



# All Age Autism Strategy

# Engagement

# Report



February 2019

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*“Autistic people deserve to be valued, listened to, respected and recognised as equal, productive members of community and society.”*

# Introduction



We are writing a plan about services for people with Autism in Kingston. It is important that we find out about people's experiences before we write the plan.

We asked 54 people what they think about what services are like now, and how they could be better. We asked:



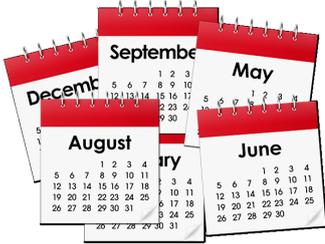
- People with autism
- Parents
- Carers
- Voluntary organisations
- Professionals

We held 2 workshops, two "drop-in" sessions, and an online survey to find out people's views.



# 1) Support, referral and assessment

## How things are now



People wait a long time to find out whether or not they have autism.



The diagnosis process is not clear to people. They are unsure what is supposed to happen, and when.

*“I was given a form and told to fill it in ourselves. I didn’t receive any proper advice or guidance about the Autism diagnosis process.”*



Accessing specialist education is “hit-and-miss”.

Services are not joined up. This means that they do not talk to each other and people have to say the same things lots of times to different professional people.

Assessments for personal budgets are too complicated. Waiting lists are too long.

People do not know where to go for support after an Autism diagnosis is given.



Express CIC and SENDIASS are very good, but need to be able to help more people.

# How to make it better



Autism clinics could help people to find more services that can help them.



Clearer information about referral and assessment.

Start an autism register, to make sure people can access services more easily throughout their lives.



There needs to be a “pathway” to help people to understand the health and social care system. Help people to know how and when people with Autism can get support during their life.



Give out clear information about autism when someone is diagnosed. It would be helpful to know about:

- The level of autism
- Whether the person also has a learning disability
- Support and equipment that will help the person

## 2) Health, care and wellbeing

### How things are now

Not enough specialist services for people with Autism. This makes it hard for people to improve their own wellbeing.



Universities have nowhere to refer autistic students to, apart from a one-off counselling session.

Reasonable adjustments (such as no waiting times and quiet rooms) are not consistent. They happen because one person has been thoughtful, not because the organisations are set up that way. These things can make a big difference to people's health, because it helps them to attend appointments.



Doctors (and other health professionals) sometimes focus too much on a person's autism, so they miss other health problems.

Parents worry about what will happen to their autistic children when they die.



Balance CIC does not have enough money, and is not supporting people as well as it used to.

# How to make it better



Health services need to work together better.

*“Services are not joined up. People bounce around the system. Better communication between services is needed.”*

Improve services at the leisure centre, to help people to improve their fitness. A specialist personal trainer would be welcomed.



Give autism training to GPs, dieticians and other health professionals.

Use Social Prescribing to support people with autism.



Change Balance CIC to make it better. Ask people who would use its services what they want it to do.



“Your Healthcare” website is great. Make it easier to use. It could help people with autism to find specialist services.



## 3) Mental health



### How things are now

Mental health services are confusing because there are so many different organisations. There is not enough mental health support.



*“There are gaps in mental health services. Many are not autism aware.”*



There is too much focus on medication.

Children suffer whilst they wait a long time for help with their mental health.



When people stop getting help from mental health services, there is no ongoing support. This makes it more likely that people will struggle again, leading to more serious problems.

The NHS Transforming Care programme has not been as effective as people had hoped. Not enough new local services have been created.

# How to make it better



Mental health support for people with autism needs to be better quality.

Assessments need to be:

- Faster
- Better quality
- Responsive
- Personalised

People need support long-term, to stop them getting ill again, and to help them have a good life.



Access to mindfulness and yoga may reduce stress levels.

There needs to be more support to help people with phobias. This means being unusually scared of particular things.



Parents and carers need mental health support too.



*“People need guidance from someone to find the services they need [edited]”*

## 4) Involving people with autism

### How things are now



People want to be more involved in decision-making. They think that Local Authorities should listen to their experiences.

People with learning disabilities and young people get more involved than adults with autism.

People who do not speak are less involved.



*“More people have to be involved to make things happen.”*



### How to make it better

Listen to the experiences of people with autism in Kingston.

Make sure you listen to a wide range of people because everyone's experiences are different.



Give people support to communicate in a variety of ways (for example; signing, symbols, video, assistive technology)

## 5) Involving parents and carers



*“When parents say ‘my child has autism’ the next question from all professionals and staff should be: ‘What would help your child here?’*

### How things are now

People are scared that their son or daughters' support will reduce after they die.



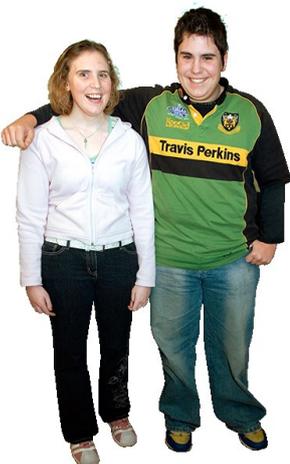
People are angry and frustrated with Kingston's Local Authorities, because support is very limited.

Carers say they feel undervalued and too stressed.

### How to make it better



Free travel for carers would be useful. This could be done using a carers card. The card could also help people to access services.



The early years parenting course could last longer. This will help parents to support their children as they get older.

Offer support to brothers and sisters of people with autism.

Young carers need to be recognised and supported too.

## 6) Independence

### How things are now



There are many changes to support services as children get older and become adults. This can be hard for people with autism.

Parents find it hard to balance work and family life. There are not enough things for autistic children to do away from their family.



Speech and language therapy stops too early.

Balance CIC supports people to understand Personal Independence Payments.

Travel is difficult, because of cost and the skills of transport staff.



There are not enough suitable houses for people with autism to live in.



*“Get it right early so that skills develop early.”*



*“People are struggling rather than being understood.”*

# How to make it better



Run groups for people with autism to support each other to be independent.

Provide activities and resources to help families to plan ahead .



Life skill workshops would help people to learn the things they need in order to be independent.

People need support to think about their dreams for the future, in a realistic way.

Run autism awareness training for transport staff.

Provide travel training for people with autism.



More choice of housing, including supported housing.



*“Autistic people deserve to be valued, listened to, respected and recognised as equal, productive members of community and society.”*

## 7) Access to Services

### How things are now

Communities in Kingston do not understand autism.



Parents are worried about their children being isolated. Many children are comfortable at home, but very anxious when they go out.



The outside world can be very confusing and stressful for people with autism. This can make people “lose it”. People around them need to understand them and help them to calm down.

It is hard to find clubs and social groups for people with autism, especially in the evenings and at weekends.



“Me Too and co.” is excellent. People asked if we could have one in Kingston.



Some people said that services don't seem interested in supporting people with autism. For example, the blue badge scheme.

*“There needs to be more places to go for my daughter with autism. More soft play areas. There are some good services, but the waiting list is too long.”*

# How to make it better



Health staff and the police need training about how to support people with autism. Introduce an autism awareness card to help with this. Branding will help spread the word about training and autism awareness.



Things like “quiet spaces” in the community can help people to be calm if they are anxious. People could have prompt cards to ask for these “reasonable adjustments”. Services could share information about the things that work well.

A step by step guide to services and social clubs would be helpful.



Express CIC needs funding to open a community centre for people with autism. They are already an “essential service” but they need a building and funding to help more people.

*“Without Express we would be lost.”*



Staff who run the blue badge scheme need training, especially when the badge can be given to people with “hidden disabilities”.

Autism training for all staff, in all services, will help people to get better support and be part of the community.



*“I could not integrate [because of staff’s lack of understanding of autism] - it did not work.”*

## 8) Education and training

### How things are now

There are not enough places in specialist autism schools.



There are no schools who provide for people with “high functioning” autism. These schools are all in other areas and are difficult to get into.

Schools do not understand autism well enough.



People are not sure about the choices they have about their education. Information and planning would help.

Young people are not involved enough in writing their EHCP (Education Health and Care Plan).



*“Sometimes it is really difficult but things do improve. Sometimes you have to fight.”*

# How to make it better



Teach people who work at the Job Centre to understand autism.

An Autism centre could help to raise awareness in schools. Teach people with autism in small groups, not big classes.



Use quiet rooms, equipment and teaching resources to help school children with autism.

Run social activities and after-school clubs.



Open a specialist school for children and young people with “high functioning” autism in Kingston.

Young people should be involved in writing their EHCP.

*“There should be more training for schools and other services for identification of autism and support. Teacher training should include it too.”*



*“Teachers in mainstream education are not trained in working with pupils with autism. So, I could not integrate, it didn’t work.”*

## 9) Access to information

### How things are now



People do not know what services are available.

Services do not communicate with each other well.

People do not get information about the progress of referrals.



There is not enough accessible information. Being told about a website is not enough.

Parents are under a lot of pressure, so if information is long and complicated, this makes things much harder.

People need opportunities to meet each other and share information. Leaflets and websites do not help with this.



Express CIC gives excellent support to people with autism and their families. They run coffee mornings.



“Balance CIC” is good and helps young people.

# How to make it better

Information needs to be in one place. People want to know about what services and support is available.



Write a communication plan about the information people need, and how they will get it.



Everyone agrees that Express CIC should get support to open a community centre for people with autism and their families. People are frustrated that there have been so many delays with this project.



Make the “Connected Kingston, Local Offer” website more autism friendly.



We could make more use of technology to offer support (You Tube, Apps, social networks...etc).



Parenting support groups for parents of young people aged 13+ will help people to get information.

# 10) Employment

## How things are now



Getting and keeping a job is difficult. There is not enough support.

Job centres do not understand autism.



Many people do not understand how benefits work and who can access them.

Balance and Express give good support, but they need to help more people.

## How to make it better



Give people support to find jobs and apprenticeships.

The Council and NHS should lead the way and employ people with autism.

Support local businesses to employ people with autism.



Teach young people the skills they will need for employment, and start this early.

All school staff should have autism training. More young people will leave school with skills and qualifications.

# What next?

## People have said they want:

- A “Community Hub” for autistic people in Kingston
- Better support in education and health services
- Access to information
- Opportunities to work
- Better support for parents and carers
- Better access to transport and blue badges



This information will now be used to write the “All Age Autism Strategy”. This is our long-term plan about how to improve services.

Other information, such as how much money is available will also be used to write the plan. We might not be able to do everything that people want.

People will see the strategy when it is ready and will be invited to say what they think.