

Contact For families with disabled children

It's co-production week! This year's theme is the impact of coproduction. We are using #ParentCarerParticipation alongside the week's hashtag #CoProWeek to highlight the impact of parent carer forums. Please join us on social media highlighting what you have achieved locally for families with children and young people with special educational needs and disabilities (SEND) by working in co-production, and sharing our posts about the impact of parent carer forums.

Although we are keen to celebrate co-production week, we must note that the last 24 hours of political turmoil have seen changes in the ministerial team responsible for SEND policy and legislation, including the Green Paper. Nadhim Zahawi MP has been promoted to Chancellor of the Exchequer, and Michelle Donelan MP has replaced him as Secretary of State for Education. Will Quince MP, Children and Families Minister has resigned his position. At the time of writing, we have no news of his replacement.

The NNPCF is well versed in meeting new Ministers and introducing them to the work of parent carer forums. Whilst Ministers change, the challenges faced by our children have deepened and regardless of who is in post, we will continue to represent the views of parent carer forums to the best of our ability and to work with officials behind the scenes.

To read more about what this means for the SEND review and the work of the NNPCF, please see our <u>news pages</u>, which are updated regularly.

Co-production

Co-production is about working in equal partnership with people using services, in our case, children and young people with SEND and their families. Working in

co-production offers a way to transform services to really support and empower families with children with SEND.

True co-production happens when parent carer forums are an integral and equal part in the decision-making process and are fully engaged in shaping, developing, implementing and evaluating services and systems.

<u>Watch this co-production video</u> or <u>watch the subtitled version</u>, where forums, local authorities, health providers and commissioners share their experiences of working in co-production and how it helped them to improve services.

Evidence shows that these partnerships often make the best use of people's time and money, whilst also improving outcomes for children and young people with SEND.

The impact of co-production

Parent carer forums are constantly striving to work in co-production to help develop and improve services for children and young people with SEND and their families.

Bedfordshire borough parent carer forum, the former forum in Luton, and central Bedfordshire parent carer forum worked together with a number of partners such as children and young people, children's services and community services NHS Trusts to develop a diagnosis support pack for children, young people and their families running up to or following a diagnosis of a neurodiversity such as Autism or Attention Deficit Hyperactivity Disorder (ADHD). The diagnosis support pack is a one-stop shop of information including things like, sleep, medication, mental health, preparing for appointments, sensory processing needs, supporting social communication and much more. Lots of steps have been taken to make it as accessible as possible so it's broken into topics so people can dip in and out as they need to, or as they feel ready to. It includes videos, interviews and animations, but also it is downloadable and printable to be provided to people who might not have internet access or appropriate technology at home. The webpage has the facility to be translated into different languages or be read out loud. Working in co-production has really enhanced this project – it meant that parent carers and young people worked together as part of the team every step of the way in creating this pack; they planned it, reviewed it, and took equal, shared responsibility in making sure it was fit for purpose and suited to the needs of the people using it.

One of many things acknowledged in the process of working together was that parent carers and children and young people's experiences of the language describing neurodiversity can focus on the challenges, and it was agreed to include more positive aspects about neurodiversity in the pack with some uplifting, empowering, and positive messaging.

Watch a video explaining the <u>co-production journey of the Diagnosis Support</u> <u>Pack</u> (10 mins) including what the pack is, and brilliant commentary from some parents and a clinician involved, on their experience of co-production.

View the Diangosis Support Pack.

View the fantastic film about the positives of neurodiversity with some of the families and young people involved.

Parent Carers Cornwall worked in partnership on the NHS England keyworker programme which is about supporting children and young people with learning disability, autism, or both, who are inpatients or at risk of being admitted to hospital. The aim of the project is that children and young people with a learning disability, autism, or both with the most complex needs will have a designated keyworker to help them navigate services and get what they need to feel safe, happy, and listened to, along with improving families' and parent carers' experiences so they feel less stressed.

Parent Carers Cornwall has been involved with this programme from day one, including supporting Cornwall to produce the bid for this pilot, designing leaflets, and chairing and attending meetings to help develop the programme to make it as helpful as possible for families.

Kay Henry the forum's strategic lead said, "The impact of the keyworkers being involved with families who have children/young people at admission avoidance to hospital is invaluable. Families are stating the kind of support the keyworkers provide has been required for a long time." A parent carer from Cornwall whose child/young person accessed the keyworker programme said "having a keyworker has given me the confidence to speak up where I felt I could not in the past. Just having someone there to listen has made such a difference."

We'd love to hear your stories of working in co-production in your area so we can help share them, and work to inspire others to work in co-production to create positive change for children and young people with SEND and their families. You can tell us about your experiences of working in co-production by emailing parent.participation@contact.org.uk

To see more stories about how parent carer forums have worked in coproduction take a look at the success <u>stories page</u> of our website.

Online learning sessions for parent carer forums

We have a range of online learning sessions available for parent carer forums, with 'Time to Talk' coming up next on 8th July. Time to Talk is a 3 year programme to support young people aged 16-25 with SEND to build confidence, provide motivation, and make plans for the future. To find out more, register your place, and find out about other online learning sessions, please see the <u>upcoming events page</u> of our website.

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