

CASE STUDY: DIAGNOSIS SUPPORT PACK

A co-production quality improvement initiative from Bedfordshire and Luton Children's Community Health Services.

Context

Neurodevelopmental disorders (NDD) are a complex group of conditions that include ADHD and Autism as common presenting problems in childhood; they are frequently associated with comorbidities such as behavioural, sensory and sleep difficulties, resulting in a negative impact on the quality of life of the affected individual. Throughout this entry the term 'Neurodiversity' in place of the clinical terminology 'Neurodevelopmental disorders (NDD)' will be used, as this has been highlighted as a preference from the young people and parents/carers involved in the project

Background

Families have described the experience of receiving a diagnosis for their child as 'like a bereavement' and following the lengthy diagnosis process are often left with little information, or understanding of 'what next?'. Having a diagnosis can help families understand the challenges as well as explore the support and strategies that are available to achieve the best possible outcomes.

Families that use the community paediatric service across Bedfordshire and Luton have participated in many service improvement projects and contributed via feedback channels such as focus groups, parent panels and family and friends test surveys. A key theme highlighted by these families was a need for information, resources and support post diagnosis of a neurodiversity.

About the project

Work has been ongoing throughout 2021 on a collaborative project across Bedfordshire and Luton Children's Services on a Co-Produced Neurodiversity Diagnosis Support Pack. The pack is a one stop shop, aiming to provide information and support following the diagnosis of a neurodiversity (for example ADHD or Autism). The pack is hosted online in a variety of creative media including videos, infographics, and animations. It can be translated into a variety of languages, audio options or easy read at the click of a button, and has printing functionality for those that cannot access online.

The project has been a truly co-produced collaboration with parents/carers and young people, focussing on 14 different work streams (as chosen by the co-produced working group) with membership of the project group including Parents and Carers, young people, Bedfordshire and Luton community paediatrics services, Child and Adolescent Mental Health Services (CAMHS), Bedford Borough, Central Bedfordshire and Luton Borough local authorities, Parent Carer Forums and third sector stakeholders such as 'Autism Beds'. The Diagnosis Support Pack can be found here: <https://www.cambscommunityservices.nhs.uk/beds-luton-community-paediatrics/diagnosis-support-pack>

The Golden Thread - The positives of neurodiversity

From the first initial discussions in the project meetings, it was highlighted by the parent/carer representatives involved that the journey through the process of a diagnosis was challenging; from language used such as 'disorder/lacks/problems' to comments on 'challenging behaviour' or 'differences' the constant negative messaging has an impact on the young person and their families self-esteem and emotional wellbeing.

Therefore, it was important to the project group that this pack would be different - there was a need for positive language, empowering messages, and positive role models. The 'positives of neurodiversity' would be a key feature throughout, in addition to a standalone section within the pack.

The 'Positives of Neurodiversity' section includes sharing through lived experience; articles written by young people, an amazing rap written by a very talented young person, inspirational role models, and additionally the project team has video recorded a series of interviews with young people, parents and clinicians talking about their experiences and the positives of neurodiversity for them. This aims to empower young people and their families, reminding them that Neurodiversity is not a weakness, and that they are not alone. A fantastic and uplifting video montage has been created using snippets from each of the interviews, please watch the video here:

<https://vimeo.com/551880453/0a3fd040ed>

The positives of neurodiversity section within the pack can be found here: <https://www.cambscommunityservices.nhs.uk/beds-luton-community-paediatrics/diagnosis-support-pack/Neuro-diversities>

What are the outcomes?

Psychoeducation involves provision of easy-to-understand and evidence-based information. A user-friendly multimedia resource pack co-produced with user groups aims not only to inform, educate and empower patients and families on neurodiversity, but also to improve the quality of both service delivery and outcomes for young people.

Additionally, with regards to the Positives of Neurodiversity element of the pack; parents/carers and young people working on the project highlighted that this was exactly what was needed and what matters to them - to support, uplift and inspire young people and their families, and also to reinforce the importance of positive language in health care and society as a whole. This in turn will contribute to the culture shift that is needed to ensure that young people with a neurodiversity are celebrated for what they are and what they can achieve - and not what they are not.

About the Co-Production Journey

Throughout the entirety of the project, parent/carer representatives were equal members of the project group. Every meeting included parent/carer representation alongside clinicians and communications specialist, facilitated by the co-production lead. The parent/carer representatives shared equal ownership and responsibility for the concept, design and implementation of the Diagnosis Support Pack in true co-production. Every element of the pack has been proof read and approved by the parents/carers. You can hear more about the pack and the co-production journey in the video here: <https://vimeo.com/636992132/ea88fd81e4>

And podcast here: <https://camhstalk.blubrry.net/2021/08/25/episode-30-digital-diagnosis-and-neurodiversity/>

Young people were also involved in collaboration throughout the project, e.g. in focus groups, by providing feedback, and by providing contributions such as articles, tips for others, reviews of interventions and even the lyrical rap!

What is the impact?

The project was launched in September 2021 across the local area with the support of our communications team and a comprehensive comms plan. Here is some feedback received from a local school:

"This is fantastic, thank you very much, this is very important to see the positive approach and detailed information. I have shared with parents and staff, and have had many great responses from parents, as well as staff, who have children with ASD. So please pass our thanks on."

A link signposting to the support pack has been added to all service communications and letters, and the Diagnosis Support Pack webpage has received 3,828 views (June 2022).

The Diagnosis Resource pack has been shared with colleagues in Cambridgeshire children's services. The Bedfordshire and Luton service has also been approached by NHS England/NHS Improvement (NHSEI) to discuss sharing the resources and best practice nationally, and an abstract submitted to The Royal College of Paediatrics and Child Health (RCPCH) has been published by the British Medical Journal (BMJ) and can be read below.

(article 1800) https://adc.bmj.com/content/archdischild/106/Suppl_1/A493.2.full.pdf