

# Thinking Differently in North East England

## A Summary of Public Consultation on Service Provision for Adults and Children with ADHD and Associated Coexisting Difficulties in North East England conducted by 'divergence'



May-June 2022

### Introduction to divergence

divergence will launch this autumn delivering a service for people with a neurodevelopmental disorder in the North of England developed and provided by people who have a diagnosed neurodivergent diagnosis. We have aligned our catchment to the North ICS area. In order to respond to what our community want to see from a new service we chose to ask them directly and undertook a six week consultation with groups and individuals, visiting support groups and publishing an online survey. The service is born of the desire of several professionals in the area who have specialised in neurodevelopmental disorders wanting to do something different, something better. We are currently finalising our application for CQC registration.



Our long term aim is to provide online and face to face appointments for the neurodivergent population and the people who love them in the North East of England. We want to offer consistency in providing support, for as long as is needed, ensuring we promote resilience and avoid dependence. We don't want to be drawn into contracts that dilute the quality of the service that we provide and will not compromise on the changes we make to improve standards of care and support to the people who ask for our help. We recognise the need to reduce the stigma and inequalities experienced by all who are neurodivergent so we aim to deliver high quality accredited training and this educational provision needs to be available nationwide.

### Key Themes

#### Access to services

Accessing services is difficult, takes a long time and there are a number of key barriers to effective communication.

Information is not well shared and people are often left with questions they feel unable to ask.

Some GP's are not aware of the less severe presentations of neurodevelopmental disorders and their co existence with many common mental health problems.

Parents feel that they have to fight to access the help they believe their child needs with assessments often being protracted

Most services are offering specific assessments, which means that if referred for one neurodevelopmental disorder assessment they don't necessarily get assessed for any others even though they are highly co existing.

At times parents would value having someone to ask for advice rather than wait until a situation deteriorates to crisis. Sources of reliable information are thought to be difficult to access and there is awareness that not all advice is good which makes it more challenging to know what to do.

#### Treatment and Support

All participants use independent support groups were their main source of support and guidance (although we recognise this is the main source of our information so there is a bias).

Peer support was highly valued and experience of living with a neurodevelopmental disorder or caring for someone is more highly regarded than professional support

There is not enough support given after diagnosis. There is a need for much improved post diagnostic work to teach people a range of skills and support them with the impact a diagnosis can have, irrespective of age.

Access to medications is challenging. Medication is a widely discussed topic in support groups. Parents and those with ADHD want to understand more about the medications they are prescribed. The lack of accessible information about medications seems to lead to people stopping treatment

People want to be able to speak with a prescriber about treatment and make informed choices, however they feel that often medications are given without a good explanation of what they are taking or why they are taking it.

Do	Focus on Strengths	Explain medication
Be direct	Be "Ordinary"	Be Affordable
Have compassion	Staff with lived experience	Don't
Discharge	Be dismissive	Have Power Dynamics
Assume our understanding	Use Jargon	Have waiting lists
Make us feel bad	Be prescriptive	Abandon



