SUFFOLK PARENT CARER NETWORK (SPCN)
SUPPORTING SEND PROGRESSION
DAY 1: THURSDAY, 1ST OCTOBER 2020
WHAT WE DO:

We work on behalf of families in Suffolk who have children and young people aged 0-25 with any additional need and/or disability (diagnosed or not)
WHO ARE OUR MEMBERS?

• Parent Carer Membership
  • Parent Carers of children and young people aged 0-25 with additional needs and/or disabilities e.g. dyslexia, mental health, autism, down’s syndrome, complex physical health issues
  • Family members (who have a significant caring role for the child/young person) e.g. grandparents
  • Foster carers

• Associate Membership
  • Practitioners from education, health and care services relevant to our families (associate membership)
  • Voluntary organisations
OUR REACH

• Facebook (over 1600 members on our open group)
  • Last 28 days:
    • reached over 10,000 people
    • 2,300+ post engagements
  • Twitter (over 2,200 followers)
  • 300+ Associate Members
  • 2,200+ Parent Carer members
OUR NATIONAL NETWORK:

Contact (Contact a Family)

Council for Disabled Children (CDC)

National Network of Parent Carer Forums (NNPCF)
HOW WE WORK IN COPRODUCTION:

A combination of **CHALLENGE** and **SUPPORT**

for example:

Where we see a consistent pattern of poor performance (by a service provider) we will **CHALLENGE** – by highlighting what we have found.

In the face of sizeable budget cuts we will work **with** providers and **SUPPORT** them to identify the most appropriate way to adjust services.
SPCN - WHO IS INVOLVED:

- Members
- Parent Representatives
- Admin
- Management Board
- Co-Chairs
HOW DO WE GET FEEDBACK ABOUT SERVICES?

1. Directly from our members
   a) Through our social media channels - closed Facebook group for parent carer members only, open Facebook group for practitioners and parent carers and Twitter
   b) Emails
   c) Phone calls
   d) Surveys – annual Parent Carer Satisfaction Survey in October (2020 1,133 responses), Covid-19 support survey, interim surveys
   e) Requests for feedback on specific services / areas
OUR AMBASSADORS ATTEND SCHOOLS AND GROUPS AND LISTEN TO PARENTS AND CARERS — FEEDING BACK THEIR ISSUES.
REPS ATTEND MEETINGS AND PRESENT THE VIEW OF PARENTS AND CARERS IN SUFFOLK – AND FEED BACK TO SPCN
REPS ENGAGE WITH PROVIDERS ON SPECIFIC ISSUES IN SUFFOLK

e.g. Transport, Speech and Language Therapy, Neuro Pathway
WHAT IS OUR SERVICE OFFER FOR FAMILIES?

All our members will have access to a variety of services and resources as follows:

- Access all our resources and services
- Add your views and experiences to our collective voice
- Receive news updates and events information via our text and e-mail service
- Attend our drop-in sessions and activities
- Use our Facebook page/group and share your experiences and views with other parents
- Be involved in consultations on new and current issues
- Be a buddy to another parent
- Attend funded training
- Annual emotional wellbeing and mental health conferences
- Open forums and drop ins
- Be invited to represent SPCN at strategic meetings
- Have a say in how the forum is run and what it delivers
- The right to nominate members of the Management Board and vote at the AGM
DURING COVID-19

Online resources
SPCN have put together a mix of free online resources to help keep children and young people occupied at home.

Peer-to-peer support
SPCN are providing peer-to-peer support if parents and carers need someone to talk to, or if they or their child/young person are struggling or if they have specific questions about where/how to access other support. They are signposting any health-related issues regarding Coronavirus to official sources. Parent and carers can contact SPCN by emailing admin@spcn.org.uk, private messaging on their social media @suffolkpcn or calling them on 07341 126455.

Family support page and pack
SPCN have also created a page on their website dedicated to parent carer support and this includes a regularly updated SPCN support pack containing local and national support organisations and online resources for parents and carers is available to download or be posted out in a printed format.
Parent Carer Support & Hearts for Care Homes

We know that being a parent carer can be a challenging role and many families tell us that they feel isolated and need support. We have started to put together a family support pack containing local and national support organisations and online resources which we hope will be of use to you. This pack will be updated regularly.

If you require a printed copy of this pack, please email admin@spcn.org.uk with your details and we will get one out to you.

Family Support Pack v1.1

Coronavirus/Covid-19

Families have told us that the Covid-19 outbreak is a really worrying time for them and they have asked for resources to help them talk to their children and young people about it as well as needing strategies to
email admin@spcn.org.uk with their request for items.

**Resources**

We have co-produced a Frequently Asked Questions document in relation to Covid-19. This is the first in a series. [CV19 Parent FAQ bulletin Issue 1 19th June 2020](#)

- 5 Tips for Families (Anxiety – Children)
- 5 Tips for Families (Anxiety – Young People)
- 5 Tips for Families (Autism – children)
- 5 Tips for Families (Autism Young People)
- 5 Tips for Families (with children who self harm )
- 5 Tips for Families (with young people who self harm )
- LD Professional Senate guidance on things to do with people with LD in isolation
- EHC plans – Guidance on temporary legislative changes[16402]

[Royal College of Paediatrics & Child Health Covid-19 Research evidence summaries](#) have provides a summary of key current evidence regarding COVID-19 in children and young people.

NHS England has produced some very helpful practical advice for both parents and carers and young people to help and support children and young people with mental ill health, suicidal thoughts or self-harming behaviours. This included signs to look out for, what to do and who to speak to during a period in which younger people may be feeling particularly anxious or upset. The resources also include information on the support that is available to those who need help during this time.

[Words and pictures – explaining Covid-19 to younger children](#)

[When suicide is on your mind EASY READ leaflet](#)
Family Support boxes (free)
The SPCN team are sending out family support boxes for children/young people with any additional need and/or disability, (diagnosed or not) and their siblings and also contain information for parents and carers about how to support children and young people and other support organisations that are available. These boxes are personalised to each family and can contain a range of items. They are available free to any parent / carer / guardian / foster carers who are members of SPCN and they simply have to email admin@spcn.org.uk with the request. SPCN are accepting new members who will then be able to ask for the free family support box.

- Colouring/puzzle books for children and young people
- Colouring books for adults
- Stress balls
- Pots of bubbles
- Sensory bags
We asked young people...

What makes an ideal worker?

The ideal worker should be someone who:

- Has good signposting skills
- Doesn’t expect too much from you
- Understands that not one size fits all
- Goes the extra mile or even cm!
- Respects your individuality
- Is non-judgemental and takes you seriously
- Tries to understand your behaviour and doesn’t assume young people are just being naughty
- Is able to give appropriate and sensitive responses
- Has knowledge of conditions and services
- Praises achievement and gives positive feedback
- Doesn’t cut you off or make assumptions
- Gives you space when you need it
- Is able to recognise signs of emotional and mental health problems
- Doesn’t give labels like attention seeking