventure playgrounds, social groups, specialist counselling, and sports clubs were found to be beneficial leading to improved well-being and supporting employment.

6.2.2 People responding from organisations

- **Health and Social Care:** People shared examples of ADHD diagnosis and support services working well. Organisations, support services and charities were felt to be knowledgeable and working well with the resources they have. There was felt to be strong support from local groups within the voluntary sector including early years and primary schools around Autism and ADHD including: effective signposting to services, helplines and referral pathways leading to access to communication paediatricians, speech and language therapy (SaLT) and occupational therapy (OT) without needing a formal diagnosis. Positive feedback was given about the specialist care coordination and social prescribing services that help people navigate available services and provide tailored support. Community paediatricians are providing holistic assessments and guiding parents towards appropriate services and support, which has been beneficial for families.
- **Training:** Multi-agency training on Autism/ADHD, strong Short Breaks offer for children and youth with Autism/ADHD, and youth groups available for these conditions. There was felt to be a significant positive impact of Ambitious About Autism in the borough.

- **Collaboration:** Positive examples of collaboration were cited with health working with community services who work with neurodivergent people to develop and offer ADHD therapeutic support. It was felt that schools are providing strong support for pupils with autism/ADHD.

6.3 What is not working well?

There are also areas where **improvement** was needed.

- Simplifying administrative processes
- Increased support for families
- Sharing best practice across schools
- Increased training and awareness
- Focussing resources on reducing waiting times for assessment & support

6.3.1 Residents and or Experts by Experience responses

Although positive experiences of assessment and referral were shared, there were a larger number of people who had experienced long wait times for assessments and diagnosis, in some cases up to 3 years. This included delays in access to medication and therapies. Post-diagnosis support was felt to be lacking, especially for adults diagnosed later in life, who found few support groups available. Delays were linked to negative impacts on mental health and subsequently an increased demand on the NHS.

People mentioned that they were struggling to find suitable housing, with several responses mentioning properties in poor repair. These challenges were made more difficult by limited financial support and accessibility issues. Accessibility issues included healthcare services that did not understand the specific needs of neurodivergent individuals, particularly in trauma and sensory care, and the increased use of online forms - which was felt to be a barrier. The offer of reasonable adjustments was felt to be inconsistent in general.

Although there were pockets of good practice, educational support for students with ADHD and autism was felt to be inconsistent, leading to poor educational outcomes, low school attendance and increased levels of stress.

Fig 9. feedback received on 'what needs improvement'

*'Accessing **healthcare** is a nightmare for me - I find it hugely stressful (e.g. the online triage process to access a GP) and there is no real understanding of why I struggle to engage with health professionals'*

*'I have been on an ADHD **assessment** waiting list for over 3 years. I just received an ADHD diagnosis, and I am now told that I will need to wait at least another 9 months'*

*'There is very little **housing** for young adults with autism/ADHD who want to develop their independence, particularly if they are still living with their parents'*

*'its a strange and intimidating world, lots of rules which are hard to follow with autism' - feedback from a young person in relation to needing support around **employment**.*

*'**Reasonable adjustments** to meet people's complex needs vary widely across organisations working with/supporting/employing people with hidden difficulties'*

*'**Communication** needs an overhaul, webchat is needed. Council website needs simplifying'*

- **Long Waiting Times for Diagnosis and Treatment**

There were multiple reports of waiting times over three years for ADHD and autism assessments, followed by additional lengthy waits for treatment and medication initiation. Long waits were also mentioned for access to mental health services and interventions, leading to conditions getting worse. Prolonged waiting times for assessments and therapy, particularly through CAMHS, causing stress and delays in support.

- **Healthcare Services**

People raised issues around mental health and trauma, including inadequate mental health support tailored to autistic people, particularly those dealing with trauma. People mentioned a lack of quiet spaces and accommodations for sensory needs in hospitals.

- **Lack of Post-Diagnosis Support**

Insufficient post-diagnosis support, leaving people feeling abandoned and leading to deteriorating mental health. People raised a lack of support groups for late-diagnosed adults with ADHD and autism. There was a request for greater support to enable people to live independently.

- **Education and School Support**

Some schools are not adequately equipped to handle the needs of students with ADHD and autism, leading to poor academic performance and high stress. High levels of stress and anxiety result in low attendance and high dropout rates. Transition to Secondary Education can be difficult. Insufficient support for transitions between educational stages, particularly during critical periods like GCSEs, was raised by people.

- **Administrative and Bureaucratic Challenges**

Council forms and procedures are difficult to understand and navigate. Poor signposting and communication within council services make it hard to know where to get help or file complaints. People reported challenges accessing appropriate services including a

reduction in the availability of someone to talk to and a reliance on online forms eg. when trying to make an appointment with a GP.

- **Housing Issues**

Challenges in finding suitable housing for people with ADHD and autism leading to poor living conditions including poor management of housing repairs and maintenance which can cause additional stress for residents. Mixed experiences with housing; some people find it satisfactory, while others struggle with unsuitable conditions and prolonged processes for securing repairs or better housing.

- **Employment and Financial Support**

People responding to the survey said they find that there is limited support and guidance for neurodivergent adults in securing employment and difficulty understanding and accessing financial support such as PIP and council tax reductions. There has been a reduction in practical support to enable people to fill in forms.

- **General Accessibility and Inclusivity**

We heard there were challenges in using public transport independently and getting to new places. There is not enough awareness and training among service providers and the public about ADHD and autism needs. There was also felt to be a lack of suitable and affordable activities for people with ADHD and autism, especially during winter months.

- **Family and Caregiver Stress**

People shared that there can be high levels of stress among parents and caregivers trying to find appropriate support for their children. Some of this stress experienced by families and caregivers is exacerbated by limited support and feelings of isolation.

- **Community and Social Inclusion**

Difficulty in forming social connections and finding community support, especially for late-diagnosed adults. Feedback suggested the need for increased awareness and better signposting for available services and support. It was felt important to be able to access social groups but transport and timings need to be considered for younger people.

- **Volunteer Challenges**

Difficulty in finding volunteer opportunities, indicating a need for better coordination and support for people who lack confidence.

6.3.2 People responding from organisations

- **Diagnosis and Waiting Times:**

We heard that there are long waiting times for Autism and ADHD diagnoses across all age groups. A prevalent nature of online assessments and the lack of support

post-assessment. A lack of resources and capacity was felt to contribute to delays in both diagnosis and subsequent treatment/support. Specific issues highlighted include long waiting lists for assessments, especially for children under 5 years old.

- **Support Services and Pathways:**

Moving from child to adult services was felt to be a challenge for many people. This includes limited availability of Speech and Language Therapy (SALT) and Occupational Therapy (OT) services after primary school. There are delays moving from Tier 2 to Tier 3 services in the Child and Adolescent Mental Health Service (CAMHS). Concerns were mentioned about the adherence to Education Health and Care Plan (EHCP) statutory guidelines, with instances of refusals.

- **Support for Families and Carers:**

There was felt to be inadequate support and intervention for carers of young people with Autism/ADHD and a lack of respite provision for families.

- **Healthcare and Service Provision Challenges:**

Limited awareness and training among social workers and care managers regarding Autism and ADHD behaviours. Need for improved training and support for Personal Assistants (PAs) to enhance their skills in handling neurodivergent individuals. General lack of understanding among professionals regarding the broad spectrum of Autism and ADHD, leading to unhelpful stereotypes.

- **Community Perspectives:**

Issues raised about the mismatch between community-based services designed for different conditions and the specific needs of those with ADHD. Calls for designated support systems tailored to 'high-functioning' Autism/ADHD individuals in workplaces and other community settings.

6.4 What can we do about it?

6.4.1 Residents and or Experts by Experience responses

These ideas for change covered key areas including prioritising accessibility, raising awareness of neurodiversity and providing the right type of support services in the borough.

It included the need to focus on timely access to diagnosis and treatment, sharing best practice across educational settings, boosting employment support and simplifying administrative processes. These ideas will need to be reflected through ongoing action planning.

Fig 10. feedback received on 'improvements and recommendations'

*'Go back to telephone requests for a **GP appointment**. Online forms are okay just don't make it the only way of doing this'*

*'**Early assessments** to identify potential indicators. School teachers to be well trained in spotting possibly signs and especially in how to support'*

*'Have regular **user groups** set up with residents who can provide timely and practical feedback on processes, procedures, forms'*

*'**More leaflets** and pamphlets in coffee shops and local papers. Not everyone has a computer or can use one. Also, bear in mind that people with neurodiversity may prefer more group face-to-face activities than being on their own and reading information.'*

*'**Quieter spaces**, such as libraries and parks, are a haven to people with sensory sensitivity. These should be preserved not just for their cultural importance to RBK but also because of their medical/well being importance'*

*'More parent groups for ideas and **information sharing**, coffee mornings, WhatsApp groups, as often parents don't know what is available'*

1. Diagnosis and Support:

- Focusing resources on reducing the wait time for therapy and diagnostic assessments is critical as prolonged waits can make symptoms worse, increase distress and put more strain on the healthcare services.
- Establish more accessible and timely assessment pathways, especially for late diagnoses.
- Develop comprehensive service directories and have dedicated support workers for individuals aged 25 and older.

2. Healthcare and Wellbeing:

- Address waiting times for assessments, improve mental health services in schools and communities, and facilitate group sessions for practical tips and peer support.
- Advocate for more accessible GP appointment options and better healthcare professional training.
- Promote holistic treatment approaches and consistent care including trauma-informed care for neurodivergent patients.
- Improve access to ADHD medication and ensure GP surgeries are aware of and accommodating to neurodiverse communication needs.
- Provide more training on neurodiversity for medical staff to improve understanding and support.
- Increase comprehensive mental health support, including specialist counselling and therapy.
- Ensure physical therapy services are well-suited to individual needs.

3. Education and Training:

- Prioritise early assessment and intervention for children to prevent long-term mental health issues.
- Include courses on special needs and early intervention in school curricula.
- Ensuring schools are proactive in recognising and providing support to children with ADHD and autism at the earliest signs.
- Provide more opportunities for training in alternative therapies.
- Utilise the expertise of the Spring School and Ambitious About Autism and knowledge in the borough to improve educational and social outcomes.
- Ensure suitable support is available for neurodivergent children, including those with ADHD and autism, within mainstream and specialist educational settings.
- Educate educators on neurodiversity challenges and advocate for fair treatment of students with SEND (Special Educational Needs and Disabilities).
- Offer more transparency and information about available support options for neurodivergent children and involve parents more in their educational and support journey.
- Create neurodiverse-friendly activities and events that are inclusive and accessible. Encourage more face-to-face activities, increase awareness through local publications and expand support groups.

4. Adult Support and Employment:

- Promote neurodivergent-friendly employment practices and making reasonable adjustments to support those in work.
- Ensure colleges and schools are informed and actively engage in making reasonable adjustments and accommodations for students with autism and ADHD.
- Encourage businesses to offer real work opportunities and internships for neurodivergent individuals.

5. Advocacy and Awareness:

- Develop more accessible and easier-to-find information on autism/ADHD-specific activities and services.
- Increase awareness of neurodiversity in schools and workplaces through awareness initiatives.
- Enhance understanding of neurodiversity through community outreach and education programs.
- Offer advocacy and support for neurodivergent people navigating services and systems, ensuring their needs are understood and met.
- Share the knowledge of the Kingston Adult Autism and ADHD team run by Your Healthcare. Including their positive engagement that can enhance services.

6. Service Coordination and Accessibility:

- Establish integrated needs assessments and specialised pathways tailored to neurodiverse populations.
- Advocate for inclusive practices and support in schools, workplaces, and community settings.
- Implement text reminders and accessible appointment systems to improve communication.
- Implement reasonable adjustments consistently across the system. Create checklists for implementing reasonable adjustments in health and care services.
- Avoid closing cases due to missed appointments and address challenges faced by neurodiverse individuals.
- Improve the AfC and Kingston Council website's navigation and transparency to make accessing information easier.
- Propose regular user groups to provide practical feedback on processes and procedures, potentially involving residents as volunteers.
- Expand post-diagnostic support groups and social prescribing initiatives.

7. Family Support:

- Provide enhanced support for families dealing with teenage behaviour and ADHD.
- Provide support services without requiring a formal diagnosis such as group sessions with practical tips.
- Strengthen the network and support for parent carers to reduce their burden and improve their wellbeing. Continue supporting parent-led groups that offer invaluable resources and activities.

8. Support Services:

- Establish dedicated agencies or persons responsible for helping people with autism/ADHD find volunteering opportunities to build confidence and skills.
- Increase the availability of activities specifically tailored for children and adults with ADHD and autism, including before a formal diagnosis has been received. Separate classes or clubs for ADHD might reduce stress and improve social outcomes.
- Enhance support for parent carers, including access to community support and reducing their isolation.
- Recommend/consider commissioning specialised services and establishing Neurodiversity One Stop Shops or Hubs.
- Enhance community support and local service development through peer-led organisations.
- Provide adequate funding and support to local charities that offer crucial support services. Recognise and support organisations that provide essential information and employment support.

9. Community and Transport:

- Offer more affordable and accessible transport options to reduce reliance on taxis.

- Ensure blue badge schemes are accessible to reduce anxiety associated with travelling.
- Support partnerships with community organisations to enhance services and support networks.
- Integrate neurodiversity into safety networks and urban planning to improve public space safety.
- Establish quiet spaces like parks and libraries in Kingston to mitigate sensory overload during events and public activities by reviving and expanding the Safe Places scheme to provide more havens for those with sensory sensitivities.
- Ensure event planning includes risk and equity impact assessments that consider the needs of autistic and ADHD individuals.

6.4.2 People responding from organisations

1. Diagnosis and Support:

- Implement strategies to shorten the waiting period for diagnosis and subsequent treatment.
- Plan sufficient staffing to serve the growing demand.
- Ensure there is a clear offer of support to people who are awaiting a diagnosis of Autism or ADHD.

2. Healthcare and Wellbeing:

- Allocate more resources to support pathways and ensure they are clear and accessible.
- Focus on timely support from specialists experienced in treating neurodivergent people.
- Provide ongoing psychosocial, occupational, and coaching support beyond initial diagnosis and medication reviews.
- Emphasise support for people diagnosed post-25 years of age with clear pathways and directories of services.
- Increase awareness and understanding of neurodiversity among health and social care providers.
- Develop checklists for reasonable adjustments in health and care services.
- Include specialist mental health practitioners in emotional health services and ensure quick referrals.

3. Education and Training:

- Ensure all staff working with neurodiverse people receive comprehensive training.
- Promote inclusive practices and support in schools and community settings.
- Extend training to private personal assistants and the broader community.
- Provide resources and training to parents, especially those of teenagers and young children.

- Ensure that the Autism Service is utilised by schools as needed for (support/consultations) whether or not a child has a confirmed diagnosis.

4. Adult Support and Employment:

- Develop initiatives to educate students about special needs and encourage businesses to provide real work opportunities for neurodiverse people.
- Call for more businesses to offer real work opportunities and internships for neurodiverse people.
- Support and collaboration with community organisations like Express CIC, ADHD Embrace, and Ambitious About Autism.

5. Advocacy and Awareness:

- No specific feedback in this area

6. Service Coordination and Accessibility:

- Ensure seamless transition across different services and stages of life, including from childhood to adulthood.
- Promote partnership working between agencies and services for better coordination and support.
- Introduce text reminders for appointments and make communication more accessible for neurodiverse people.
- Implement policies that do not penalise people for missing appointments due to their neurodivergent conditions.
- Create symbols or systems (similar to the rainbow sign for the LGBT+ community) that indicate a business or service is neurodiversity-friendly.
- Provide resources to existing peer support groups and consider developing similar groups for autistic residents to enhance community support and shape local services.
- Commission specialised services and establish Neurodiversity One Stop Shops or Hubs.
- Foster collaboration between local authorities, service providers, and neurodiverse people to improve service delivery and support.

7. Family Support

- No specific feedback in this area

8. Support Services:

- Establish trust and provide dedicated support workers who can work one-on-one with people.
- Establish hubs that offer therapy, social activities, and support for the neurodiverse community.

9. Community and transport:

- No specific feedback in this area.

7. Next Steps and Conclusions

7.1 What next?

The development of Kingston upon Thames' All Age Autism and ADHD strategy is driven by community feedback and expert insights. The strategy aims to address the needs of people with autism and ADHD across the areas that have been highlighted and the findings listed in this document will inform the draft strategy. A second phase of engagement will take place on the draft strategy during autumn 2024.

This section demonstrates how the feedback that has been received will influence the development of the strategy and a five-year action plan.

7.1.1 You said

People who engaged in focus groups and surveys told us about the priorities and wider challenges in education, healthcare, access to services, employment, mental health and housing. The feedback was extensive and has been summarised below.

Feedback on priorities

Some people felt that all the priorities were equally important and found it difficult to choose just one as their main priority. Feedback also highlighted that many of the priorities overlap which suggests it will be important to identify how partners work well together to share challenges and progress. Some respondents said it would be necessary to ensure that our priorities are practical, specific and measurable. Other key areas of feedback included mental health challenges, support for people who do not yet have a diagnosis and raising awareness of the conditions. It was also clear that everyone's experience of Autism and ADHD was different.

Autistic people and/or people with ADHD:

- Will be given the right support at the right time, including diagnosis (*around half the people who completed the survey chose this as their top priority*).
- Will be involved in planning and developing services
- Will be supported into employment
- Will easily find information and support
- Will feel safe and included in their community

Kingston Council and partners:

- Will increase the awareness of Autism and ADHD

- Will support young people as they move to adulthood
 - *This priority did not have many people advocating for it to be included, however, we do know that for many this still remains a challenging time.*
- Will focus on people's strengths to overcome barriers
 - *This priority had the least support, however, there were clear links made between strengths and employment and raising awareness of Autism and ADHD.*

What's working well, what's not, and what can we do about it? (improvements)

- **Diagnosis and Support**
Survey respondents emphasised the need to reduce wait times for therapy and diagnostic assessments to prevent worsening symptoms and increased distress. They called for more accessible and timely assessment pathways, especially for late diagnoses, and the development of comprehensive service directories with dedicated support workers for individuals aged 25 and older.
- **Healthcare and Wellbeing**
There is a demand for improved mental health services in schools and communities, more accessible GP appointment options, and better-trained healthcare professionals. People advocated for holistic and trauma-informed care for neurodivergent patients, improved access to ADHD medication and increased neurodiversity training for medical staff. Comprehensive mental health support including specialist counselling and therapy and personalised physical therapy services were also highlighted as crucial needs.
- **Education and Training**
Early assessment and intervention for children were seen as critical to preventing long-term mental health issues. People urged for the inclusion of early intervention courses in school curricula, proactive support in schools for children with ADHD and autism and increased training in alternative therapies. They also called for transparency in support options, more involvement of parents and the creation of neurodiverse-friendly activities and events. Educating educators on neurodiversity related challenges and advocating for fair treatment of students with SEND were also key points.
- **Adult Support and Employment**
Promoting neurodivergent-friendly employment practices and making reasonable adjustments to support those in work were highlighted as current challenges. There was a call for colleges and schools to engage in making accommodations for students with autism and ADHD and for businesses to offer real work opportunities and internships for neurodiverse individuals. People also emphasised the need for better service coordination and accessibility including integrated needs assessments, inclusive practices and improved communication systems.

7.1.2 What we are going to do

This document will inform the continuing development of the priorities of autistic people and people with ADHD in Kingston. It will be used to identify the key areas that help to make the priorities real by having specific areas of focus in an action plan. The engagement has generated many very worthwhile ideas. We plan to build on these and when possible, taking account of other demands and commitments, take forward the most promising ones.

By having an action plan that covers all ages within health, social care and the wider reach of the Council we will work towards becoming a more inclusive and supportive community for Autistic people, people who have ADHD and other neurodivergent conditions, ensuring their needs are met as children, young people and adults.

The Autism and ADHD Partnership Board will help to prioritise the findings and steer the development of an action plan. This will be guided by good practice already in place, joint opportunities to target resources and the Board's strong commitment to making a difference for Autistic people and people with ADHD.

Examples may include:

Note: these points are not listed in a priority order

- Ensuring a focus on reducing waiting times for assessments and treatment, ensuring timely support for those in need.
- Seek opportunities to develop and expand post-diagnosis support services for adults, including mental health interventions and employment guidance.
- Streamline and simplify administrative procedures within Kingston Council to make them more accessible and user-friendly for neurodivergent people.
- Provide better training for educators and focus on providing resources to support Autistic children and children with ADHD in schools.
- Work with health to implement training programs for healthcare professionals to improve understanding and support for neurodivergent patients in clinical settings.
- Work with housing to ensure options are suitable and accessible for people with disabilities and improve public transport accessibility.
- Develop comprehensive training programs across sectors to enhance awareness and understanding of neurodivergent conditions and improve service delivery.
- Work with partners to introduce support programs specifically designed to assist families and carers in navigating challenges associated with neurodivergent conditions.

Following the second phase of engagement on the draft strategy and the analysis of comments we receive, the Board will aim to sign off Kingston's All Age Autism and ADHD Strategy and Action Plan in early 2025.

7.2 Conclusion

This engagement set out to test the priorities from the draft new All Age Autism and ADHD strategy 2025-2030, it also sought to gain information on what we were doing well in Kingston, and what could be improved.

The authors of this report would like to thank the Autism and ADHD Partnership Board and all those who gave up their time to participate in the development of the priorities, who contributed to the design and development of the engagement, who delivered focus groups and who completed the survey or gave feedback in another way.

There has been a strong correlation between the feedback of both professionals and those who have lived experiences of services. Less feedback was heard from professionals in relation to family support, community transport and accessible information but these were strong themes from Experts by Experience. Whilst there was positive input from professionals on solutions and ideas for change, the largest number of practical changes for improvements came from people Experts by Experience.

It is clear that the input of people who have lived experience of services is essential to build a holistic understanding of the successes and challenges for autistic people or people with ADHD. We will continue to seek people's voices and experiences as we develop the strategy further.

8. Contact Information

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9. Glossary of terms

ADHD - Attention-deficit hyperactivity disorder, or ADHD for short, is a lifelong neurodevelopmental disorder in which the brain grows and works differently. The core symptoms of ADHD include issues with attention and/or issues with hyperactivity and impulsiveness. ([Psychiatry UK](#))

Autism - Autism is a lifelong developmental disability which affects how people communicate and interact with the world. More than one in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK. ([National Autistic Society](#))

CAMHS - CAMHS stands for Child and Adolescent Mental Health Services. CAMHS is the NHS mental health services for children and young people. CAMHS support covers depression, problems with food and eating, self-harm, abuse, violence or anger, bipolar disorder, schizophrenia and anxiety, and other difficulties. ([Young Minds](#))

Expert by Experience - For this survey, an expert by experience is an autistic person and/or someone who has ADHD. It also includes someone who might give support, like a family member.