

Kingston upon Thames All Age Autism and ADHD Strategy

Engagement Report 2024

February 2025

1. Introduction

In 2024, The Royal Borough of Kingston upon Thames (RBK) undertook engagement for a five year All Age Autism and ADHD Strategy. The engagement was co-designed with a group of Experts by Experience¹ (EbE's) from the Autism and ADHD Partnership Board. Community feedback and expert insights directly influenced the development of the strategy.

This report looks at the responses received from online surveys, focus groups and other feedback. The majority of this feedback was provided by Experts by Experience (EbE's) which provided detailed content and directly informed the development of the strategy and action plan.

Experts by Experience and professionals shared their views² over two phases of the engagement, with some participants contributing feedback in both phases. A 'You Said, We Did' document has been produced to demonstrate how feedback was considered and included into the final strategy.

¹ Experts by Experience - For this engagement, 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.

² Some people may be counted twice if they took part in both Part 1 +2.

2. Executive Summary

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 having the right type of support services in the borough.

In total the two phases of engagement were 12 weeks long. The first phase sought feedback on the draft priorities for the strategy and asked people to have their say on what is working well, what is not working well and suggestions for improvements. In the second phase, an early draft strategy was shared, and people were asked whether it captured the most important issues and whether views had been properly understood.

Feedback was received from people with lived experience of services, residents (children, young people and adults), community, health and care organisations and other professionals such as colleagues in the education sector. Over 240 people shared their views through surveys, focus groups (12) as well as feedback received by emails and structured telephone calls.

This work highlighted examples of things working well in Kingston including support from the Community and Voluntary sector, great work within Health and some schools/colleges and examples of good practice by GP's including quick referrals.

There was a clear message on improvements needed including placing a focus on timely access to diagnosis and treatment, sharing best practice across educational settings, boosting employment support and simplifying administrative processes. This has been included in the strategy and action plan.

We should also recognise limitations of engagement and consider the voices and opinions of those that were not heard. In proportion to the demographics of Kingston, less feedback was heard from young people, parents of younger children, and people of Asian ethnicity. There were gaps in relation to areas we expected feedback including: fear of crime/offending, and relationships.

The work undertaken informs a five year strategy and it is important that in developing action plans under-represented groups and voices are sought.

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3. Phase one Engagement



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.

3.1 Method

Feedback was gathered via electronic surveys (hosted on RBK's Let's Talk engagement platform), focus groups, emails and phone calls. Overall around 140 responses were received (including focus group participants).

A partnership approach to the engagement delivery was used, with board members sharing links to the survey, supporting its promotion and the development of the resident survey. Some partners 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 in a safe space.

The survey was hosted online on the Council Let's Talk engagement portal and structured to separate responses as residents/or experts by experience, focus groups and organisations/professionals to allow for comparative analysis.

Supporting accessible engagement

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.

Example of co-design: 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.

In consideration that some people may not have access to a computer or a mobile phone, prefer information in written form or have the opportunity to talk to someone in person, different options were available for completing the survey.

This approach incorporates best practice and Kingston Healthwatch recommendations in their ‘Including Digitally Excluded Communities Engagement Report’³. Options made available included:

1. 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 and two people shared their thoughts via email.
2. Focus groups were offered as an alternative way to contribute.
3. Images and pictures were used alongside text to make the survey more accessible.
4. Focus group leaders were provided with an easy-read equalities form.
5. As the engagement period fell during exam time, focus groups led by AfC were extended.

Survey detail:

- 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, plain English supported by images
- 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:

- 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.”*⁴)
- Kingston Council’s Staff Disability & Wellbeing Network/ Neurodiversity Champions
- Kingston Council’s Community Safety Team
- Experts by Experience from the Autism and ADHD Partnership Board
- Achieving for Children (AfC) – young people in the Recruits Crew⁵
- Achieving for Children – held a focus group at a local school at which they spoke to a group of learners with autism/ADHD

³

<https://www.healthwatchkingston.org.uk/report/2024-07-05/including-digitally-excluded-communities-engagement-report>

⁴ <https://adhdkingston.org.uk/>

⁵ Where young people who have previously used the Emotional Health Service/Mental Health Support Team have a say in new clinicians.

Limitations of engagement

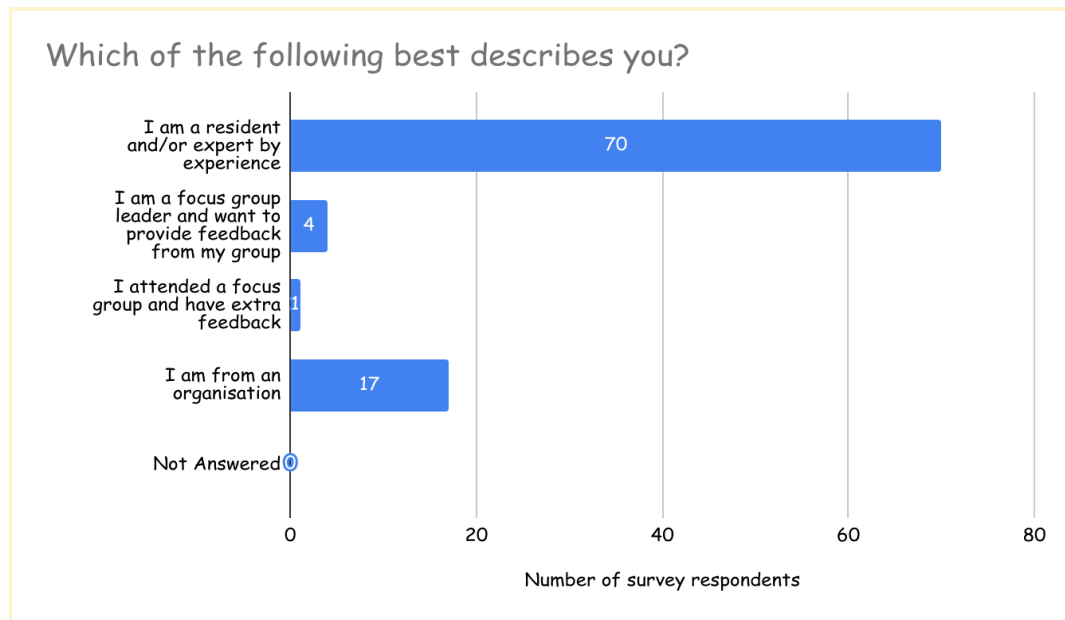
1. A General Election was called while the survey was live. As a result, there were some limitations around certain promotional channels.
2. The engagement period fell during school/ college exam season. To mitigate this barrier, we gave AfC additional time to hold focus groups with this cohort in July.
3. Unforeseen circumstances meant that some of the partners who had committed to delivering a focus group were unable to do so.

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. 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).

Respondents: Residents, experts by experience and organisations

Fig. 1 Number of people completing the survey by experience



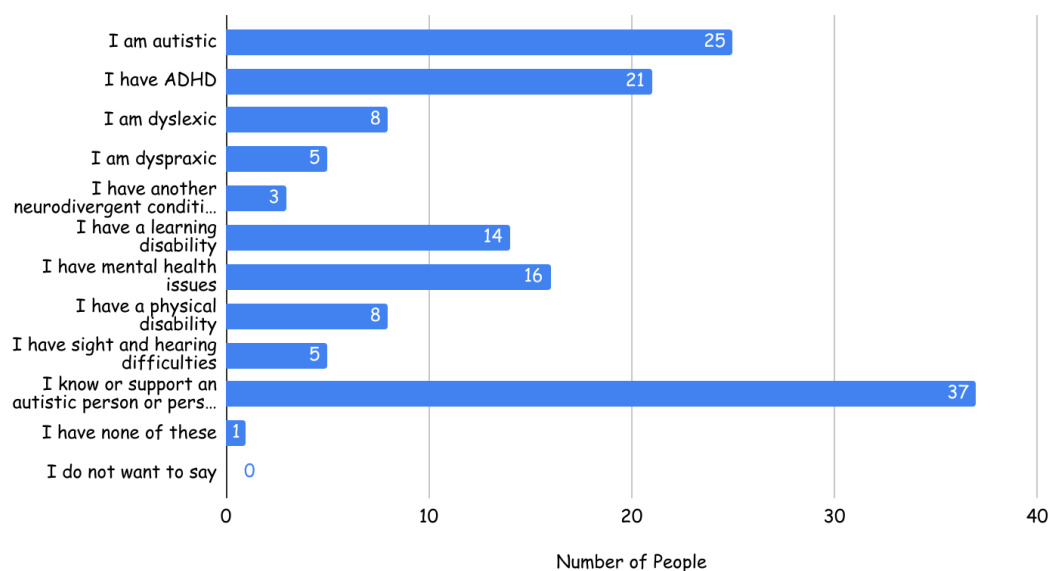
- 70 people described themselves as a resident/and or expert by experience.
- Four people stated they were focus group leaders providing feedback from a group.

- 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/ CIC⁶. There were also responses from day opportunities, supported living, care home/ homecare, NHS and health, education and a statutory service. (more than one option could be selected)

Disability

Fig. 2 Disability type

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



- Two people responding on behalf of organisations told us they were neurodivergent
- Experts by Experience Survey outcome:
 - 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.

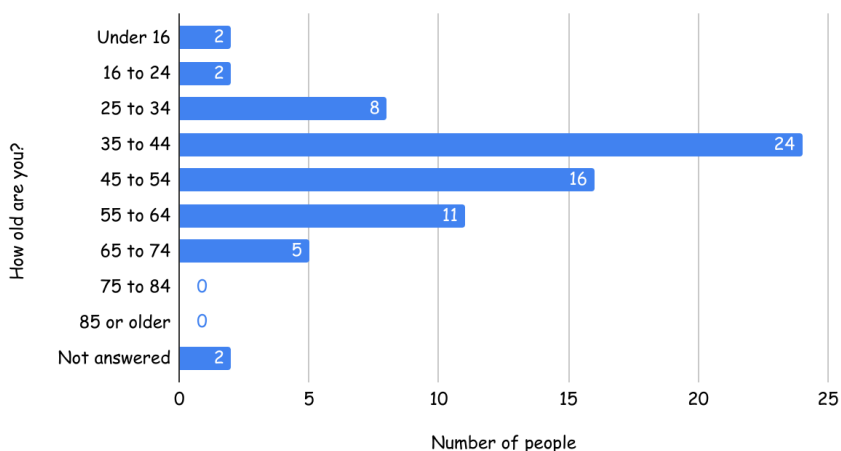
⁶ CIC – Community Interest Company. A Community Interest Company (CIC) is a limited company, with special additional features, created for the use of people who want to conduct a business or other activity for community benefit, and not purely for private advantage.
(<https://www.gov.uk/government/publications/community-interest-companies-business-activities>)

- 20% said they had a learning disability, 23% said they had a mental health condition.
- Many people selected multiple options.
- 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

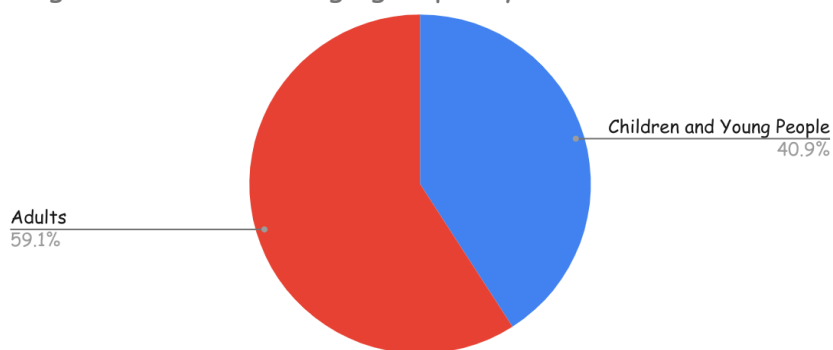


- There were four survey responses from young people aged 24 and under. There were no EbE survey responses from residents aged 75+. Therefore, the voices of residents at either end of the age spectrum are underrepresented in this survey data (the general age distribution in Kingston is 30.6% under 24 and 6.5% over 75)⁷
- Over half of the people responding to the resident/ EbE survey were between 35 and 54.
- Four focus group leaders reported speaking to adults and two groups spoke to children and young people.
- 10 children under 16 and 1 young person aged 16-24 attended the focus groups led by Achieving for Children.

⁷ 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?

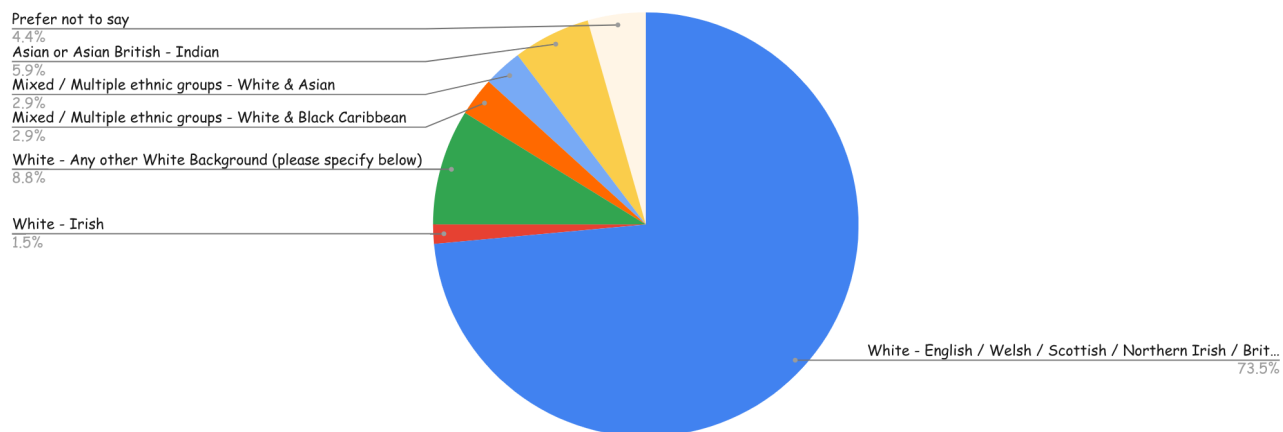


- 59% of the organisations who responded worked with adults, and 41% of the organisations worked with children and young people.

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 EbE's 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. Two groups provided a summary of ethnicity, reporting speaking to people who were: White British, Indian, Pakistani, Bengali, Caribbean, White and Black Caribbean, White other.
- The two Achieving for Children 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

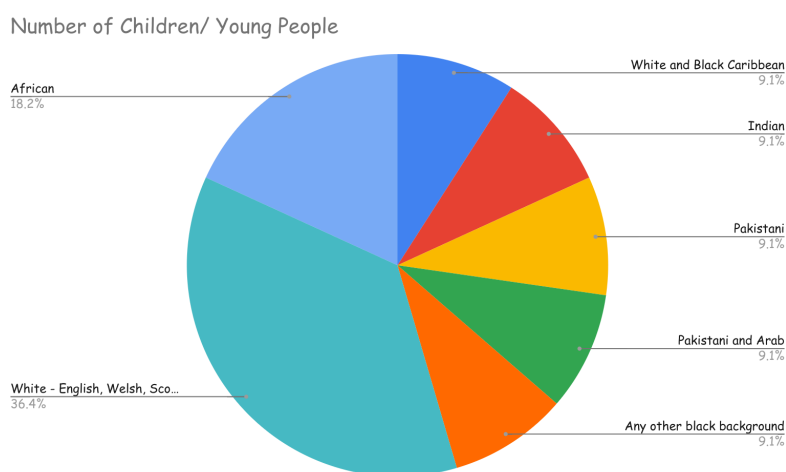
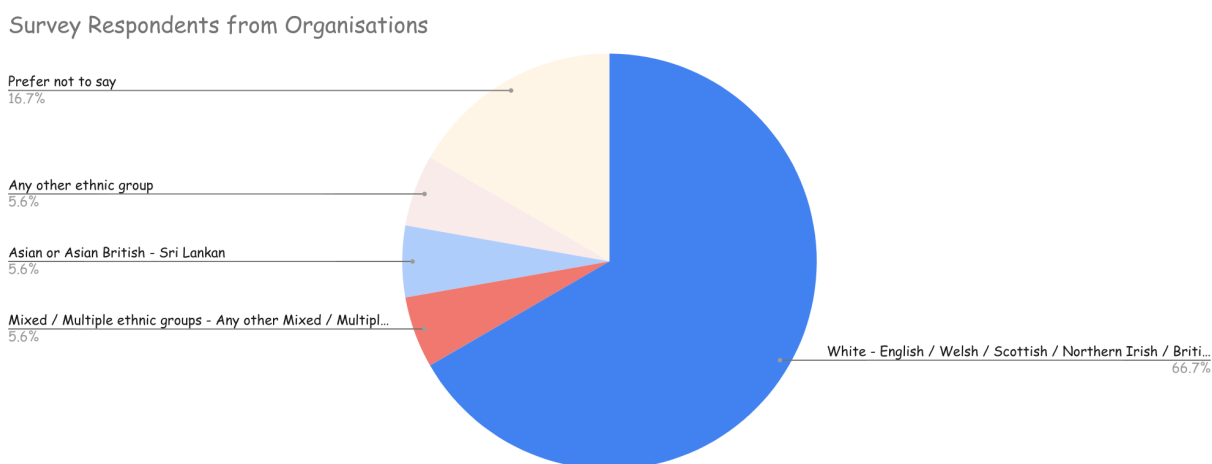


Fig. 7 Survey people from Organisations



3.2 Feedback summary (phase one)

This summary shares key findings and recommendations from the surveys and focus groups with the following sections providing further detail.

Although there were similarities between the feedback of both professionals and those who have lived experiences of services, a greater level of detail was heard from EbE's in relation to the importance of **family support, community transport and accessible information**. Experts by Experience also contributed the most in relation to practical ideas/changes for improvements.

People told us about the priorities and wider challenges in education, healthcare, access to services, employment, mental health and housing. The feedback was extensive and for the purpose of strategy development comparative analysis was undertaken between those who responded from organisations and those with lived experience of autism and ADHD. Further detail is provided in the appendix, and the findings are summarised in this section.

Key findings from responses

- Support is needed for people while waiting for a diagnosis of Autism or ADHD.
- Increasing awareness of Autism and ADHD is important to people, especially young people and young adults. This includes the need for specialist neurodiverse friendly services/ training/ support/ engagement.
- There is a need for practical support (e.g. form filling, housing, bills or benefits), issues accessing ADHD medication and support for parents.
- 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').
- It was clear from the range of feedback received, that everyone's experience of Autism and ADHD was different.

'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!'

Priorities

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?

(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

3.2.1 Feedback on priorities

The priorities were developed by considering national policy⁸, neighbouring boroughs' strategies (Richmond, Sutton and Merton), previous engagement with the Autism and ADHD board and wider work including findings from HealthWatch's 2022 Pulse Check report⁹.

Top Priority: Diagnosis/ Support



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

People largely agreed that all the priorities were important. The most important priority chosen was *'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). Notably **'Will be supported into employment'** was selected by young people from the focus groups as one of the most important areas.

Priorities with the least votes:



Will focus on people's strengths to overcome barriers

The priority with the least support was 'maintaining a focus on people's strengths to overcome barriers' and there was some scepticism that this approach could be prioritised over other areas such as being able to receive timely support. Additionally people felt that focusing on strengths came under the priority about employment. Based on this feedback, this priority was removed from the strategy and brought into a wider strengths-based approach that cuts across all areas of best practice, and raising awareness of Autism and ADHD.

⁸ 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 2018

⁹ Healthwatch Kingston Pulse Check report: Neurodiversity and health and care services 2022



Will support young people as they move to adulthood

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 and overall it was clear that everyone's experience of autism and ADHD is different. In this first phase of engagement, supporting young people as they move into adulthood was not selected as a priority, however wider feedback tells us that for young people and their families, moving to adulthood is an important time and we will seek to understand this in the second phase of engagement.

3.2.2 Feedback on 'What's working well, what's not, and what can we do about it'?

What's working well?

We heard that there are examples of good support from their GPs and the Kingston Adult Autism and ADHD team¹⁰. Collaboration between healthcare providers and community groups is playing an important role.

There were 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 CIC¹¹, Fastminds Adult ADHD support group, and the

¹⁰ The Kingston and Richmond Autism Service is a specialist NHS service providing ASD (Autism Spectrum Disorder) assessment for adults living in Kingston and Richmond

¹¹ Express CiC is a user led organisation, supporting autistic people and their families and promoting awareness in the community

Working Well Trust¹² were mentioned as offering valuable support, enhanced by resources such as the 'Neurodiverse Friendly Collection' on Connected Kingston.¹³

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 acceptance and understanding of neurodiversity. The Sunflower lanyard¹⁴ is increasingly recognised, including on bus transport.

Quotes for '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.'*

What is not working well?

There are areas where the need for **improvement** was identified. These included:

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

¹² Working Well Trust is a supported Employment service in Kingston

¹³ Connected Kingston is an online Information, Advice and Guidance portal to help residents find services

¹⁴ Sunflower - This programme 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 programme commit to being inclusive, and increasing awareness.

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.

Quotes from '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 to start any kind of medication.'*
- *'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'*

What can we do about it?

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.

1. 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.

2. 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.

3. 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.

4. 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.

Quotes 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'*

4. Phase two Engagement

4.1 Method

For Part 2 of the engagement, people shared their views on the draft strategy to check it reflected the feedback we had received in phase 1. As in the first phase, this was by focus groups, an online survey and by accepting feedback by email and by telephone.

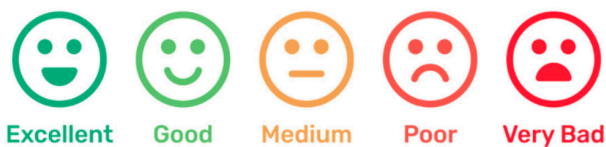
We shared the full document and an easy-read version and asked whether views had been properly understood, and if the strategy would support autistic people/ people with ADHD and their families via a short online survey (a version for EbE's and one for professionals) which was open for 6 weeks: 09/09/2024 to 21/10/2024.

People could also participate in one of 6 focus group conversations. As with phase 1, we took a partnership approach to engagement and asked Board Members to run these groups.

The questions:

Across the engagement, everyone was asked the same 3 key questions (and professionals were asked additional questions about Action Planning):

1. What do you think about the strategy? (Pick a rating)



Eg. Does it cover the most important things to help improve the lives of Autistic people/ people with ADHD?

2. Why did you choose this rating?

3. Is there anything else you want to tell us about the strategy?

In seeking to increase the reach of the engagement, other groups were approached in order to support a more diverse group of residents to have their say. The groups are listed below, and our approach is outlined.

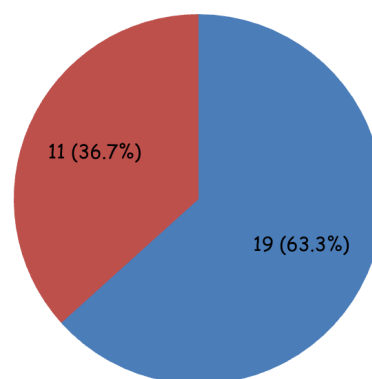
Children and young people	<ul style="list-style-type: none"> • Access All Areas 2024 - SEND Transition and Careers Fair • AfC Participation colleagues led two focus groups with children and young people.
Mental Health Wellbeing Group or Place Mental Health Group	Details of the second phase of the engagement were promoted through Kingston's Mental Health and Wellbeing Group.
Kingston Council's Violence against Women and Girls (VAWG) survivors forum.	Kingston Council didn't have a budget for this engagement so we were unable to meet the requirements of the group to deliver a feedback session at the indicated costs. There were no existing events that we could join during the timeframe. The Community Safety Team did, however, share the survey link with the group.
CLICK Cafe	Colleagues at EnhanceAble offered to run a focus group but no participants came forward. The survey link was shared with the group.
Partner-led focus groups	There were 6 partner-led focus groups in this second part of the engagement. Autism and ADHD Partnership Board EbE's, RBK neurodivergent staff/ Disabilities and Wellbeing Network, 2 Children and Young People focus groups led by AfC, Healthwatch Kingston, and Fastminds Adult ADHD support group
Wider faith and community groups.	<p>We visited the Rise Community Cafe at Kingston Quaker Centre to raise awareness about the work we are doing.</p> <p>We liaised with our Community Development colleagues at the council who advised that for some multicultural groups, we will need to raise awareness first about what Autism and ADHD are, as residents are unable to give feedback on something that may not be fully understood in their communities.</p>
People who have used advocacy services	The survey link and promotional poster were shared directly with Cambridge House Advocacy so they could promote it to their clients.

Who did we hear from?

The total number of people engaged in Part 2 of the engagement was over 100 (This does not include colleagues on Boards or attendees to the Access All Areas event). In this Part 2, more people attended focus groups than completed the survey.

Type of survey respondent

● Resident and/or expert by experience ● Organisation



1. Survey

- 30 respondents
- 19 residents and/or experts by experience
- 11 organisations

2. Focus Groups

- Number of focus groups: 6
- Number of participants in focus groups: **52**
 - Autism and ADHD Partnership Board EbEs (in person)- 13
 - RBK neurodivergent staff/ DAWN network (online)- 3
 - X2 Children and Young People (in person) led by AfC at local schools- 24
 - Healthwatch Kingston- 4
 - Fastminds-8

3. Awareness-raising visits/ event attendance x 2

- Rise Cafe Visit- approx. **10** people
- AfC 'Access All Areas' SEND Transition and Careers Fair
- AALDPB Partnership Board
- Kingston Place Based Partnership Committee
- Autism (NDT) Pathway Review Steering Group
- Kingstons Market Management Group
- Suicide Prevention Group

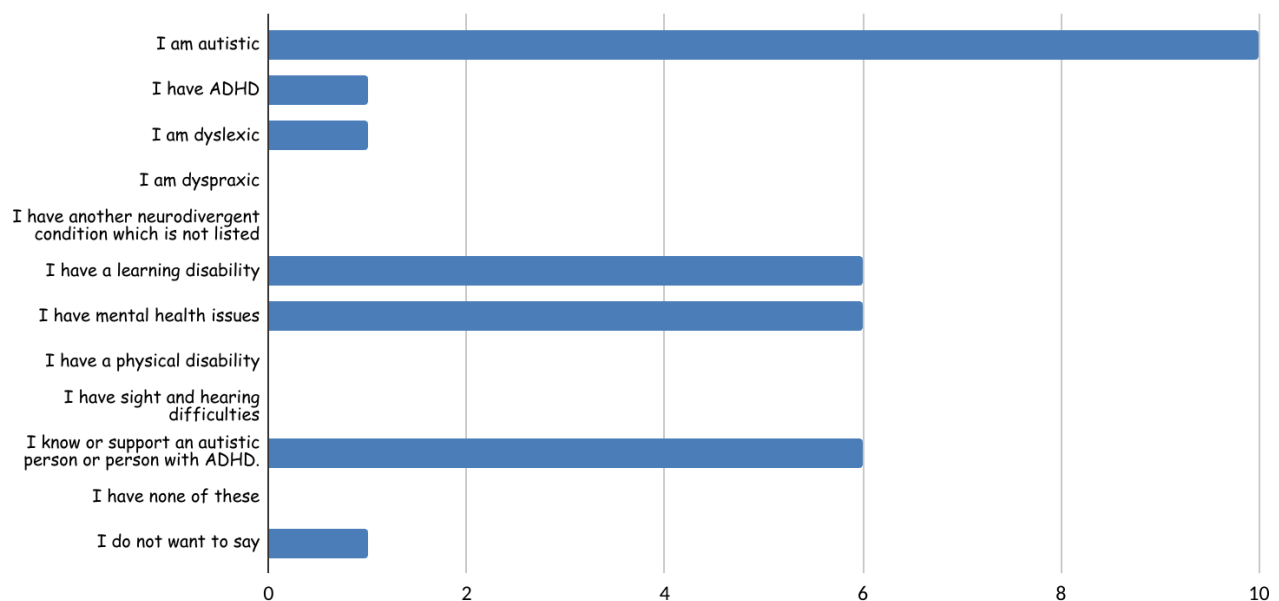
4. Email feedback- 4

Neurodivergence (Survey)

- Organisations: 2 respondents to the online survey said that they were neurodivergent.
- Residents and/or experts by experience (*people were able to select multiple answers*)
 - Nearly all EbE respondents to the online survey were Autistic. Only one person identified as having ADHD.
 - Around half of respondents said they know or support an autistic person/ someone with ADHD.
 - Around half of the respondents said they had a learning disability.
 - Around half of the respondents said they had mental health issues.

This graph shows responses from the resident/ expert by experience online survey

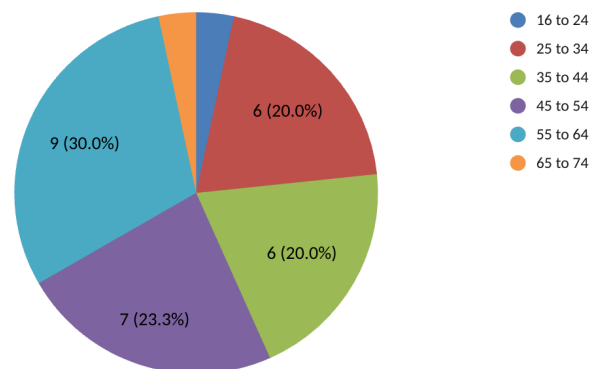
Which of the following best describes you?



Age

The following chart shows the ages of the people who completed the survey. Not all respondents gave their age. The majority of respondents were aged 25-64. The category with the most respondents was 55 to 64. There was one 16-24 year old and one 65 to 74 year old. There were no respondents aged 75+.

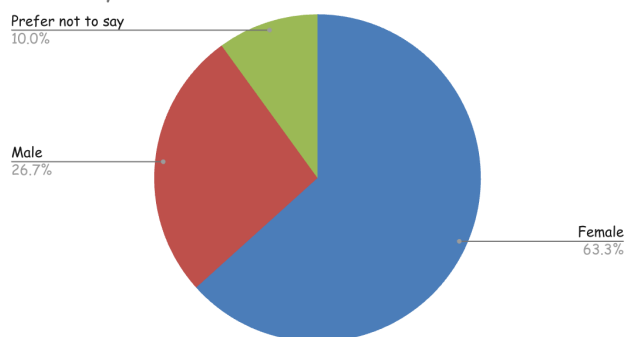
Age of Survey Respondents



Sex

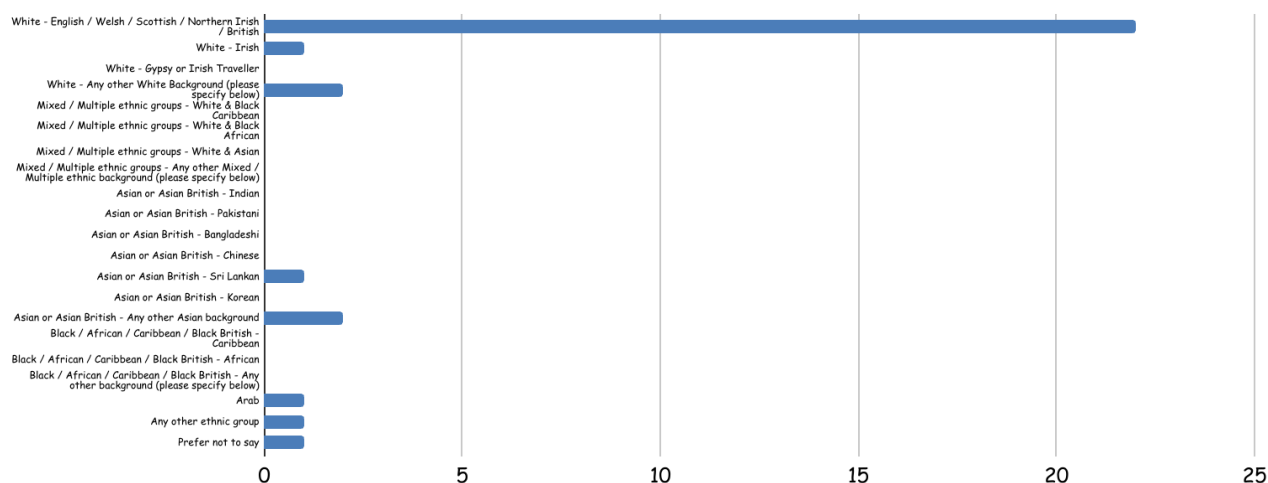
The chart shows the sex of people who completed the survey. Most respondents were female.

What is your sex?



Ethnicity

What is your background/ ethnic group?



- In the online survey, the majority of respondents identified as White - English / Welsh / Scottish / Northern Irish / British.
- We also heard from White - Irish, White - Any other White Background, Asian or Asian British - Sri Lankan, Asian or Asian British - Any other Asian background and Arab members of the community.
- Any other ethnic group - 'Finnish', 'Human', 'Irish-Japanese'
- There was little representation of respondents from different ethnicities within the 30 responses to this second phase engagement survey.

Types of organisation that completed the survey

- Voluntary sector/CIC organisations were represented the most.
- Other types of organisations included: day opportunities, supported living, NHS and health, and colleagues from the local authority.
- All covered the Borough of Kingston. Some organisations also covered the Borough of Richmond and/or the Borough of Elmbridge, 'other local boroughs', Runnymede, Mole Valley, Epsom and Ewell and Spelthorne.
- There were no responses from care homes, homecare or education.
- 10 of 11 organisations work with adults. Whereas, just 2 said they worked with children and young people.

Limitations of engagement

1. Some partners had limited capacity to participate or contribute within timescales, therefore, we are keen to work with board members to support them in taking ownership of elements of the Action Plans.
2. There were very few existing community events in the time span that could be used for a focus group session.
3. We had also planned to display posters about the survey with QR codes on community notice boards but, unfortunately, there was an issue distributing them so this did not happen.

4.2 Feedback summary (phase two)

Overall, across all types of engagement, ‘good’ was the most commonly selected rating for the draft strategy.



Many people appreciated its focus on key issues, including diagnosis and employment support for autistic people and people with ADHD. Three EbEs rated the strategy as ‘poor’, and said that this is because they didn’t feel confident that anything would change.

A ‘We asked, You said, We did’ document was written to state how this feedback shaped the strategy and action plan.

Focus Groups

- Autism and ADHD Partnership Board EbE Focus Group: 23% Excellent + 77% Good
- Children and Young People Focus Groups (x2): ‘Excellent’ and ‘Good’ were the most common ratings.
- Kingston Council Staff Disability and Wellbeing Staff Network: The strategy is ‘good’.

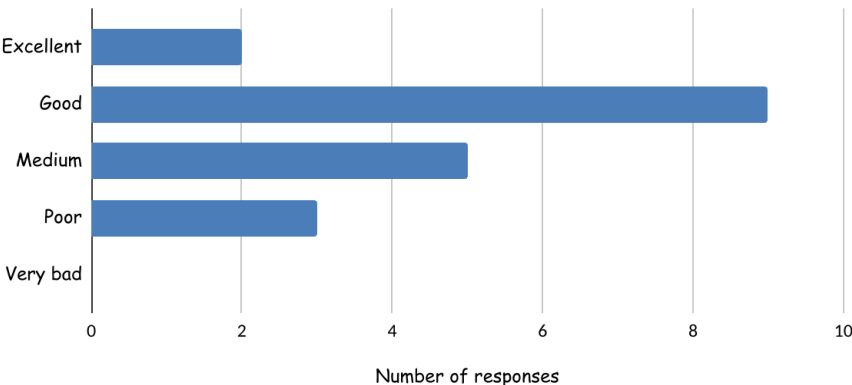
Survey respondents

Overall survey figures including both EbEs and organisations (see graphs below for a breakdown):

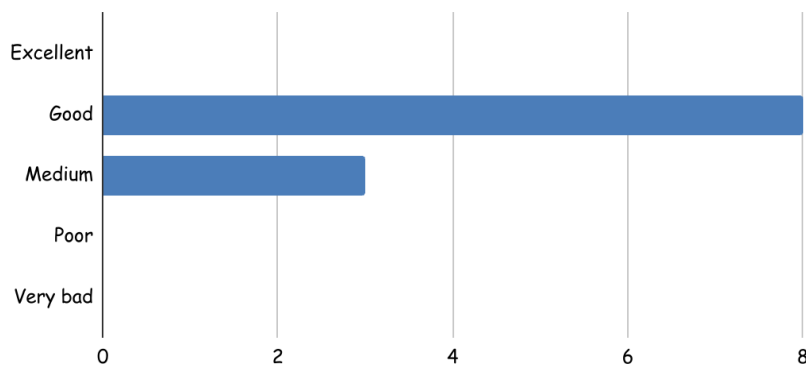
- Overall, 63% of survey respondents rated the strategy as ‘good’ or ‘excellent’
- ‘Good’ was the most frequently selected rating with 57% of the total vote.
- 34% of respondents rated the strategy as ‘medium’
- 3% people rated the strategy as ‘poor’, however, nobody rated it as ‘very bad’

Graphs showing the breakdown of results from survey responses:

What do you think about the strategy? (Residents/ EbEs)



What do you think about the strategy? (Organisations)



Organisations who responded to the survey were affiliated with strategic boards including: SEND Partnership Board, Mental Health & Wellbeing Group, Autism and ADHD Partnership Board, All Age Learning Disability Partnership Board and the Safeguarding Adults Board.

4.2.1 Additional Feedback

Some feedback related to the same key themes shared with us in Part 1 of the engagement, so these areas have been clarified or strengthened in the strategy. Further detail is provided in the ‘You said, We did’ summary. They included;

- Initiatives that increase practical support (including activities)
- Information, advice and guidance
- Reasonable adjustments and accessibility
- Training and awareness
- Education
- Advocacy and support
- Feedback about the layout, visual elements and wording of the strategy document.

Additional Experts by Experience (EbE) feedback

Areas of EbE feedback included the importance of being up-front about the challenges of implementing change in the constraints of finance and resources. It was suggested the strategy should explicitly reference duties on other organisations such as the Children and Family Act, emphasising the role of Education, Health and Care Plans (EHCPs) in providing necessary support and the role of the ICB to implement the Dynamic Support Register. Important in this context

to reference the Care Act 2014- that social care commission support services that meet the needs of people eligible for social care, and the requirement for reasonable adaptations under the Equality Act 2010.

Quotes from feedback from phase two

- *'Pathways into adult services can be confusing for parents and carers.'*
- *'Without the right support networks, parents and carers can easily feel isolated and alone.'*
- *Supporting parent carers who are also neurodivergent themselves: 'having a condition and being alone, while trying to support your child with a condition is beyond difficult.'*
- *'Consider adult support needs when a parent or carer dies, as part of bereavement support.'*
- *'There is a need for better data to inform the development of services.'*

Feedback by theme (experts by experience and organisations)

1. Diagnosis and support

- Both organisations and experts by experience highlighted that earlier diagnosis is a cost saver as mental health/ physical health conditions worsen. Mental health link is often not a cause but a by-product of not being supported properly and this can be life threatening.
- People are having to pay a lot of money privately to have assessments because the wait is so long which creates an imbalance/unfairness for equity.
- Suggestion: national level hub for info & advice - local hubs feed into national. Things happening nationally and how it links in- not just looking at other boroughs to bench mark- be a leader not a follower.
- There is a lot of pressure on charities to support neurodivergent people.

1. Healthcare and Wellbeing

- Decluttering/ hoarding and organisation can be really difficult for neurodiverse people which can impact on their housing and wellbeing.
- 'I don't want to be invisible anymore.' 'I struggle to find the words to explain - you don't want to understand.'
- Neurodivergent people need more time to speak to professionals.

2. Education and Training

- Professionals need to understand linked conditions e.g. neurodiversity and hypermobility. Also the additional challenges people can face when they are neurodivergent and going through the menopause.
- Reasonable adjustments in schools were highlighted, especially regarding absence policies for anxious students.
- Medical staff need to be more aware of how neurodiverse people deal with pain.
- Establish Neurodiversity champions and Diversity and inclusion officers in all services to improve consistency among professionals.

3. Adult Support and Employment

- One person asked for recognition of people who are neurodiverse and LGBTQ+ in the strategy, for better signposting and information, or for the support needs of ASD and ADHD people who are LGBTQ+ to be assessed.
- People with ADHD need a 'body double'.

4. Advocacy and Awareness

- RBK suicide strategy to call-out/include ADHD alongside autism.
- LeDeR (Learning from Lives and Deaths) reviews to include people with ADHD
- Increasing training/ awareness of Autism and ADHD in females for professionals.

5. Accessibility and Service Coordination

- Creating an ADHD Passport in the same way there is an Autism Passport.
- Internally at Kingston Council, neurodiversity resources such as reasonable adjustment passports exist so how can these be shared more within the organisation.
- More consideration needs to be made in terms of the working environment- e.g. lighting needs to be looked at re sensory issues.
- The importance of non-digital options as online doesn't work for everyone, this is related to all areas including information/communication/ engagement and in terms of face to face appointments.

Organisations/professionals feedback

Overall, the strategy was regarded as well-considered with good intentions. Organisations who responded to the survey on Let's Talk data rated the draft strategy 'good' or 'medium'. It was felt to align well with the experiences and priorities of Experts by Experience, particularly in areas such as diagnosis, healthcare access, and employment support.

While the strategy's priorities were deemed sensible, there are concerns about the real challenge of making changes, particularly regarding diagnosis wait times and a lack of information on children under five. The strategy should also emphasise the need for support for adults, particularly those with severe autism and ADHD. Some people felt the strategy did not adequately address 0-5 data.

In terms of raising awareness, sharing good practice around Autism and ADHD was highlighted as a potential action.

Data anomalies were highlighted between the number of autistic people in Kingston, based on national prevalence data (1700) and the numbers worked up from current rates of diagnosis in Kingston (2,742 children and young people with a primary need of autism in their EHCP).

Design and layout and wording of the strategy

- The strategy was criticised for being too text-heavy: suggestions to include more infographics, flow charts, visual elements or video/ audio versions to enhance the readability and understanding of the document and the processes it describes. People also asked for more detail and further information to be included.
- Producing a child/young person-friendly version of the strategy which works visually and in terms of relevant themes and relatable content.
- Young people asked for the strategy to be in a format that is smart phone compatible and printable.
- 'Making it Real' section- some EbEs were 'confused and frustrated by this section'.
- Inconsistencies in the definitions of autism between the easy-read version and the full strategy need to be addressed. It needs to be clearly articulated that autism is a lifelong condition affecting communication and interaction.
- Wording: specific changes are needed. For example
 - People did not like the descriptor of 'inattention' in the ADHD section.

- There's also a need to address information regarding ADHD and co-occurring conditions, to include mental health issues and emotional dysregulation.
- There was concern over the vague language in the How will we know it is working 'The implementation of the strategy will be overseen by the Autism and ADHD Partnership Board and measures may include'

Feedback on the action plan

- The action plan should have a structured approach, breaking down goals into short-term (less than 6 months), medium-term (up to 2 years), and long-term (up to 5 years).
- People emphasised the need for SMART targets to demonstrate how changes will be implemented effectively. One suggestion was the development of an Autism and ADHD charter and track how many organisations sign up to the charter over the duration of the strategy.

Current or upcoming plans of partner organisations, which link to the workstreams in the strategy

We also asked professionals who completed the survey to tell us about the work that they are doing now, and planned for the future which relate to the action plan areas. These partners include Your Healthcare, Adult Social Care, Princes Alice Hospice, Community Paediatrician and Achieving for Children.

Planned work included;

- Promotion of the Oliver McGowan training
- Support for autistic people in hospital settings
- Work across South West London to increase capacity for ADHD assessments
- Creating additional resources through pilot projects to increase social prescribing and care-coordination.
- Providing training to the NHS mental health services to develop their skills working with autistic adults.
- Ensuring there is a clear diagnostic pathway in place for children under 5 years old
- Online GP awareness training and autism training for school staff.
- Joint assessments for ADHD and Autism where possible to reduced wait times, and the need to repeat life story.
- Advocating increased funding to develop existing services and increase capacity.
- Collaboration across South West London to identify best practice.

5. Conclusions

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.

It is clear that the input of people who have lived experience of services is essential to build a better understanding of the successes and challenges for autistic people or people with ADHD. Kingston Council will continue to seek people's voices and experiences as action plans are developed and the strategy is implemented.

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.

Next steps

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

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:

1. Ensuring a focus on reducing waiting times for assessments and treatment, ensuring timely support for those in need.
2. Seek opportunities to develop and expand post-diagnosis support services for adults, including mental health interventions and employment guidance.

3. Streamline and simplify administrative procedures within Kingston Council to make them more accessible and user-friendly for neurodivergent people.
4. Provide better training for educators and focus on providing resources to support Autistic children and children with ADHD in schools.
5. Work with health to implement training programs for healthcare professionals to improve understanding and support for neurodivergent patients in clinical settings.
6. Work with housing to ensure options are suitable and accessible for people with disabilities and improve public transport accessibility.
7. Develop comprehensive training programs across sectors to enhance awareness and understanding of neurodivergent conditions and improve service delivery.
8. Work with partners to introduce support programs specifically designed to assist families and carers in navigating challenges associated with neurodivergent conditions.

Final note

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.

6. Contact Information

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7. 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.

8. Appendix

8.1 Detailed feedback from residents and experts by experience/organisations

Residents and or Experts by Experience responses ‘What's working well?’

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 shared with medical and emergency services personnel who demonstrated neurodiversity-friendly approaches.

Awareness

We heard 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 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.

What is not working well?

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. 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 people felt schools were not adequately equipped to manage the needs of autistic students and students with ADHD, 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 often be difficult with insufficient support for transitions between educational stages, particularly during critical periods like GCSEs.

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 autistic people and people with ADHD leading to poor living conditions including poor management of housing repairs and maintenance which can cause additional stress for residents. Some people spoke of 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.

What can we do about it?

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.

People responding from organisations ‘What's working well’?

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.

What's not working well?

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.

What can we do about it?

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.