Introducing Contact a Family

Jacqui Adams
Regional Development Manager North East & Cumbria
Our vision

That all families with disabled children and young people are empowered to live the lives they choose to live, and achieve their full potential.
Our key outcomes

• Families with disabled children will know how to get the right support.

• Families with disabled children will be more confident to deal with the challenges they face.

• Making sure families with disabled children are understood, valued and included as equals in their communities and society as a whole.

• Reducing the financial disadvantage that families with disabled children face.
Some of the issues for parent carers

• Endless explanations
• Impact on family life
• Friends and peers
• A life full of appointments
• Responsibility for their child for a longer period than expected
• Financial disadvantage
Areas families might need support with

- Finance and benefits
- Transport and mobility
- Health services
- Education/transition
- Social services
- Employment
- Support groups
- Parenting/relationships
- Equipment and adaptations
- Leisure
- Childcare
What parents may find difficult

• Coming to terms with a diagnosis
• Living without a diagnosis
• Understanding the full implications of the condition
• Realising that practitioners don’t have all the answers
• Carrying on with everyday life
• Knowing where to go for help
• What questions to asks
Difficulties in getting information

Parents
• Don’t know what support exists so don’t look for it or know where to look for it
• Don’t see themselves as ‘carers’ so don’t look for support for themselves
• Expect a professional to tell them

Practitioners
• Assume someone else is providing the information
• Only have knowledgeable of their own area
What we do to help

We provide advice, information and support to families of all disabled children and young people aged 0-25 with or without a diagnosis. This includes:

- long-term medical conditions
- rare conditions
- physical disability
- learning disability
- behavioural problems
- life-threatening conditions
- mental health issues
How we do this

• Providing **good quality advice and information** on any aspect of caring for a disabled child. (National Helpline, online or in person through North East office)

• Putting **families in contact with each other** through a network of parent support groups, online communities workshops and events nationally, regionally and locally

• Supporting parents to **have a voice** locally and nationally with government, commissioners and providers

• **In the North East & Cumbria** we have an office in Newcastle, provide newsletters & e-bulletins, drop in’s, information sessions, workshops, support parent groups and forums, work in partnership with other organisations
Contact a Family
information resources
Newsletters

• **What's new** – monthly news and information
• **Rare conditions e-newsletter** - Bi-monthly on policy issues concerning rare disorders.
• **E-newsletter for practitioners** – information to support you in your work with families with children with special educational needs.
• **Connected** - magazine for families with disabled children and all those that work with them. Personal stories, articles and useful resources.
• **Participation bulletin (England)** joint information bulletin with NNPCF. News from the NNPCF and opportunities for forums to participate.
• **Parent carer participation good practice e-bulletin** - every three months examples of how parent carer participation is improving services for disabled children.
Free Helpline

- Freephone helpline for parents and practitioners across the UK staffed by trained parent advisors
- Providing information and advice on a wide range of issues including short breaks, local services and local support
- Specialist advisors for SEN and Welfare Rights
- Provides a listening ear for parents
- Access to interpreters in over 170 languages
Parent Participation

• Find out what services families need
• Provide evidence for change
• Create better services that meet peoples needs
• Reduces stress caused by dissatisfaction with service
• Improves professional–parent relationship
• In the long term, saves time and money
Policy and Campaigns

• We work to bring issues for families with disabled children to the forefront of the political agenda

• Campaigns raise awareness of issues for families, including poverty and social exclusion

• We actively participate in policy development by collecting evidence and submitting views on key consultations

• Part of national campaigns with other organisations
Counting the Costs Campaign
Sharp rise in families with disabled children going without heating and food leads to ill health.

31% going without food
22% say their child's health has worsened
33% going without heating

TAKE ACTION!
Join the campaign at www.cafamily.org.uk/takeaction

CALL OUR FREEPHONE HELPLINE FOR ADVICE
0808 808 3555
SEN reforms, why change?

- Too many children have had their needs picked up late
- Not enough focus on raising aspiration and achievement
- Different laws covering SEN and disabled young people
- Lack of joined up assessments and support across education health and social care
- Different systems for school and further education
Main changes from old to new system

• Children and young people with SEN in mainstream education receive help through a system called **SEN support**. (This replaces early years/school action and early years/school action plus.)

• Children and young people who need more help might have an **Education, Health and Care (EHC) needs assessment**. (This replaces the statutory assessment.)

• This assessment may lead to a child receiving an **Education, Health and Care (EHC) plan**. (This replaces the statement of special educational needs.)

• Children and young people are supported from birth to age 25, so there are changes to the way young people are supported in **post-16 education**. (The EHC plans replace Learning Difficulty Assessments (S139a))

• Local authorities must publish a **local offer** of education, health and social care support available in the area.
Improvements

• One system from birth to 25
• Focus on outcomes
• Academies have to follow SEN law too
• Stronger rights to ask for preferred school
• Parents and young people have more say
• Education Health and Social Care must work together
But also questions

- SEN support – process and record keeping
- No EHC plan unless educational need
- Education health and social care not joined up
- No single point of appeal about EHC plan
- Transition between old and new system
- Local offer – no duty to provide what is in it
Concerns from parents

• How will SEN Support work in practice and will it change their level of their child’s support?
• Personal budgets – what is their scope, can they fund alternative education, e.g. online learning, health social care – how will they join up?
• Nursery provision and specialist support – will the nursery provide 1:1 support? (parents being deterred from applying as nursery cannot provide this)
• What are the local arrangements for transfer from a statement to an EHC plan or SEN Support and how to apply, where do you go for help?
• Will I loose the legal rights I had for support in my child’s statement?
Myths

• A single assessment across education, health and care services
• Statements end on 1st September 2014
• Fewer children and young people will get an Education, Health and Care plan than get a statement of special educational needs
How we can help

• SEN experts on our helpline
• Online support - Netmums, Facebook
• Support to parent carers forums to get involved
• A series of factsheets to help families understand recent changes to the special educational needs system
  – Introduction to the Children and Families Act 2014
  – Changing from the old system to the new - how will it happen?
  – Extra support in mainstream school - SEN support
  – Education, Health and Care needs assessments
  – Education, Health and Care plans
  – The local offer explained

Early years factsheet on it’s way soon!
The demand for our service

- Last year we supported over 320,000 families UK wide

- **In the North East & Cumbria** last year we received 1149 enquiries. Over half (51%) were directly from parent/carers. Quarterly newsletters have a circulation of over 4,000 with 3,150 going directly to North East parent/carers.

- **Nationally** we are contributing to debates in relation to the Children & Families Act, Care Act and Welfare Reforms

We continue to deliver good quality support to families across north east and enable parent carers voices to influence local and national service agendas
Thank you for listening

For more information about the North East office contact Jacqui Adams or Sarah Lewis:
Phone: 0191 213 6300
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National Freephone Helpline
Open 9:30am- 5pm, Monday - Friday

0808 808 3555
www.cafamily.org.uk