

# Assenti Research

## Access to Mental Health Services for Autistic Adults Lived Experience Research Report November 2021

### Easy Read of Main Points



## Why was this report written?



The Scottish Government and **COSLA** have been working together.



**COSLA** is an organisation that works for councils across Scotland.



These two organisations have introduced a new plan.



This is a plan to make sure that people with learning disabilities and autistic people are leading change.



There will be different topics looked at as part of this plan.

Learning/Intellectual  
Disability and Autism  
Towards Transformation

The Towards Transformation plan was written by  
The Scottish Government and COSLA.

March 2021

COSLA

Scottish Government  
Rèiseachd na h-Àite  
gov.scot



This plan was published in 2021.



Towards Transformation said that being able to get  
help for mental health is really important.

Assenti Research

This report is about some research done by a  
company called Assenti Research.



The research was about access to mental health services.

This research was done with autistic adults.



There has been other research done with people who have learning disabilities and parents and carers.



This report is an easy read of the main points from this research.

## What did the research want to find out?



The research wanted to find out if people were able to tell when someone had a mental health issue.



The research wanted to know how autistic adults and are supported to know when they have a mental health issue.



The research wanted to find out if there is anything that makes it hard to get support for mental health.



The research wanted to find out about people's experiences of getting help from mental health services.



The research wanted to come up with a list of things that need to be done to make mental health services better.

## Some things that the research found out



Most of the people who responded to the consultation said they have had mental health issues.



Most of these people said that they had good times and bad times.



Only a small amount of people said they got the help they needed.



Less than half of those who got help said it was helpful.



Most of the times people talked about good experiences it was with individual staff.



These staff were health professionals who had a good attitude and approach to working with people.



These good workers sometimes limited by working in the NHS.

## What problems did people say they had trying to access services?



Almost everyone who took part in the research had difficulty trying to get the help they needed.



People said that they thought that health professionals did not understand autism.



There were long waiting lists for services.



Waiting times were a problem because autistic people waited till their mental health was really bad before they asked for help.





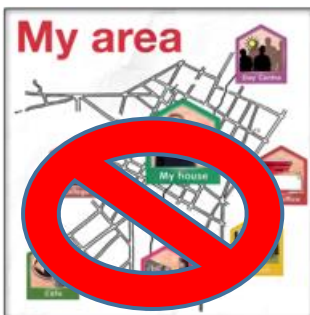
Most autistic people said that they did not think that mental health services were able to understand their needs.



A lot of people felt anxious about having to go to a new service and would like to have long term support so they do not need to change.



Half of the people asked said they did not know where to go for help.



More than half said they had no local service to go to.



People had bad experiences in the past and this meant they did not trust that services are good.



If autistic people have a bad experience they might decide not to ask for help again.



This can mean that things get much worse for them.



Services need to be able to adapt to meet the needs of autistic people from the very beginning.



A lot of people said that they wanted to see more involvement from autistic people in designing services and in service improvement.



People said they would really like all services to be delivered by autistic health professionals.



If this cannot happen the next best thing was for autistic people to be involved is designing and delivering training.

These are the recommendations made in the report

These are the recommendations for Doctors, Social Care Staff and Community based services.



Most of the people who took part in the research had approached their usual doctor for help.



People said that their doctor did not always have a good understanding of autism.



There needs to be autism informed training for all staff who work directly with people.



Doctors need to have a better understanding of autism and how it impacts on mental health.



It needs to be easier to make appointments.



There should be more ways to make appointments.



These options should include online and email booking.



People do not like having to tell the receptionist why they want to see the doctor.



There should be more screening for autism when people go to their doctor lots about the same mental health issues.



This can be a sign that they have autism.



Some people might have autism that has not been diagnosed and this could mean they are missing out on support.



There needs to be some effort made to make sure that people know about the different support that is available for mental health.



Longer appointment times should be offered to autistic people so they have time to communicate.



People should be able to bring someone with them to appointments if they want.



This might be a friend, family member, advocate or support worker.

## These are the recommendations for mental health services.



People who work in mental health services need to have training about autism.



This training will help them to make their services work better for autistic people.



When there are long waiting lists people should be given clear information about the wait.



When people are on a waiting list they should be given good advice about what to do to help themselves stay well.





When people are on a waiting list they should be given clear information about how to get help quickly if things get worse.



Services should give very clear information in advance of appointments to tell people what to expect.



This information should include clear directions to the appointment including public transport information.



The information should include photographs of the building and the people that will be at the appointment.



The information should include how long the appointment will take and what will happen during it.



Before someone comes to an appointment there should be a discussion with them about their communication and support needs.



If needed there should be adaptations made to how things are normally done to suit the person.



There should be a range of ways to provide support available.



This should include groups for autistic people.



This should also include options for help to be offered using video calls.



This should include creative therapy.



People should be offered longer or shorter appointments if they need them.



People working in mental health services should keep language simple so that it can be understood.

## Recommendations for everyone.



Autistic people should be able to communicate in the way that they prefer.



This means offering video call appointments.



This means allowing people to bring written notes.



This means allowing people to use written notes to communicate during appointments.



If appointments are running late then it is important to tell people there is a delay.



When asking questions make them very clear, it is a good idea to offer examples of how they could answer them.



It is important that autistic people are given support like reminders that they have appointments.

## There needs to be ongoing support for people's mental health



More than half of people who spoke to the researchers said they wanted support for as long as they needed it.



A lot of people said they were not sure if they would know when they needed help for their mental health.



If people had long term support they would have help to recognise if they were becoming unwell.



If people got help sooner this could stop things getting really bad.



If people got long term support they would not need to re apply for services and spend time on waiting lists waiting.



The kind of support that people wanted to have long term was something quite informal and could be flexible.



There were times when support would be really useful to help to prevent mental health problems.



These times were during transitions and after getting a diagnoses of autism.



It is recommended that there is a mental health service that people can refer themselves to without having to go to their doctor first.



This service needs to be good at understanding autistic people.



People would like to be able to use these sorts of services for ongoing long term support within their community.



Many autistic people would prefer to go to a service that is just for autistic people.