

# An Educational Project to Develop and Coproduce an NDD Post-diagnosis Resource Pack for Children and Families

Dr Chinnaiah Yemula, Dr Kate Head, Dr Francesca Omisakin, Professor Frank Besag,  
Dr Ahmed Abouelnaga, Tim Long, Lydia Rosseter, Tabassum Mirza, Kerri Rennie, Sonia Phillips and Sheryl Walsh

Neurodevelopmental disorders (NDD), including ADHD and autism are often associated with comorbidities. They can have a negative impact on the quality of life of children and young people. Families using our service have highlighted a need for post diagnosis resources and support.

Therefore, we have undertaken an educational project to co-produce an all-encompassing 'Post Diagnosis Resource Pack' for NDD and to host it online, including printable and multimedia digital resources.

## Our improvement journey and steps we took

Sep 2020

Research issues and identify gaps with parents and young people

Set the structure and initiate workshops

Complete work steams

July 2021

Review  
Amend  
Develop

## Results

14 different work streams commenced with a "task-and-finish group" including both parents and professionals collaborating together for each one.

The pack is accessible and can be translated into different languages and an easy read format.

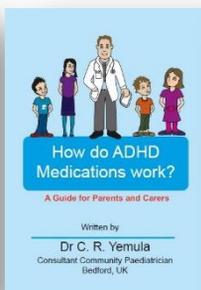
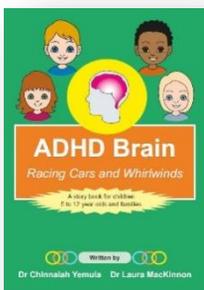


Some of the topics include the following:

- What should I expect at my appointment?
- How can I speak to my child and family about a diagnosis?
- Positives of neurodiversity
- Jargon buster,
- What do I need to know about medications?
- Sleep problems.



## Examples of some of our resources

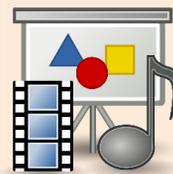


## Methods

We have initiated a project group to collaborate with parents and key stakeholders, meeting (virtually) on a monthly basis.

- Community paediatric services, Speech and Language Therapy, CAMHS, 3 Local Authorities and Parent Carer Forums and third sector stakeholders such as Autism Bedfordshire.

We also engaged with children and young people and parents/carers to ensure the pack was fit for purpose and truly co-produced.



Many professionals and parents contributed to resources that included:

- brief educational videos
- infographics and animations

## Conclusions

Psychoeducation involves providing an easy-to-understand and evidence-based information.

**Our user-friendly multimedia resource pack co-produced with user groups, helps to**

- Empower patients and families
- Improve the quality of both the service delivery and outcomes.

## Free online links

<http://>

You can download a few resources from [HERE](#)

Video link:  [The positives of Neurodiversity](#)