



Report on the Experiences of Families accessing Education, Health & Care Services during the Covid-19 Pandemic from March to December and subsequent system responses

December 2020

Executive Summary

Introduction

The Covid-19 pandemic has been particularly hard on children and young people with special educational needs and disabilities and their families for a number of reasons. This report sets out the contacts Suffolk Parent Carer Network (SPCN) has had with families during this time, the support offer that has been provided, the themes from these contacts and the results of the surveys we have carried out. It also details some of the actions taken across education, health and care services in response to the lived experience of families and the challenges they have faced during the pandemic.

The period covered by this report is March to mid-December 2020.

Support Provided by SPCN

- Family Support Boxes distributed to 2,522 children, young people and families
- Requests for support via social media and email from 2,433 parents and carers
- Facebook posts providing families with information and updates 2,241
- Facebook reach over the period of this report 249,000 people
- 3,000+ pairs of #heartsofcareservices distributed to young people and adults in care homes and mental health inpatient wards across Norfolk and Suffolk

Key themes from families

- Unclear and conflicting messages causing confusion and distress
- There was an increase in behaviour that challenges as a result of lockdown across the age range 2-25
- In the first lockdown some young people living in supported accommodating were brought home by their families as they felt it was safer
- The impact of lockdown on children and young people with a learning disability or autism was particularly significant
- Digital poverty was an issue for many families – lack of internet access / shortage of devices in households preventing children and young people from accessing home learning.
- Home learning caused a number of challenges:
 - Work being set by schools was not always being differentiated for children and young people with Special Educational Needs and Disabilities (SEND)
 - “Home is home and school is school” was the view of many children and young people with additional needs and/or disabilities and so learning at home was not an option
 - Lack of consistency across Suffolk about who was considered a keyworker for the purposes of their child(ren) being in school
 - Balancing working from home and home learning was a significant challenge particularly when there was more than 1 child in the household.
- Emotional wellbeing and mental health of children young people and families was affected
 - Difficulties accessing services even if at crisis point
 - For some children and young people not being at school improved their mental health
 - Lack of emotional wellbeing support when parents and carers needed it

- Lack of crisis support
- People with visual or hearing impairments were particularly affected by lockdown and social distancing and reported abuse e.g. in shops as they were unable to see / hear instructions
- Sleep was significantly affected for children, young people and families
- The impact of reduced or no services pushed families to breaking point and, for others, made it incredibly difficult for them to manage and this got worse the longer lockdown went on
- Lockdown gave some children and young people time to focus on their interests
- For some parents and carers lockdown was nothing new – they always felt isolated and alone and had little opportunity to leave their house as a result of their caring responsibilities
- Loneliness and the impact of not seeing family and friends was a recurring theme for almost all families
- Sheer exhaustion and no opportunity to re-charge your batteries
- Families requiring in home or away from home respite
- Children and young people not being allowed to return to school on health and safety grounds
- Anxiety about the return to school:
 - how safe is it?
 - how do parents make a decision?
 - How will children and young people cope with it being different?
 - Will children and young people with SEND get the support they had before lockdown?
- Provision in Education, Health and Care Plans not being provided or only being offered virtually
- Education, health and care services not contacting many families during lockdown
- A significant number of families report fixed term exclusions in the autumn term, some as early as a few days into the start of term and some families reported repeated exclusions
- Some families reported part-time timetables being the only option for their child/young person to attend school in September with some of these being used as a longer term provision
- Significant numbers of families were not involved in discussions about whether their child/young person should attend school or not during lockdown or how the provision in their education, health and care plan could be met.
- Many families reported that health services their child/young person received did not contact them during lockdown to discuss what support they could provide.
- Families reported that education, health and care services did not contact them to discuss alternative ways that provision in EHCPs could be provided.
- There were mixed experiences of how easy education, health and care services were to contact during lockdown.
- The majority of families completing the SPCN reported they had not been involved in a transition plan or risk assessment to support their child/young person's return to school in September. Many children and young people were not able to have the transition plans that had been scheduled for them when moving into new settings or leaving education/starting employment which caused additional distress.
- 63% of families reported they had not received contact from services about what provision would be in place when their child/young person returned to education or training.
- Families were told by a range of education and health services that they would only be providing virtual or no services during the autumn term
- Of significant concern was the reports from many families about the lack of contact from mental health services.

Some of the developments to support families

- SPCN Support Offer – including virtual and phone support, web page
- Family Support Boxes
- Five Top Tips for Families developed with the Suffolk County Council Psychology and Therapeutic Services
- Escalation of individual cases which resulted in resolution in the majority of cases (some are still ongoing)

- Additional commissioning by the CCGs which SPCN were able to refer families into
 - East and West Suffolk: Kooth, Homestart (Suffolk), 4YP, Noise Solution, Autism and ADHD, Barnardo's and Suffolk Family Carers
 - Norfolk & Waveney – Family Action (Waveney)
- Virtual Behaviour Support Service
- Flexible use of Activities Unlimited budgets and Social Care budgets
- Information for families: keeping families updated with national developments, translating some of the national messages into documents/videos families could use e.g. exercising more than once a day, PPE video, transport cards, frequently asked questions
- Return to school work with SENDIASS and other organisations

Recommendations

1. SPCN are deeply disappointed that the voices of families are being ignored or, as some of the responses from services indicate, the experiences of some families are being directly refuted. There needs to be an agreement between SPCN, Suffolk County Council and the Clinical Commissioning Groups about how responses to reports, surveys and feedback from families will be provided.
2. Education, Health and Care commissioners and providers need to demonstrate to families that they value hearing about their lived experiences by providing actions that have been taken in response to these.
3. Services need to provide clear escalation routes for families to use when their experiences do not reflect the services they believe they are providing.
4. There needs to be the continued translation of national messages into understandable local ones, including Easy Read versions.
5. Digital poverty needs to be addressed. Where services know that families do not have access to the internet, there needs to be alternative ways of communicating with them.
6. There needs to be more transparent accountability of the holding to account of education, health and care services when provision within Education, Health and Care Plans is not being provided.
7. Commissioners need to take urgent action regarding services to ensure that families are receiving contact and services during the current lockdown, especially in relation to mental health services.
8. If risk assessments are used in a future lockdown, Suffolk County Council need to assure themselves that education and learning providers are completing these in partnership with families and that nil returns from provision are acted upon more urgently than in the autumn term.
9. Suffolk County Council and the Clinical Commissioning Groups need to consider the findings from the support survey and how the identified needs in the findings can be met.
10. There needs to be urgent work in relation to SEND and remote learning, including addressing issues regarding lack of differentiation and issues with engaging in online learning.
11. We need to see a significant move to a You Said, We Did Culture and focus on outcomes for families, children and young people.