

# **A report about support people get after being diagnosed with autism**

**Easy Read**

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**Scottish Government**  
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# **A report about support people get after being diagnosed with autism**



## **Easy Read Version**

This Easy Read is based upon an original report authored by Richard Mills, AT-Autism, and Scottish Autism's Centre for Practice Innovation.

The Scottish Government asked 7 autism support organisations to help them.



Diagnosis means a doctor telling you that you have a condition.



The time after getting a diagnosis is hard for people.

They are not always sure of what happens next.



Scottish Government and the organisations want to make things better for people after they get a diagnosis.



The activities were to be done during 2021.



They did this by asking people to take part in a new way of getting support after diagnosis.



The organisations did some things the same and some different things.

All the activity was done online or on the phone because of the pandemic.

The activities that people thought were good will be used by all the organisations in future.



This means people who get a diagnosis will know what support they should get.



After they took part, they were asked questions about the new way of getting support.



Most of the people who answered the questions were adults.



Some people answered for their child.



**The things we found out from the questions.**



People said they liked the things the organisations did with them.

They said they were very helpful.



They said they gave important support to communities and the Scottish Government



People said it is hard to get a diagnosis.

They said it felt like a battle.



They said getting a diagnosis took too long and it was very stressful.

Some people said because of this they decided to go private for a diagnosis.



Most of the adults diagnosed were female.



People did not get much help or support when they were getting their diagnosis.

Some people said they did get good help and support.



These examples can be used to make things better for other people.



Some people said they were worried about what professionals thought about autism.



They felt what the professionals knew about autism was outdated.

They felt this was more true about women and girls with autism.



People said that even though it was hard, getting a diagnosis helped them with:

- what to do next
- connections
- health
- education
- work
- dealing with professionals



Many people said it was good because they already thought they or their child were autistic.



People said things were better after a diagnosis.

They said they got good information and people listened to them.



People felt more confident after taking part in the activities.



They said now they know where and how to get more information and help.



People said they know more autistic people now and understand how it affects them.



Some people said:

- they are less isolated or anxious
- they are more able to cope with the unknown
- their health and mental health is better



Most people said they would recommend taking part in the activities to other people.

People said getting support from other autistic people was good.

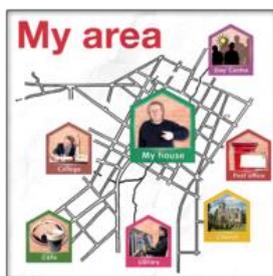


They felt understood and a part of something, some for the first time.



Families said being listened to was good.

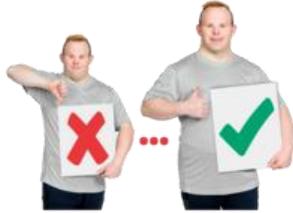
Having support after diagnosis was very good.



Many people said no services near them was a problem.



## What people thought should happen next



1. The organisations should be supported to get better at what to do.

They should work with different groups of people.



2. Develop after diagnosis support so that everyone will know what to expect.

3. Scottish Government and a lead agency set up a system of support.



All the agencies should be part of this.



**4.** Make the diagnosis process easier for everyone.

Make sure everyone gets treated as quickly as possible.



Everyone should get an information pack after getting a diagnosis.



**5.** Make sure that the support organisations give a quality service.



Include autistic people. Ask them what they think good service should look like.



**6.** Update training for professionals.

This should include how to work with people and families effectively.

Trainers should be autistic people.



Scottish Government have given more funding for this work. It will carry on until **June 2022.**



Scottish Government want to do more to support autistic people.

This work is **1** thing to be included in that future plan.



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