

Embracing Complexity



Time to think differently

**Working together across
neurodevelopmental conditions**

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



SUNSHINE SUPPORT
Empowering parents, carers and professionals who support children & young people with Special Educational Needs
www.sunshine-support.org.uk



Tourettes action

Young Epilepsy



DYSPRAXIA FOUNDATION
Incorporating Developmental Co-ordination Disorder (DCD)



ADHD FOUNDATION
Mental Health, Education and Training Services



Families In Focus CIC
LOOKING FORWARD TOGETHER



The FragileX Society



williams SYNDROME FOUNDATION



NATIONAL ORGANISATION FOR FASD



Hope for families with life-limiting epilepsy



Ambitious about Autism



Children & Young People's Mental Health Coalition



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MQ

Transforming mental health through research



GROW COMMUNICATION

University of Kent

Tizard Centre



Support today, hope for tomorrow



WILL YOU PAY #ATTENTIONUK?
FIGHTING ADHD STIGMA SINCE 2017

Afasic
voice For life



ACTION CEREBRAL PALSY IDENTIFY INTERVENE IMPACT



helps children communicate

POTENTIAL KIDS



The voice of learning disability



Special Networks
CELEBRATING & SUPPORTING DIFFERENCE

tsa
tuberous sclerosis association

NAPLIC
Professionals supporting language and communication development



for brothers and sisters of disabled children & adults

PWSA UK
PRADER-WILLI SYNDROME ASSOCIATION UK

MCPin
Foundation



Working wonders for children with brain conditions

Royal College of Occupational Therapists



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”



TOURETTES

DOWN SYNDROME

AUTISM

EPILEPSY

**People often have
more than one
neurodevelopmental
condition**

DYSCALCULIA


DYSPRAXIA

DYSLEXIA

INTELLECTUAL DISABILITY

ADHD





“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.”

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

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

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

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

“I don’t feel like I have many options for my future.”

Launch of Embracing Complexity



We launched with 16 members...





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helps children communicate

EA Employment Autism
opportunity in work | fulfilment in life



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Seen & Heard THERAPY



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connecting sight, sound and life



MQ

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CEREBRA
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Embracing Complexity in Diagnosis



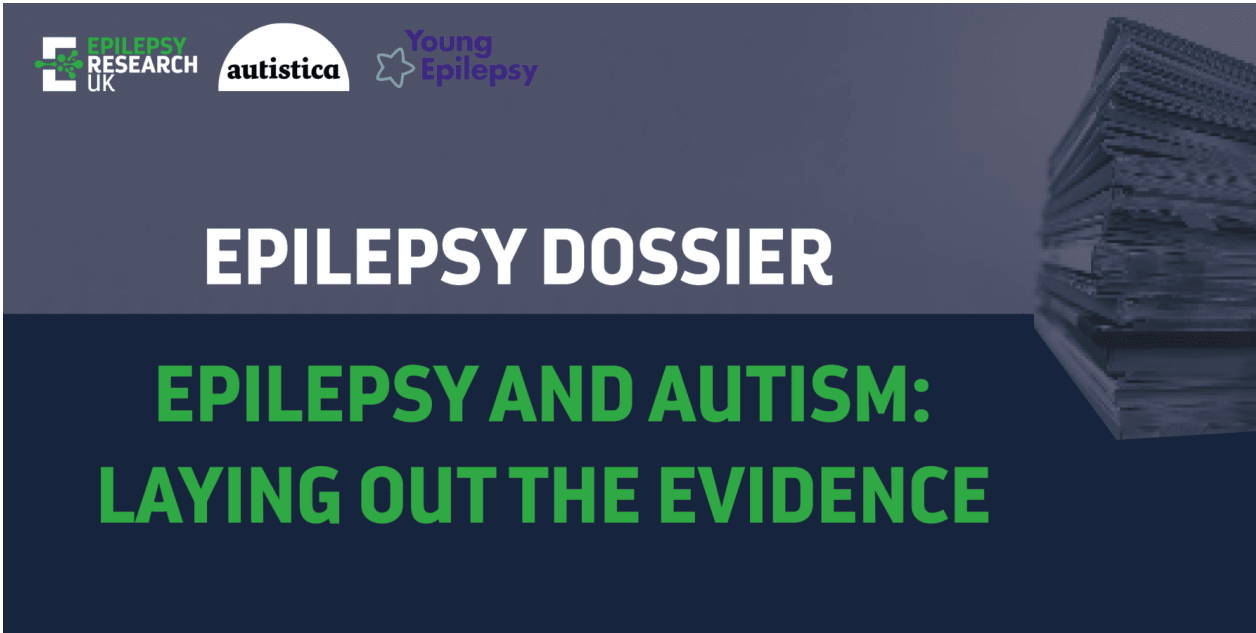
Multi-Diagnostic Pathways
for Neurodevelopmental
Conditions

#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



**Emerging
Minds**

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!