

# Current and future priorities for parent carers

**Anna Bird**

**Chief Executive, Contact**

Planning partners:

Sponsors:



# Current and future priorities for parent carers



# This presentation

- Introduction to me and Contact
- Current issues facing families with disabled children
- The need for transformational change, and how we can get there





contact *For families  
with disabled children*



# About Contact

- National charity, 4 nations.
- Last year, we supported 291,000 families with disabled children to navigate health, social care and education services.
- We provide trusted information, advice, and support - national helpline, website, online community, workshops, 1:1 support.
- We support up to 153 parent carer forums that make up the National Network of Parent Carer Forums - to ensure voices of parent carers of disabled children are heard by strategic decision makers.



# Current challenges for families with disabled children



# Education

- Schools not recognising SEND needs, failing to put SEN support plans in place, or not implementing SEN support plans
- Long waiting lists for assessments and diagnosis, CAMHS
- 21% increase in helpline calls related to school exclusions
- Absence – home visits, families threatened with court proceedings and fines because of absences explained by health conditions/disability, parents feel blamed



# Social care

- Only 1 in 7 families think they have the right level of care support, 1 in 4 families told they didn't meet the threshold for assessment (DCP research)
- Concern that reviews to care plans will lead to reduction in support and access to short breaks.
- Direct payments offered but nothing available to purchase
- Parents accused of failing to establish boundaries – sent on parenting courses rather than being offered support





# Finances

- Sky high energy bills – on average, families with disabled children spend £1600 more a year
- 39% families have turned off essential equipment to reduce costs
- During pandemic 30% of families with disabled children went without heating, 37% of parent carers went without food themselves to afford food and heating for their children
- Due to lack of support, 60% of parent carers have given up work or reduced hours – average loss of earnings = £21k





# Towards transformational change



# First steps towards transformational change

- Briefing all parties ahead of the election, seeking commitments for wider reform that enables families to get the right support when they need it across education, health and social care
- Recommending to the Law Commission review of children's social care that it proposes a principle-driven approach, better mechanisms for accountability, and new rights to advocacy for families
- An assertive comms strategy, calling out the media outlets and politicians peddling blame parental narratives
- At DCP, discussing how we might work together across the sector to shift public attitudes around SEND
- Designing a new strategy for Contact, where campaigning for structural change goes hand in hand with our vital information, advice and support for families



# Be involved!

Contact's new strategy is being co-produced with parents of disabled children. That means that:

- In both our Board and senior team, parent carers make up the majority of people round the table.
- We have recruited a small number of parent partners who are involved at every step of the journey.
- Insights from families we support are used to inform every decision.
- We surveyed parents about their priorities to inform our future priorities – thank you to all those who contributed.
- NNPCF were interviewed at an early stage too.

As our ideas develop, we would love to share our thoughts and hear yours.

Watch this space!

