

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 |



Community

Schools are seen by the community as having a key opportunity to address the stigma associated with difference. They have the opportunity to screen for problems and don't have the level of awareness needed to take these opportunities.

Social perceptions in the community are having a negative impact on access to services as well as the people who use those services. People are avoiding services because of the long waits and challenges that they have heard about in engaging with them.

There is a need for a navigator role that can support parents to access the range of supports in the community for children as these can be difficult to identify and access. This extends beyond the supports of school and the health care system.

There is an appetite for social action to address the issue of stigma and some excellent ideas of how this could be achieved.



Notes on Language

Divergence • We chose the name divergence because we are wanting to diverge from the routine care that we have experienced in a range of services. We want to be different. We understand that neurodivergence is a term that some people do not think right to describe their difference. That is a matter of personal choice.

Disability • We consider disability to be something that is created by the society we live in. The word does not describe an internal difference, rather it is the difficulty experienced by an individual in society because society does not accommodate their needs effectively

Our Values

Respectful • Innovative • Determined • Safe • Candid • Informative • Inspiring • Inquisitive

As a result of this consultation we are...

Improving accessibility by working on a website that will address the range of suggestions that people gave us to be a one stop information hub with links and information about ALL services and information that is useful to people who think that they might need a service. This website will evolve to be a central point of access to not only our services but the information that is available around the region. This website will allow you to check whether having our initial assessment could be helpful or whether another service can be more helpful. It will also build to be a resource for people to access reliable and approved guidance from others. We will offer assessments for ADHD and Autism, however these will be identified as necessary in our initial assessment rather than those assessments being the start point.

Improving Treatment and Support by designing a service founded on the ideas and principles that we heard from the people we spoke with combined with our own expertise and experiences as neurodevelopmental disorder professionals and service users. We will be delivering an initial assessment that considers what may be helpful and how you can access it. We will be focussing on strengths and making recommendations beyond medical options.

Being clear about costs by working to make our service as affordable and accessible as possible and avoid excessive growth that would dilute the quality of service we will provide. We will have clear billing and monthly payment so that you can plan your care around your budget and we will provide information about options other than the services we provide so that you can make an informed choice about what you want us to do.

Engaging the community by working to develop a community strategy that addresses the concerns about stigma and improve understanding around the issues that people are facing. We have already begun working with some schools to develop curriculum centred work that will raise awareness and the profile of difference in our society.

Continuing to Listen by linking with absolutely anyone involved in community work around neurodevelopmental disorders and if we haven't linked in with you then please do contact us.

We are happy to share more detail on our findings with those that would like to know more and there is a comprehensive 25 page full report available by request.

Contact us

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