Embracing Complexity
Time to think differently
Working together across neurodevelopmental conditions
embracingcomplexity.org.uk @EmbraceComplex
About Autistica

• The UK’s leading autism research and campaigning charity

• Our vision: A world where every autistic person lives a happy, healthy, long life

• Research based on community priorities – often co-occurring conditions
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What is a neurodevelopmental condition?

“Any lifelong condition, generally present from the early stages of life, which affects the brain and influences how people think, perceive the world or interact with others”
People often have more than one neurodevelopmental condition.
"Having professionals who consider my girls as individuals rather than looking only for one set of symptoms at a time would have made a huge difference."

“They would not see beyond Down’s syndrome.”  "There isn’t one thing – it’s a constellation of challenges.”  "My anxiety was blamed for my seizures.”  "We just got passed from pillar to post until our daughter self-harmed.”

“I feel if my son’s disabilities had been recognised faster, he would not have been out of school for two years.”  "Referred to ADHD pathway, told not ADHD. Referred to ASD pathway, told not ASD. Referred to ADHD pathway then diagnosed.”
“Education doesn’t deal well with difference. On paper my son failed his GCSEs, but those exams don’t represent the other skills he has.”

“She was refused investigations for kidney problems because she was ‘disturbed’.”

“I have never felt included or accepted in society.”

“We have to manage his mental health alone. We are utterly exhausted and frustrated at the lack of help available.”

“My son has to take a 4-hour road journey to a school that can support his needs.”

“I don’t feel like I have many options for my future.”
Launch of Embracing Complexity

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We launched with 16 members...
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Embracing Complexity in Diagnosis

Multi-Diagnostic Pathways for Neurodevelopmental Conditions

#ECDiagnosis
What we found

• Emerging success after difficult beginnings
• Need for further evaluation and research
• Aimed at a fairly limited group – for now!
• Implications for wider service design
• Opportunity for pre-diagnostic support
Research

Epilepsy Dossier
Epilepsy and Autism: Laying Out the Evidence

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Embracing Complexity in Research on Neurodevelopmental Conditions and Mental Health
What we found

• Research not aligned with priorities

• Difficulties starting studies across NDCs

• Need for improved infrastructure
Working together during COVID-19

• NICE critical care triage guidance

• Support resources

• Joint Select Committee responses
COVID Complexity

Learning from lockdown to support those who think differently
Our grand plan

A world where people with NDCs:
• Receive accurate and fast diagnoses as well as the personalised support they need across the whole lifespan.
• Feel consulted and listened to about their condition and empowered to manage it.
• Have the same life prospects as people without NDCs.
What can you do?

• Brains don’t always fit our boxes!

• Look out for co-occurring conditions

• Reach out to other services
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Thank you!

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