

Co-Production in Pathway/ Service Re-Design and Evaluation A Guide



Introduction and background

The Council for Disabled Children (CDC) has been approached by a number of local areas requesting support to strengthen and monitor the local Neuro-Development/ Autism Pathway. Through supporting these areas, CDC has developed a step-by-step process for thinking about pathway redesign and evaluation which is widely applicable, and places the voices of children, young people and parent carers at the heart of decision-making.

CDC was invited by regional leaders in the South West to deliver a workshop on this approach, giving local leaders and parent carer representatives an opportunity to discuss local strengths and challenges of working in this way. This support was provided through the Delivering Better Outcomes Together programme, funded by the Department for Education.

CDC would like to thank all of the individuals and local areas who have contributed to this resource, particularly those who have shared their examples of good practice.

Who is this resource for?

This resource aims to give anyone involved in the commissioning or recommissioning of pathways or services a broad understanding of what this process should look like with family perspectives at the centre. This includes strategic leaders, commissioners, parent carer representatives, service managers etc.

Using this resource

While this resource provides an overall guide to the process, individual local areas will interpret this differently, depending on local structures and the pathways/ services in question. While true co-productions at all levels is not always possible, the principles and spirit of this approach should run throughout commissioning decisions.

Please note: All of the examples in this resource are Neuro-developmental/ Autism pathways. This does not preclude the approach from being used for other services and pathways. CDC would like to hear from local areas using a similar approach to co-produce other pathways and services.

Terminology

These are some key terms which will be used throughout this resource:

>> Working together Dif

Different levels and approaches of working meaningfully with children, young people and families, including co-production, co-design and consultation. Different levels will be appropriate at different times.

>> Monitoring

Reviewing change on an on-going basis. Are we doing what we said we would do, are we doing it well, and is it making a difference?

Evaluation

More in-depth reviews at agreed points in the programme (e.g. halfway through, at the end)

>> Strategic outcomes

The big, holistic life outcomes that make up a good life for any child or young person; everyone in the SEND System should be working towards these. Read more about strategic outcomes here.

Overview of the approach

CDC's approach to pathway/ service redesign and evaluation follows the commissioning cycle:



At each stage of the process, there are key questions which can only be answered by working together with children, young people and their families to understand their experiences, their hopes, and their recommendations for change.

Step 1: Developing the vision

Local areas usually have a model of care in place for a pathway or service, which 'describes how services are organised and delivered'. While this is a very important document, it does not include how children and young people's lives should change as a result of being on the pathway or accessing the service. It also does not include how families want to feel while they are accessing the support. An outcomes-based vision should do both of these things; the model of care then explains how the vision will be achieved in practice.

Developing the vision should start with the local area's <u>strategic outcomes</u>, if the area has them. This is to make sure that the service or pathway is aligned with the local area's system-wide aims for children and young people.

If the area does not already have strategic outcomes, this document explains CDC's approach to developing them.

Key questions to answer with families in order to develop a vision:

- 1. What do the strategic outcomes mean to this particular group of children and young people?
- 2. If the pathway/ service were working perfectly, what would that feel and look like?



Example:

Derbyshire and Derby City's Neuro-Development Pathway

Partners across Derbyshire and Derby City came together in two workshops to work together and a vision for the new Neuro-Developmental Pathway. This included neuro-diverse children and young people currently accessing the pathway, their parent carers, and neuro-diverse adults. Through a series of open conversations, the group identified key principles and outcomes for the pathway which everyone involved can work towards.



Outcomes of the Pathway







Parent carers will:

See that their child or young person is happy at school

Have the skills and knowledge to parent their neuro-diverse child or young person

Be empowered and know where to get help

Children and young people will:

Live their best life

Be happy at school

Have social activity opportunities

Have a sense of community

Have a positive future, including a job and their own home

Feel understood and have their needs met

Be successful in a way that is important to them

Schools and settings will:

Be confident
and competent
in teaching and
supporting
neuro-diverse
children and young

Have the skills and knowledge to support neurodiverse children and young people

Be Autism-friendly

Principles

In order to achieve the outcomes, professionals working on the pathway:

- Are child-centred in our approach
- Work through co-production and are professionally generous and open
- Consider neuro-diversity in its widest sense and what it means for individuals as they transition to adulthood
- Look at the whole child and meeting their needs in their locality through a community response
- Aim to support CYP and their families at the right level at the right time
- Aspire to a system that is integrated across Derby and Derbyshire, across education, health and social care
- Are brave in order to make the changes that are needed.
- Demonstrate fairness to all stakeholders

Step 2: Using the vision to guide changes

The vision tells us what an ideal scenario looks like; it is something for all partners to work towards and there may be many barriers to achieving it. This means that the next step is to work in partnership with children, young people and families to identify what needs to change in order to improve family experiences of the pathway/ service and children and young people's outcomes.

Key questions to address with families:

- 1. What is preventing us from having an efficient, effective pathway/service now?
- 2. What is holding the children and young people who access this pathway/ service back from achieving the outcomes?
- 3. What are we already doing well that we can learn from and build on?
- 4. What are other areas doing well that we can learn from, adapt or borrow?
- 5. What changes do we need to see, and who is responsible for making them happen?

In order to manage expectations while demonstrating rapid change, it might be helpful to identify which of these changes are:

- Quick wins
- Realistically achievable with time and resources
- Future ambitions



Example:

Somerset's Next Steps referral process

Like many local areas, Somerset was facing increasing numbers of referrals for Autism diagnosis, very long waits for assessment and falling capacity of paediatricians to support the referral process. These challenges were recognised in Somerset's SEND Inspection, and addressing them was a priority in the area's Written Statement of Action.



To address these challenges, Somerset County Council and Somerset CCG have been working in partnership with families and a wide range of professionals to identify barriers in the current process and realistic solutions to overcome these. A series of workshops were held to identify:

- Key values for the pathway
- Key additional support needed across the system
- Principles for communication
- Key recommendations for improvements

In response to the recommendations from the workshops, so far partners in Somerset have produced:

- Pre-assessment pathway documents, to help all partners understand the pathway
- Next Steps referral form, to involve schools more fully in the referral process
- Guidance on Autism/ADHD interventions in education settings as part of the Graduated Response
- Explanation of the interagency and multi-disciplinary triage process

Although these documents are still in draft form and work is ongoing, so far data is showing a significant improvement with diagnoses taking 4 months, down from 4 years in some areas.

Ongoing work on Somerset's Autism and ADHD pathway can be found on the <u>Local Offer</u>

Step 3: Using the vision to develop an accountability framework

Local areas are generally very good at measuring and evidencing what has been delivered as part of a pathway or service, usually with a focus on quantity (e.g. number of assessments, number of clinics, number of family support groups). However, this information only tells part of the story: what are professionals doing to provide this pathway/ service? It does not provide information about how successful the pathway is, and whether families are having a positive experience.

The vision can help with this. A well co-produced vision is a summary of the impact and experiences that children, young people and their families want to see as a result of their support, so it should be used as a framework to measure success. This means capturing data on each of the points in the vision (both in terms of outcomes and experience), so local areas can celebrate success and address challenges.

CDC recommends using Mark Friedman's Results-Based Accountability approach to do this, using three key questions:

- How much have we done?
- How well have we done it?
- Is anybody better off as a result?

To put this in the context of pathway/ service redesign, that means working with families to answer:

- What have we done to improve the pathway/ service?
- What are we delivering as part of the pathway/ service?
- Are families having a more positive experience of the pathway/ service, as laid out in the vision?
- Are children and young people achieving better holistic outcomes as a result of their support, in line with the vision? Are they happier/ more included/ independent etc.?

The key thing to remember here is that accessing support is only the first step to success; children and young people's lives must improve for the pathway or service to be truly effective. After all, a timely diagnosis has limited meaning to a child if they are unhappy, lonely or lack confidence about their future. Only families can tell us the true impact of their support, so their experiences are central to evidencing the effectiveness of the pathway.

Having access to this data is also important in terms of communicating with families. It takes a long time for change at the strategic or operational level to have a direct impact on families. Planning communications to families using these key questions enables professionals in local areas to be open and transparent about what is or isn't being done, and how much difference this is making. This can help to build trust with families that real change is taking place even if they are not feeling it on the ground yet; it also means that families can hold leaders to account for meaningful progress.

Any examples?

Although a number of local areas have made a start on using this approach with CDC, they are still at the beginning of their journey and are not yet able to demonstrate what difference this has made. Routinely hearing and recording families' experiences is not easy, although there are some suggestions in this CDC Data Bulletin, and many other creative approaches.

If your local area is taking this or a similar approach to data in monitoring a pathway or service and you would like to share your approach, please contact Philippa at pwatts@ncb.org.uk.