

Supporting families of children with additional needs

A guide for churches



Care for the Family
Tovey House
Cleppa Park
Newport
NP10 8BA

029 2081 0800
cff.org.uk

© Care for the Family.
All rights reserved.

Except as stated, no part of this guide may be reproduced, stored in a retrieval system or transmitted in any form or by any means – electronic, mechanical, scan, photocopy, recording or otherwise – for any purpose whatsoever, without written permission of the publisher.

A Christian initiative to strengthen family life, offering support to everyone.
Care for the Family is a registered charity (England and Wales: 1066905; Scotland: SC038497).
A company limited by guarantee no. 3482910. Registered in England and Wales.



Contents

Introduction	2
What are additional needs?	3
Like any other family (but with extras)	4
Supporting additional needs families	6
Some dos and don'ts	10
Additional Needs Support from Care for the Family	12
Other helpful organisations	14

Introduction

Families come in all shapes and sizes, each with their own blend of personalities and abilities, hopes and challenges. This is just as true for families of children with additional needs; they are the same as other families... but with 'extras'. This booklet has been written to help you gain insight into the lives of these families and to suggest ways in which you can support them in your church and community.

Perhaps you know many families who face the challenge of raising children with additional needs. You may already share in their ups and downs, their joys and their trials. Or it may be that you have very little experience of supporting them. Whatever your previous involvement and understanding, we hope that you find the information, advice and guidance in this booklet useful.

What are additional needs?

'Additional needs' is a term which covers a wide range of conditions and experiences, including; neurodiversity, diagnosed conditions, long-term illness and learning difficulties.

These may include autism, ADHD, dyslexia, dyspraxia, anxiety, eating disorders, Down's syndrome, cerebral palsy, epilepsy, learning or physical disabilities and developmental delay. Each have a significant impact on the families of those affected.

The impact on families

- In 2019/20, 80,135 children in England with a statement of SEN or an Education, Health and Care (EHC) plan had a primary SEN associated with learning disability or difficulty.¹
- 10% of children in the UK live in a family with at least one disabled child.³
- On average, a family with a disabled child would have to pay £581 a month to have the same standard of living as a family with a non-disabled child. For 1 in 5 families, these extra costs come to more than £1000 a month.⁴
- Less than one in five (18%) local authorities in England report sufficient childcare for children with disabilities.⁵

- Caring for a disabled child can result in strained parental relationships. 24% of couples with a disabled child only find time for a date night once a year or less, compared to 17% of other parents. Finances were also a factor. 39% of parents of a child with a learning disability identified money worries as a strain on their relationship – compared to 29% of other parents. Mental health was the second biggest relationship strain, with 24% identifying this as an issue – more than twice as many as other parents.⁶



An estimated

16 million

people in the UK had a disability in 2021/22. This represents 24% of the total population. Of these, 11% were children.²

Like any other family... but with 'extras'

A family with a child who has additional needs is like any other family – clothes still need to be washed, meals still need to be prepared, and children still need to be taken to activities.

But having a child with additional needs places extra demands on the whole family. For parents, these may include getting appropriate care and support, promoting acceptance in the extended family, school and community, planning for an uncertain future, and adjusting routines and expectations.

Understanding how parents feel

When we asked parents of children with an additional need what 'extras' they dealt with as a family, here's what they said:

- 'Prescription collection and picking up equipment.'
- 'Feeling isolated and lonely.'
- 'Needing more accessibility wherever we go.'
- 'Being "on call" all the time.'
- 'Uncertainty.'
- 'More laundry.'
- 'Extra meetings.'
- 'Worries about the future.'
- 'Everything taking longer.'

**'Less time available
for my partner and
other children'**



- 'Child being more dependent for longer/indefinitely.'
- 'Having to plan everything in detail.'
- 'Not being able to work.'
- 'Financial issues.'
- 'Issues for siblings (embarrassment and receiving less attention).'
- 'Constant need for close supervision.'
- 'Stress over needing to fight to access or receive services.'
- 'Sleepless nights.'
- 'Lack of after-school care.'
- 'No "me" time.'
- 'Difficulty holding down a job.'

'Lack of childcare for children with additional needs'





Supporting additional needs families

The church has a great opportunity to care for families of children with additional needs, to make them feel welcome, supported and understood in the everyday challenges that they face.

You may want to consider becoming an inclusive church by equipping relevant team members with specialised training. You could also improve the understanding of the whole church community by utilising some of the ideas below.

Ideas for the whole church

Accept them as they are

Understand that you cannot 'fix' the child or maybe even the situation. Never assume, always ask.

Earn their trust

Take time to get to know the family and earn the trust of all of the children, then you will be in a good place to support them.



Get a picture of daily life

Try to get a picture of the family's daily life. Ask the parents to describe what a typical day is like for them and to tell you about their child. Actively listen to their answer. Speak about any issues or difficulties.

Listen to parents

Remember that there can be hidden additional needs that may not be apparent from looking at the child. Listen carefully to what the parents tell you.

Talk to the child

Talk to a child with additional needs as you would to any child, even if it is apparent that the child cannot reply. Get down to their level if they are in a wheelchair and ask parents if touching, hugs, handshakes, eye contact etc. are helpful or not. Talk to the siblings too.

Lead by example

In a group situation, other people may be anxious about the unpredictable behaviour of some children with additional needs. Lead by example in your own response. Ask the parents about 'triggers' and helpful coping techniques if the child becomes upset.

Offer childcare

Getting babysitters and childcare for children with additional needs can be so much harder – the sense of isolation often experienced by parents can be even greater. Most parents will appreciate the offer of some reliable childcare, or looking after siblings so parents can go to appointments. Other practical support could include help with transport for hospital visits or after school activities, and help with accessing support or filling in forms.

Be there for the long haul

Remember that these parents face a lifetime of coping with challenging circumstances and they may need support every step of the way, particularly during times of change. When the child reaches adulthood, the additional needs will not disappear. Be the friend who is there for the long haul.



What parents have said

Here's some comments from parents about some of the ways that their local church has helped them to feel cared for and less isolated:

- 'It's amazing that the church feeds my kids when I work late.'
- 'It was great when someone asked us what they could do to help.'
- 'I have been thrilled with the way my son has been welcomed into the youth group by the young people.'
- 'Someone from church regularly takes my son out to watch a football match.'
- 'It was really helpful to have an opportunity to discuss my child's needs when she wasn't present.'
- 'My church has after-school clubs for children and young people with additional needs two days a week.'
- 'Someone from church comes to my house after school to look after my child so that I can spend time with my other children.'
- 'It was helpful when people were sensitive to the fact that my son didn't like physical touch.'
- 'The minister always makes a point of talking to my son.'



Some dos and don'ts

At Care for the Family we speak to many parents of children with additional needs. We asked them what has helped them and what doesn't help. Here's what they said:

- **DO affirm my parenting.** Find positive things to say. I know that my child's behaviour can be tricky sometimes.
- **DON'T ask me what is 'wrong' with my child.** In my eyes they are perfect, but of course I sometimes wish they could do all the things that other children can do.
- **DO listen to me.** I sometimes need to talk and I love it if you really listen.
- **DON'T criticise me.** I really am doing my best. I can see when people give me a disapproving look.
- **DO accept my child, and our family, just the way we are.** Even though we may not fit into a 'normal' pattern.
- **DON'T make assumptions** about what my child can or cannot do, say, hear, see or understand.
- **DO get down to my child's level.** They don't want to look up your nostrils or have you towering over them!
- **DON'T ignore my child, or me.** We have feelings too.
- **DO include my child** in our conversation.
- **DON'T assume that my child doesn't understand.** Talk to us both.
- **DO use straightforward language with my child.** Speak in your normal voice.
- **DON'T tell me that I am coping so well.** You may not know how things really are.
- **DO ask about other family members too** – chat about normal family things!
- **DON'T tell me that I must be so strong.** I am not.
- **DO offer practical support.** I will know what to ask for if I know you are genuinely available.
- **DON'T say you understand unless you really do.** I have no idea about your daily life either.
- **DO always ask.** Then be patient while I try to explain.
- **DON'T try to fix my child, or me.** We may not seem perfect to you, but we are not broken.





Additional Needs Support from Care for the Family

Discovering that their child has additional needs can generate a whole range of emotions and concerns for parents.

There can be good days and tough days, but the feeling of being alone and misunderstood can, at times, be particularly overwhelming. This is

when it can be so valuable to have someone to talk to openly and honestly about how life really is.

'Talking with another parent in a similar situation helps me to deal with the well-meaning but often inappropriate comments from other parents around me who just don't get it.'

Telephone befriending service

Care for the Family's befriending service offers understanding and support to parents of children with additional needs. All our befrienders are trained,

and are themselves parents of children with additional needs who can share insights and encouragement from their own personal experiences.

Through our befriending support, many parents have found it a huge help to speak with someone who has 'been there' too. Here are some of their comments:

- 'Strangely, off-loading my emotions and sharing practical issues with someone who had an understanding really helped me and my relationship with other family members.'
- 'Care for the Family provided a network to help me raise my child so that I am no longer just one mum in isolation.'

Resources to share

The Additional Needs Support team produce encouraging and informative resources for parents through a regular email newsletter, Facebook page and web content.

Online events and courses

Encourage parents to attend one of our *Just for You* or *Time Out for Parents* sessions online. These sessions offer specialised support and often become a lifeline for parents. The dates for these sessions vary throughout the year, check our website for further details.

cff.org.uk/ans

facebook.com/cffadditionalneeds

029 2081 0800

Other helpful organisations

Additional Needs Alliance

Resourcing the church to make inclusion and belonging a reality for children and young people with additional needs or disabilities.

additionalneedsalliance.org.uk

Through the Roof

A charity that aims 'to positively influence church and society' through equipping churches to be more inclusive.

throughtheroof.org

The National Autistic Society

A UK charity for people with autism and their families. They provide information and support for people with autism and their carers.

autism.org.uk

The Down's Syndrome Association

The association provides clear information and support on all aspects of living with Down's syndrome through research, campaigning, resources and an information helpline.

downs-syndrome.org.uk

Scope

A charity providing support for those with cerebral palsy and aims to see disabled people and their families having the same opportunities as everyone else.

scope.org.uk

Contact

A charity that gives support to the families of disabled children, whatever their condition or disability, through a helpline, information and advice.

contact.org.uk

Sibs

A UK charity representing the needs of siblings of disabled people. It offers information and advice for young siblings, adult siblings, parents and professionals.

sibs.org.uk

You can find a full list of other organisations, alongside further information about additional needs support on our website.

cff.org.uk/ans



Endnotes

(1) Mencap.org.uk, 'Children - research and statistics' [mencap.org.uk/learning-disability-explained/research-and-statistics/children-research-and-statistics](https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/children-research-and-statistics)

(2) House of Commons Library 'UK disability statistics: Prevalence and life experiences' 2013 [researchbriefings.files.parliament.uk/documents/CBP-9602/CBP-9602.pdf](https://www.researchbriefings.files.parliament.uk/documents/CBP-9602/CBP-9602.pdf)

(3) Papworth Trust, 'Facts and Figures 2018: Disability in the United Kingdom' www.papworthtrust.org.uk/about-us/publications/papworth-trust-disability-facts-and-figures-2018.pdf

(4) Scope, 'Life costs more for disabled children and their families' 2019 [scope.org.uk/news-and-stories/life-costs-more-for-disabled-children-and-their-families](https://www.scope.org.uk/news-and-stories/life-costs-more-for-disabled-children-and-their-families)

(5) Coram, 'Coram survey finds childcare shortages ...' 2023 [coram.org.uk/news/coram-survey-finds-childcare-shortages-nationwide-with-the-most-disadvantaged-children-missing-out](https://www.coram.org.uk/news/coram-survey-finds-childcare-shortages-nationwide-with-the-most-disadvantaged-children-missing-out)

(6) Mencap, 'One in three parents of a child with a learning disability is in a distressed relationship' 2017 [mencap.org.uk/press-release/one-three-parents-child-learning-disability-distressed-relationship](https://www.mencap.org.uk/press-release/one-three-parents-child-learning-disability-distressed-relationship)

About Care for the Family

Established in 1988, Care for the Family is a charity based in the UK, but with an increasing reach internationally. Our aim is to support families whatever their circumstances. We provide this support, online and in person, for parents, couples and those who are bereaved, through events, courses, podcasts, volunteer befrienders, books and other evidence-based, accessible resources. We also train those who work with families whether in a professional or informal capacity.

Further guides for churches include:

- [Supporting people through bereavement](#)
- [Supporting people through divorce and separation](#)
- [Supporting new parents through mental health challenges](#)

029 2081 0800

cff.org.uk



A Christian initiative to strengthen family life, offering support to everyone.
Care for the Family is a registered charity (England and Wales: 1066905; Scotland: SC038497).
A company limited by guarantee no. 3482910. Registered in England and Wales.
Registered office: Tovey House, Cleppa Park, Newport, NP10 8BA.

