

Embracing Complexity

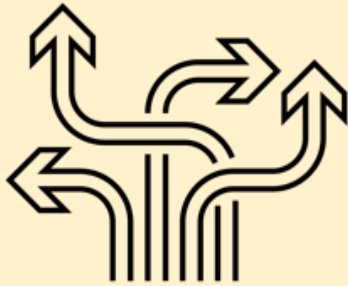
Top 10 important questions for research on neurodivergence

easy read version



Embracing Complexity logo

What does 'neurodivergent' mean?





Neurodivergent people's brains work in different ways.

They have had brain (neurodevelopmental) differences all their lives.

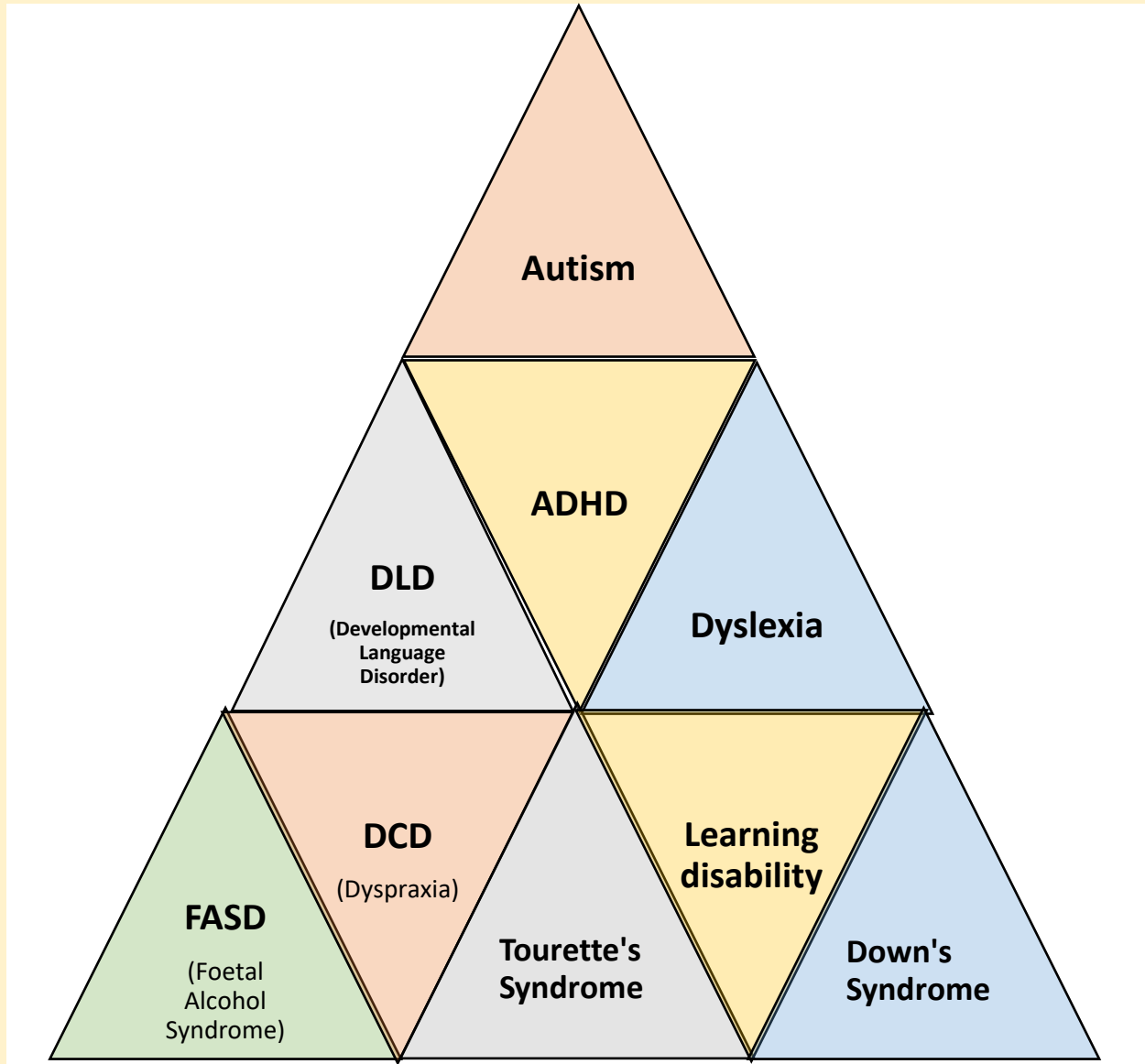


Neurodivergent people take in and think about information in a different way.

	<p>They may react to the world around them in a different way.</p>
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	<p>They may behave in a different way.</p>
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Neurodevelopmental Differences



Why do we need research about neurodivergence?



Researchers collect and study information about a subject.



Research can help us understand more about the everyday experiences of neurodivergent people,



Involving neurodivergent people in research helps us find out what is important for them.



Embracing Complexity wants to tell the public about the experiences of neurodivergent people.

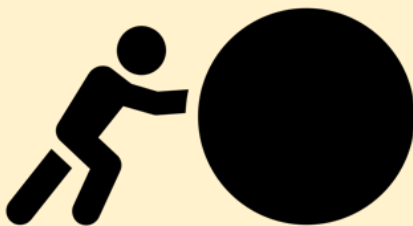
What's the problem?



Society and services are not set up in useful ways for neurodivergent people.



This isn't fair and needs to be changed.

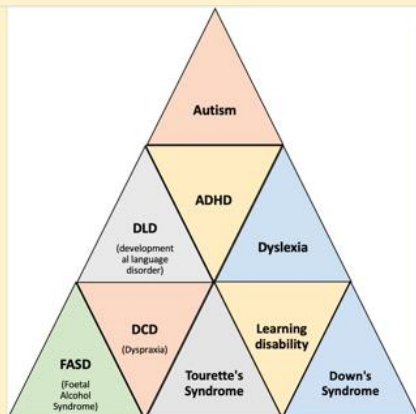


It makes it harder for neurodivergent people to work, learn, stay healthy and make friends and relationships.

What is special about this project?



This is the first project that has asked about the experiences of different neurodivergent people.



We asked people with different kinds of diagnosis.

Some people had more than one diagnosis.

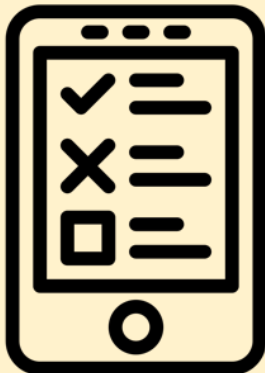


Embracing Complexity wanted to see if they had some of the same challenges.

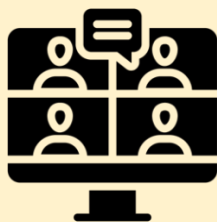
How did this project work?



6 neurodivergent people with different conditions met the researchers and made a list of 36 issues that were important to them.



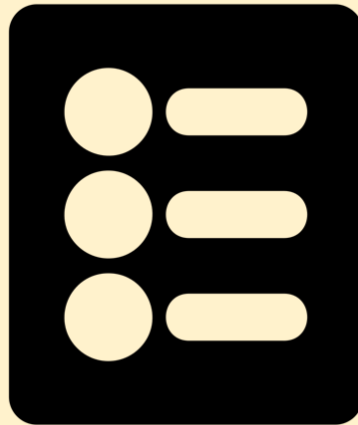
231 people filled in a survey to choose the 20 most important ones.



27 people came to 2 online workshops to agree on the **top 10 most important questions.**



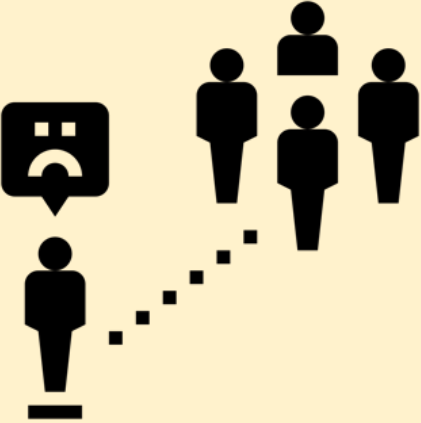
They were neurodivergent people, their families and carers, researchers, educators, mental health workers and speech and language therapists.

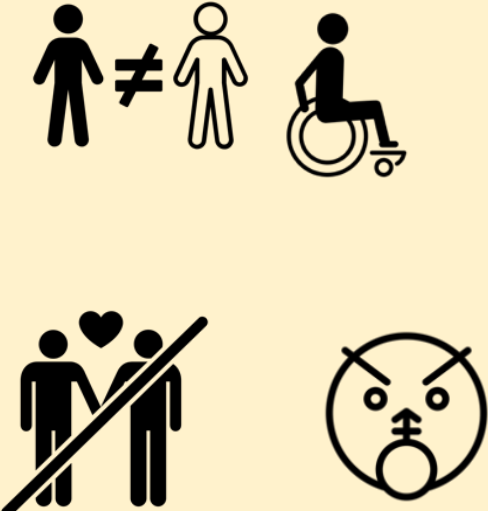


Top 10 important
research questions?

(Things neurodivergent people
said are shown in speech
bubbles after each question)

Question 1: How can we include and support neurodivergent people from marginalised communities?

	<p>Neurodivergent people have to deal with discrimination and being excluded.</p>
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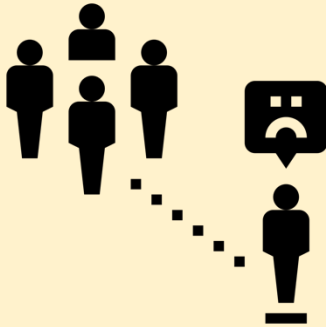
	<p>They may be even more discriminated against and excluded because of:</p> <ul style="list-style-type: none">• Their race• Their gender• Their sexuality• Their class• Their disability
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[Acceptance] was never [for] someone who looked like me.

Question 2: How can we end negative attitudes toward neurodivergent people?



People often have wrong ideas about neurodivergent people.



This can lead to them discriminating against neurodivergent people and excluding them.



We need to find ways of building more positive attitudes towards neurodivergent people.

Attitudes from other people created barriers for me. Because they didn't understand my neurodivergence. This has stopped me from socialising.

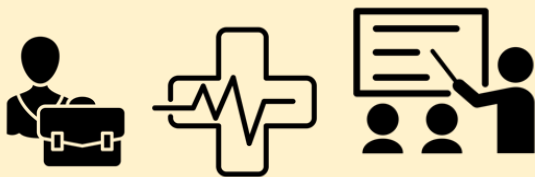
Question 3: How can we help neurodivergent people to understand themselves and get the support and adjustments they need?



It takes time and support to understand your own needs fully.



It takes time and support to know what your rights are



Understanding their needs and knowing their rights help neurodivergent people get jobs, education and healthcare

I suspect that if I had more self-knowledge back at the time it wouldn't be as difficult, as I would be more aware of my needs.

Question 4: What is the relationship between undiagnosed neurodevelopmental conditions and mental health issues?



Being diagnosed as neurodivergent as early in your life as possible can be very helpful.



Not understanding your needs can harm your mental health.

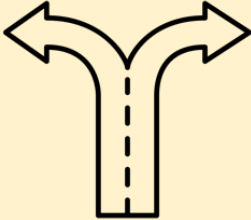



Neurodivergent people often suffer from issues like masking, anxiety, depression, low self-esteem and burnout.

When I was working at a help desk a while ago I experienced a lot of anxiety and fear of getting something wrong. Having to talk to people was hard, and it was a fast-paced environment.

Question 5: How could mental health and neurodevelopmental services work better together?

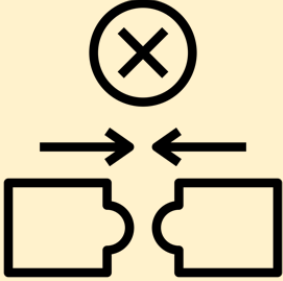
	<p>Mental health difficulties are common in neurodivergent people.</p>
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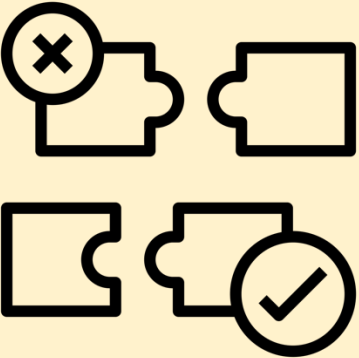
	<p>Mental health difficulties may show in different ways in neurodivergent people</p>
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	<p>Mental health workers should have training to support both these needs together.</p>
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The mental health condition is often seen before the neurodevelopmental differences and both need to be tackled together.

Question 6: How can we make it easier for neurodivergent people to access mental health services?

	<p>It is often very difficult for neurodivergent people to get mental health support.</p>
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	<p>Mental health services may not make reasonable adjustments for neurodivergent people.</p>
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[Local mental health services offered me] a 6-week group Cognitive Behavioural Therapy (CBT) even though I said I struggled with groups due to being autistic....they said it was this or nothing else.”

Question 7: How can we improve access to benefits and social care for neurodivergent people?



Neurodivergent people need more access to benefits because it is difficult for them to get jobs and keep them.



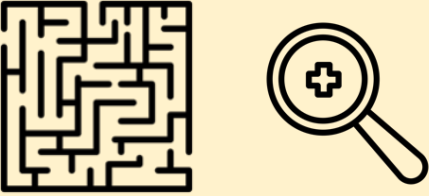



This may be because of a lack of reasonable adjustments or health problems.



Neurodivergent people need more access to social care to help them be more independent.


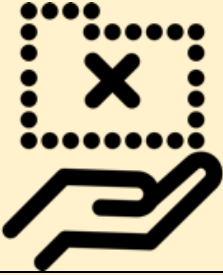
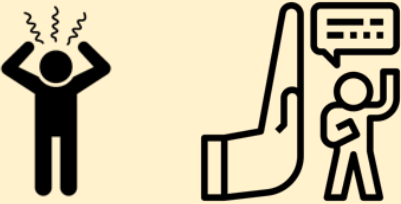
It's hard to make a claim for PIP because it's done via a written form, with too many questions. It's hard for me to write about my disability. I find it easier to talk about it.

Question 8: How can we create services where the whole range of neurodevelopmental differences could be diagnosed?

	<p>Getting a diagnosis of a neurodevelopmental difference in the UK is a complicated process.</p>
	<p>There are long waiting-lists</p>
	<p>People often have more than one neurodevelopmental difference but these are diagnosed by different services.</p>
	<p>Getting a diagnosis often doesn't lead to getting support.</p>

“Diagnoses are [separated] and don't look at the whole person, but put neurodivergent people into separate categories, which isn't helpful as it means you get [separated] support too.”

Question 9: How can schools and college be more inclusive for neurodivergent students?

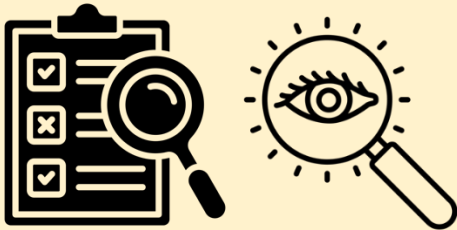
	<p>Neurodivergent children and young people need adaptations to learn, communicate and make friends.</p>
	<p>These adaptations and support are often not available.</p>
	<p>This causes distress to children and young people and can lead to them being excluded from school/college.</p>

My children are not allowed to fidget in a classroom and that could help them to relieve their anxiety. They are not even allowed to leave the classroom to get water during lessons.

Question 10: What are the best ways to assess and support neurodivergent students in schools and colleges?



Different neurodivergent students have different needs.



School/college staff and healthcare workers need the right training and tools to find out about their needs.



This will make a positive difference to the learning and mental health of neurodivergent students.

In...college I was told that I didn't need support because I wasn't physically disabled....I needed support to help me on an emotional level as well as an academic level. This prevented me from reaching my full potential.

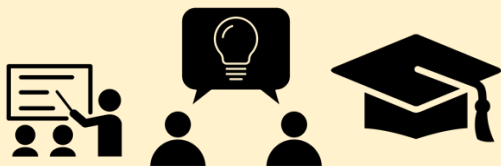
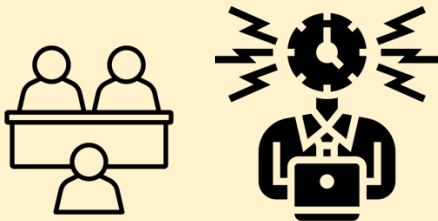
Other important questions



We agreed to choose the top 10 important research questions for neurodivergent people.



There were other important questions but they couldn't be included this time.

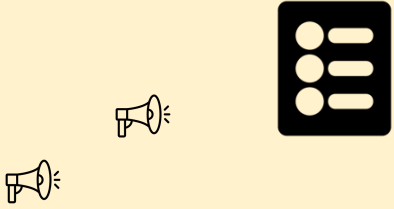


The questions were about how to make other areas more accessible for neurodivergent people like:

- Job applications
- Workplaces
- Contacting healthcare services
- University

And helping school staff and children understand neurodiversity

What happens next?

	<p>Embracing Complexity will tell people about the top 10 questions for neurodivergent people.</p>
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	<p>We will tell:</p> <ul style="list-style-type: none">• People who do research• People who give the money for research• People who plan and provide services
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Thank you to everyone who took part in this project.



The report was written by Agata Ostazewska (from Embracing Complexity) and Georgia Harper (from Austistica)

Easy read version – Rachel Sievers



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