

We Asked, You Said, We Did

Autism and ADHD Strategy Engagement 2024

Introduction

The Royal Borough of Kingston-upon-Thames undertook community engagement during 2024, to inform the development of a five year, all-ages Autism and ADHD strategy. The strategy aimed to set out priority areas for improvement, for Kingston to be a place where autistic people and people with ADHD have the opportunities and support to live their lives well.

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.

Over 240 people shared their feedback, the majority of which were autistic people, people with ADHD or their family or friends. The feedback was used to identify priority areas we wanted to focus on. We also identified areas which we call 'principles' which were ways of working that cover all aspects of change.

Summary Conclusions from Engagement

Feedback highlighted the need for prioritising accessibility, raising awareness of neurodiversity, and having the right type of support services in the borough. An engagement report was written containing full details of feedback which supports the development of the strategy.

This work highlighted examples of things working well in Kingston including support from the Community and Voluntary sector. There were examples of positive, best practice within Health, schools/colleges and GP's including quick referrals however these were not consistent and it was clear that people's experience of accessing services and support were different.

There was clear feedback on improvements that need to be made including a focus on timely access to diagnosis and treatment, sharing best practice across educational settings, boosting employment support and simplifying administrative processes. These alongside other recommendations were included in the strategy and will help shape action plans.

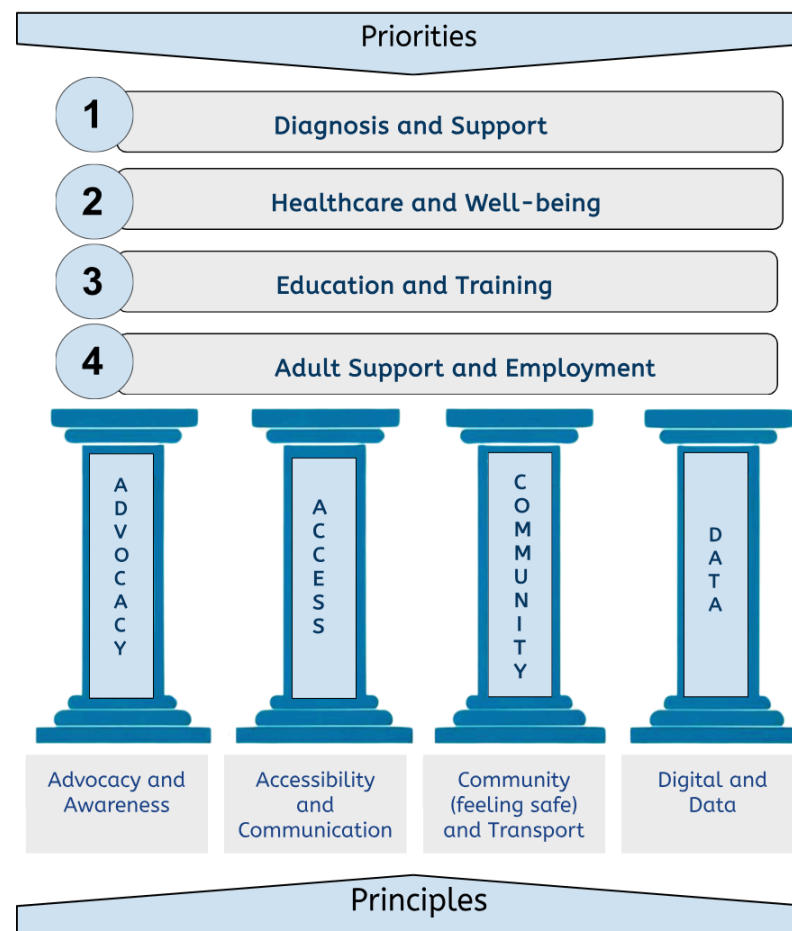
We must also consider the voices and opinions of those that were not heard. Less feedback was heard from young people, parents of younger children, and people of Asian ethnicity. There were also gaps in relation to areas we expected including: fear of crime/offending, and relationships. In developing action plans, further work is recommended to ensure the views of under-represented groups are heard, and experts by experience remain at the heart of this work following the participatory principle of 'Nothing about us, without us'.

1. Priorities and Principles

Four clear priority areas emerged from the feedback. In order of priority they were Diagnosis (and support whilst waiting for a diagnosis), Healthcare and Well-being with a focus around mental health support, Education and Training and Adult Support and Employment which included support to get employment and support to continue and thrive in work.

We identified 'themes' from the feedback that support people's voices being heard, to have fair access to services and to feel safe in the community and we have called these our 'principles'.

In developing the strategy, we found there were gaps in information, especially for people with ADHD. Data is necessary to understand current needs for autistic people and people with ADHD and plan well for the future and for this reason was also included as a principle.



2. Summary: We asked, you said, we did

This summary shows how peoples suggestions were used to develop the Kingston All Age Autism and ADHD Strategy, and decide on the Action Plan areas.

We asked...
Part 1 Engagement <ul style="list-style-type: none">What do you think of the draft priorities for the strategy?What is working well in Kingston for autistic people and people with ADHD and what can we do better? Part 2 Engagement <ul style="list-style-type: none">We shared the draft strategy and asked for people’s feedback on it.

	You Said	We Did	Completed/Next steps
1	<p>The top priority was: ‘We will be given the right support at the right time, including diagnosis.’</p> <p>There are long waiting times for a diagnosis of Autism or ADHD which is not good and support is also needed for people who are waiting.</p>	<p>This is part of the action plan which focuses on 5 areas of diagnosis and support. This includes: creating easier access to get an assessment, trying to reduce waiting times for a diagnosis and ensuring there is support for people while they are waiting.</p>	Completed

2	People want to see action from the strategy and make sure this is monitored .	There is an action plan in the strategy and there are groups of partners from the Autism and ADHD Partnership Board working on the themes to make them happen. The strategy also includes a list of ways in which we will measure our progress.	Next steps to monitor progress (see section 3)
3	Some autistic residents and people with ADHD need practical support . This may mean hands-on help to manage daily lives eg. with form filling, housing, bills or benefits.	One of our actions is to highlight the responsibility of Kingston Council to deliver their Care Act duty. To have the right preventative services in place, including the need for practical support to help people live independently. This is now clearly stated in Strategy in the 'legislation' section.	Completed
4	Mental health issues were a common theme in the engagement.	We have included actions in the strategy about mental health: <ul style="list-style-type: none"> • 'Early identification and support for children to prevent long-term mental health issues.' • 'Improve mental health services in schools and communities including specialist counselling and therapy, and personalised physical therapy services.' 	Completed
5	Training and awareness around neurodivergent conditions need to be improved.	A key reason to have a strategy is to bring together local organisations and the wider community to raise awareness of neurodiversity. <ul style="list-style-type: none"> • There is an action in the strategy about providing more specific training about Autism and ADHD for health and medical staff, social care and educators. 	Next steps will be to monitor progress (see section 3)
6	It was clear that everyone's experience of being autistic or having ADHD was different .	This feedback has helped us to develop some key principles to make sure that people have a consistent and good experience of services including accessibility and reasonable adjustments.	Completed

	Some people had really good experiences of services and some people had poor experiences.		
7	<p>You asked for better support for families.</p> <hr/> <p>Also, some people are worried about what will happen to their adult children who are autistic/ have ADHD when they are no longer around to support them.</p>	<p>Within the action plan, we include support for families such as practical support, bereavement support, the need for advocacy and recognising the risk of isolation.</p> <hr/> <p>We have added this to the strategy. It is also an area of focus in the Carers Strategy Action Plans so we will make sure we are linked up with this work.</p>	Next steps will be to monitor progress (see section 3)
8	You asked if we could make the strategy more child-friendly and relevant for them so they can engage with it more easily.	Achieving for Children (AfC) produced a widget-based summary for their engagement with children and young people in Part 2.	We are exploring how we can have a version of the strategy specifically targeted at children/young people.
9	You said the full draft strategy document had too much text and you would like more pictures or infographics .	<p>An easy-read version of the strategy with pictures is available produced by our in-house INVOLVE team who are themselves experts by experience.</p> <p>There will also be a short summary of the strategy which includes more images.</p>	We are setting up a focus group with EbEs on the Board to work on the design with our Communications Team.

10	There was a request for a clear explanation of why we need a strategy , and the benefits of this.	Strengthening of the 'Why do we need a strategy?' section	Completed
11	The co-occurring conditions section in the strategy should include mental health issues and emotional dysregulation .	Inclusion of suggested edit in 'Co-occurring conditions'	Completed
12	There are differences between the content of the strategy and the easy-read .	We are acknowledge that there are some differences between these two documents	To be updated, and checked by the INVOLVE team
13	Reference the role of the ICB to implement the Dynamic Support Register .	We have captured this feedback	We will include this in final strategy
14	There needs to be more emphasis on pathways into support as young people move into adult services.	This has been included in our priority 2. Accessibility and Service Coordination	Completed
15	Reference the Children and Family Act and emphasise the importance of Education, Health and Care Plans (EHCPs)	Included in Assessment and Support section. Education section has been updated to include wider responsibilities meet needs.	Completed

16	There needs to be a national directory of services for autistic people and people with ADHD, linked to a local worker who has a responsibility to keep it up to date.	There are plans at a national level to look at how this type of information is shared and Kingston Council will seek to influence this. In Kingston, we commissioned 'Connected Kingston' and worked with them to create a dedicated page for services that support people with neurodivergent conditions.	Completed
17	'People need support to stay in employment and thrive. It is not enough to just have support to get employed'	This has been included in the fourth priority Employment and Support.	Next steps will be to monitor progress (see section 3)
18	There should be a Neurodiversity charter to set good standards, and so we can measure the progress and impact of the strategy.	This has been included as a development piece of work and part of our set of measures on the effectiveness of the strategy	Co-develop a neurodiversity charter with experts by experience
19	Include co-occurring conditions such as conduct disorders and Oppositional Defiant Disorder (ODD) should be mentioned.	This was not included as the research is still developing in this area and there are varying opinions around the relationship of ODD and other Neurodivergent conditions.	Completed
20	There is a lack of reference to statutory Advocacy support and practical peer support.	Advocacy and Awareness is one of the principles that supports change in all areas of our work. This section has been strengthened to reference the local authorities duty to provide an independent advocate where that person meets the criteria.	Completed

21	‘Include a list of examples of the types of reasonable adjustment options that others with ADHD and Autism have had that they've found helpful. That way they can use choose some and adapt them for their own applications/discussions’	Reasonable adjustments have been highlighted in the strategy with reference to organisations responsibility under the Equality Act 2010. It has not been possible to include all the types of adjustments that could be beneficial but examples have been provided <i>“Offer telephone requests for a GP appointment. Online forms are okay, just don't make it the only way of doing this”</i>	Completed
22	Some data is wrong, the estimated number of autistic people based on national prevalence data is lower than the numbers from current rates of diagnosis	National prevalence estimates are now out of date, and from the local data analysed, we can see that there are a significantly higher number of people being diagnosed with Autism and ADHD.. There are other issues with Data collection needed to accurately project how many people are likely to have these conditions,which informs our fourth ‘Digital and Data’ principle.	This section will be updated, and reworded. Recommendation of a joint needs assessment with Public Health on Autism and ADHD
23	Housing is only mentioned three times in the document, it would be good to know more about the support offered by Kingston council.	In comparison with other feedback received there were less comments about housing, however we recognise that housing is an issue that affects everyone and additions have been made to the wording of the strategy including ‘Make use of Disabled Facility Grants (DFGs), to help towards the cost of making adaptations to your home’	To bring actions around housing into our priority area ‘Health and Wellbeing’

3. Monitoring: How will we know if it is working?

People asked how progress will be monitored. To do this we need an understanding of what is happening now, and if we have made a difference by implementing our strategy. The Action Plan will be overseen by the Autism and ADHD Partnership Board to monitor progress.



The measures we propose to use to measure change are:

1. **Annual quality of life surveys** for people with neurodivergent conditions to establish a baseline and improvement in key areas of the action plan.
2. **Annual reporting** back against the key themes, for example: waiting times and the number of people accessing specialist services.
3. **Tracking employment rates** and job retention for autistic people and people with ADHD.
4. **Developing a Neurodiversity Charter** and track the number of people signing up.
5. **Establishing a community of practice** to share best practice across social care, education, health and community-led services.
6. **Developing better local data** gathering on the number of children, young people and adults with a diagnosis of autism and/or ADHD in Kingston.
7. **Providing regular updates** on the work of the Autism and ADHD Partnership Board, including sharing developments from action plans on Kingston Council's website.
8. **Working with other experts** to consider other ways of measuring the progress we make against our goals for the strategy.

What next?

- You can go to Council's [Let's Talk Website](#) to find out more about the engagement we did.
- The Kingston All Age Autism and ADHD Strategy will launch in March 2025.
- It will be on Kingston Council's website so you can read it.
- Partners from the Autism and ADHD Partnership Board are working together on Action Plans to make the strategy happen over the next 5 years.

If you have any questions please contact:

adultscommissioning@kingston.gov.uk or call the Contact Centre on 0208547 5005.