

# We Asked, You Said, We Did

# Autism and ADHD Strategy Engagement 2024



This is an Easy Read document about the 2024 Autism and ADHD Strategy Engagement and what we are doing next with your feedback.







Involve

# Introduction



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• In 2024, we talked to the community. We wanted to make a plan for Autistic people and people with ADHD, we call this our 'strategy'. This strategy is for five years. It is for people of all ages.

- The plan is how we will make lives better for autistic people and people with ADHD in Kingston.
- The plan focuses on the areas that need the most improvement. The community's ideas have helped make the plan. It is important for everyone to be included.

• Kingston wants to be a good place for everyone. They want Autistic people and people with ADHD to feel happy. The plan will help make this happen.











- The engagement lasted 12 weeks in total.
- In the first part, people gave feedback on what was good and what needed fixing. They also shared ideas to make things better.
- In the second part, an early plan was shown.
- People were asked if it covered important issues and if their views were understood.
- More than 240 people gave their thoughts. Most were autistic or had ADHD, or their family or friends. Their feedback helped us to write the strategy and find important areas to work on. We also found **'principles'** which guide all our changes.
- We used your feedback to help us write the **Kingston All Age Autism and ADHD Strategy 2025-2030**.

# We asked, you said, we did

# We asked...



- 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 1 Engagement

#### Part 2 Engagement



• We shared the draft strategy and asked for people's feedback on it.

# This is a summary of some of the key things people told us.



#### 1. You Said

- The top priority was: 'We will be given the right **support** at the right time, such as **diagnosis**.'
- 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.

#### We Did

- The plan looks at 5 areas to help people. The plan will aim to make it easier for people to get checked, to make waiting times shorter and for people to get help while they wait for a diagnosis.
- The plan aims to make things better for everyone. It wants to make sure people get the support they need. This will help people feel less worried while they wait.

## 2. You Said

• People want to see **action** from the strategy. To make sure progress is being made.

#### We Did

- 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 has a list of ways in which we will measure our progress.



# Care Act 2014

# 3. You Said

• Some autistic residents and people with ADHD need **extra support**. This may mean practical help to manage daily lives e.g. with form filling, housing, bills or benefits.

#### We Did

- We want Kingston Council to do their job under the Care Act. They should help people live on their own. This means having the right services to stop problems before they start.
- The Strategy now says this in the 'legislation' (law) part.

# 4. You Said

• Mental health issues were a common theme in the engagement.

#### We Did

We have included actions in the strategy about mental health:

- Finding and helping children early to prevent long-term mental health problems.
- 'Improve mental health services in schools and communities such as specialist counselling and therapy, and personalised physical therapy services.'



- **Training and awareness** around neurodivergent conditions needs to be better.

#### We Did

- A key reason to have a strategy is to bring together local organisations and the wider community to raise awareness of neurodiversity.
- There is an action in the strategy about more specific training about Autism and ADHD for health and medical staff, social care and teachers.

#### 6. You Said

- It was clear that everyone's experience of being autistic or having ADHD was different.
- Some people had really good experiences of services and some people had poor experiences.

#### We Did

• This feedback has helped us to develop some key **principles** to make sure that people have a good experience of services such as accessibility and reasonable adjustments.



- You asked for **better support for families**.
- 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.

#### We Did

- The action plan includes support for families, like help with everyday tasks, bereavement support, the need for advocacy and knowing the risk of loneliness.
- 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.

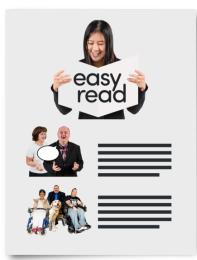
## 8. You Said

• You asked if we could **make the strategy more child-friendly** and the right information for them so they can engage with it more easily.

#### We Did

- Achieving for Children (AfC) made a widget-based summary for their engagement with children and young people in Part 2.
- We will make sure the strategy is smartphone-friendly and printable.





• You said the full draft strategy document had **too much text** and you would like **more pictures.** 

#### We Did

- An easy-read version of the strategy with pictures is available made by our in-house INVOLVE team who are themselves experts by experience.
- There will also be a short summary of the strategy which has more images. We held a focus group with Experts by Experience and the Communications Team about graphic design.

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## 10. You Said

• There was a request for clear information as to **why we need a strategy**, and the benefits of this.

#### We Did

• We have made this clear in our 'Why do we need a strategy?' section.

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- The section in the strategy that focuses on health conditions that cross over with Autism and ADHD should include **mental health issues and emotional dysregulation.**
- Emotional dysregulation means it's hard to control feelings. People might feel very angry or sad, even if the problem is small. It can be tough to manage these big emotions.



• We have added the changes.

## 12. You Said

• There needs to be more focus on **how to get support** as young people move into adult services.

#### We Did

• This has been included in the Accessibility and Service Coordination section of the strategy.





• Reference the Children and Family Act and the importance of **Education, Health** and Care Plans (EHCPs)

#### We Did

• This information has been added to the Assessment and Support section of the strategy. The education section has been changed to include more ways to meet needs.

## 14. You Said

• There should be a national list of services for autistic people and people with ADHD, linked to a local worker who keeps it updated.

#### We Did

 There are national plans to see how this information is shared, and Kingston
Council will try to help with this. In Kingston, we have 'Connected Kingston' and worked with them to create a dedicated page for services that support people with neurodivergent conditions.





• 'People need support to stay in **employment** and thrive. It is not enough to just have support to get employed'

#### We Did

• This has been included in the fourth priority Employment and Support.

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# 16. You Said

• We need a Neurodiversity charter. This will help us set good rules and check how well the plan is working.

#### We Did

• This has been added as part of our plan to measure how well the strategy works.

- Co-occurring conditions should be mentioned.
- Some people might have other conditions like conduct disorders or Oppositional Defiant Disorder (ODD) along with their main condition. It's important to talk about these too, as they can affect how someone feels and behaves.

#### We Did

• This was not included because the research is still developing, and there are different opinions about the link between ODD and other neurodivergent conditions.

#### 18. You Said

- There is not enough mention of legal advocacy support and practical help from peers.
- Statutory advocacy means you have a right to an advocate. This is if you are treated under the Mental Health Act or can't make decisions yourself. An advocate helps you understand and speak up for your rights.

#### We Did

• Advocacy and Awareness is an important part of making changes in our work. This section has been updated to include the local authority's duty to provide an independent advocate if the person meets the criteria.



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- Include a list of examples of reasonable adjustments that Autistic people and people with ADHD have found helpful. This way, they can choose and adapt them for their own needs or discussions.
- Reasonable adjustments are changes to help people with disabilities. They make things fairer at work, school, and other places.

#### We Did

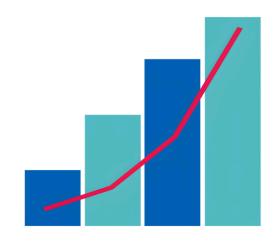
- Reasonable adjustments are highlighted in the strategy, with mention of organisations' responsibilities under the Equality Act 2010.
- It has not been possible to include all types of adjustments that could be helpful.
- However, examples have been provided, such as: 'Offer telephone requests for a GP appointment. Online forms are fine, but don't make them the only option.

# 20. You Said

• Some data is wrong, the estimated number of autistic people based on national data is lower than the numbers from current rates of diagnosis.

#### We Did

- The old numbers about Autism and ADHD are not right anymore. New local numbers show more people have these conditions. We need better ways to count and understand how many people have Autism and ADHD.
- This helps with our 'Digital and Data' plan. It's important to have the right numbers to help people better. We need to improve how we collect and use this information.

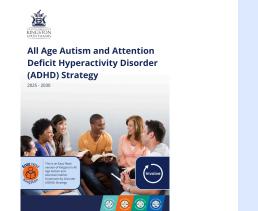




• Housing is only mentioned three times in the document, it would be good to know more about the support offered by Kingston council.

#### We Did

• Compared to other feedback, there were fewer comments about housing. However, we understand that housing affects everyone, so we've added to the strategy, including: 'Make use of Disabled Facility Grants (DFGs) to help with the cost of making adaptations to your home.



- The Kingston All Age Autism and ADHD Strategy will launch in Spring 2025. It will be on Kingston Council's website.
- Partners from the Autism and ADHD Partnership Board are working together on action plans to make the strategy happen over the next 5 years.