

Accessing mental health and social care support

ESPCF report on access to services

28 January 2024

Summary

This report highlights the difficulties that families who have children and young people with special educational needs and disabilities (SEND) often face when trying to access mental health and social care support, including overnight respite. The report looks at the Single Point of Advice (SPoA) and explains what it is and which services can only be accessed via SPoA.

ESPCF has heard from a number of parent carers who have used SPoA with varying degrees of effectiveness, as evidenced by the quotes in this report. ESPCF has also frequently heard from parent carers about the difficulty in accessing any kind of respite, whether a few hours or overnight. This is particularly challenging for families where a child or young person has complex needs and requires specialist provision.

ESPCF has met with the professionals responsible for SPoA and associated services and presented the feedback from parent carers. This report includes the information and responses ESPCF received. The report also details the concerns that ESPCF still has on behalf of SEND families and which it will continue to pursue.

ESPCF would like to thank all the parent carers who responded to requests for feedback and shared their experiences.

Key findings

Single Point of Advice (SPoA)

- The local authority SPoA webpage is **not at all helpful** for parent carers. The webpage is not in any way user-friendly and is commonly interpreted as the place to report safeguarding concerns. This is **completely off-putting for families** who can often see safeguarding as meaning a child at risk from their parents or other family members. Feedback shows that some families believe there is a risk that engaging with the service leads to 'losing control' of their family. (Pages 4 & 5)

CAMHS (Child and Adolescent Mental Health Services)

- The Sussex Partnership NHS Foundation Trust has a website for the East Sussex SPoA. However, parent carer feedback indicates that SPoA itself **does not always meet the aims set out on this website**. (Page 5)

Social care support

- The Children's Disability Service (CDS) criteria is very specific and **does not offer support to families in need** where the child or young person does not have a severe learning disability. (Page 6)
- ESPCF was told that families in need of social care support who do not meet the CDS criteria need to contact SPoA. However, for some parent carers **this has not been at all helpful**. (Page 6)

Conclusion

- Currently there is no single webpage/website that accurately explains which services can be accessed via SPoA and specifically which services can *only* be accessed via SPoA. (Page 6)
- ESPCF has **on several occasions outlined these concerns and has requested precise information** about when to use SPoA and asked that the local authority SPoA webpage is updated and made accessible. (Page 6)
- ESPCF parent carer feedback is varied on whether contacting SPoA has been useful, but even when it is, the criteria for support is high and there are gaps in services, leaving some families struggling and heading towards risk of breakdown. The information and signposting provided for those who do not meet the required criteria is not consistent and sometimes signposts families to services that have long waiting lists. (Page 7)

Respite services

- ESPCF has **repeatedly requested more information about what overnight respite support is (or should be) offered to families who do not fit the CDS criteria and has not had adequate answers**. (Page 9)
- The feedback ESPCF has received from parent carers about the difficulty accessing support and services via SPoA is quite extensive and very concerning. The long waiting lists to access CAMHS (for mental health support and for neurodevelopmental assessments) are already well documented, but the data is lacking on social care support and services in regard to unmet need. (Page 9)
- ESPCF has raised concerns that there is a lack of discussion and data on those families needing respite who do not meet the CDS criteria. ESPCF has asked that this data is captured and acknowledged. (Page 11)
- ESPCF will continue to request information, to highlight the gaps in services, and try to influence services to meet the needs left by these gaps and keep parent carers informed. (Page 11)

Single Point of Advice (SPoA)

Parent carer feedback

The feedback from parent carers who have contacted SPoA is variable. Some have found the staff helpful and knowledgeable and others seem to have had quite dreadful experiences. Below are some of the examples provided to ESPCF:

"SPoA have been very helpful. They have guided, advised and provided resources in a timely way. Sometimes these are a little low level and basic so it can feel repetitive and patronising. The assessment of need is good and compassionate. I have been supported with safeguarding which had been very helpful. Please can you develop support and resources for children about parental mental health."

"SPoA were really helpful. They got through to CAMHS for us and got them to call back straight away."

"Son aged 8, had initial assessment with Child Development Clinic now on waiting list for ADOS assessment also on 2-4 year waiting list with CAMHS for ADHD. Contacted SPOA last year when boy was 6 after he was admitted to hospital for self-harming, violent, wanting to die. He was admitted onto a ward by A and E nurse and was told he would be seen by CAMHS the next day but when CAMHS found out he was 6 years old he was not accepted by CAMHS as too young so was discharged home with very little help. I contacted SPOA who were very helpful and straight away took a lot of information and then immediately contacted CAMHS who then contacted me in 2 days and accepted my son and was put on the waiting list. I had an awful experience at the initial assessment at the CDC."

(Parent carer said) despite her difficulties, she was not classed as in need enough for their support from a self-referral, and there was nothing else offered as an alternative. She also said that she was reticent to include issues about her child being aggressive towards a sibling in case the sibling was 'taken away' from her.

"When our son was referred to CAMHS for an ADHD assessment, it was done via SPOA. They felt like a reception service and had limited information on what to expect and waiting times. The triage process was explained but it felt very robotic. They couldn't really give more than a prescribed response. I liked that they had visibility to see our son was also waiting for a paediatric assessment for ASD. However, they said "Gosh you've been

waiting a long time for that". I asked the waiting time for ADHD assessment and got the response "not as long as the wait for the ASD assessment, currently about 18 months". Not sure why they thought this was good (our current wait time is 15mths).

"We've not heard anything since that point. The last email was 12th July 2022. Not even just a note to say we are still on a list (feedback provided Sept 2023). As a parent I'm not actually sure what value they bring, how is it different to the Dr making the paediatric referral? You don't get any additional support. I'd imagine it makes it easier for services, but it's not any better or informative for the parents."

"Our child had a hospital admission in 2020 for overdose (aged 12). Discharged 3 days later with no ongoing support. SPoA probably has a separate file for all the SARS submitted over the years, but Children's Services do not have the expertise or knowledge to support families like ours. One police call out (aged 8yrs) but only because THIS is what CAMHS and Children's Services recommend – how is this beneficial to a child?"

"This has got to be 1 of the worse agencies I have ever spoken to!! My child had bleeding skin from self-harming daily, 2 escapes, suicidal thoughts, was not attending school and was under Mental Health Crisis team. He is autistic and this service was recommended. However I would never ever recommend them. I was highly disappointed with their responses and how unorganised they were. They did not listen appropriately with such serious nature incidents. You do not get the correct help and when signposted it is non-existent! I found out more from online charities and forums than I did this service. I will never ever work with this service again and I can fully understand why parents like me feel so alone!"

Information and advice

ESPCF has already fed back that the local authority SPoA webpage is **not at all helpful** for parent carers. An initial search results in a page for professionals with a redirection to a [page for the public](#). However, the redirection is to a 'report a concern' page which does not mention the services accessed via SPoA, such as the Child and Adolescent Mental Health Services (CAMHS), or the Children's Disability Service (CDS).

The webpage is not in any way user friendly and is commonly interpreted as the place to report safeguarding concerns. This is **completely off-putting for families** who can often see safeguarding

as meaning a child at risk from their parents or other family members. Feedback shows that some families believe there is a risk that engaging with the service leads to 'losing control' of their family.

[Sussex Health and Care](#) also has a SPoA webpage but this does not readily appear within a search for SPoA. This webpage describes the service as:

SPoA is a single point of contact to discuss concerns about a young person or child.

It is a multi-agency headed by Sussex Partnership NHS Foundation Trust and East Sussex County Council Children's Services staff who are experienced with children and young people, they will work together to deal with concerns.

CAMHS (Child and Adolescent Mental Health Services)

The Sussex Partnership NHS Foundation Trust has a website for the [East Sussex SPoA](#). This is a more helpful page but it is only in relation to CAMHS. Its website states:

A new referral process for 0–18-year-olds who are experiencing social, emotional, and mental health difficulties has been put in place. All referrals will be triaged at the multi-agency Single Point of Advice (SPoA) hub by staff from Sussex Partnership and East Sussex County Council Children's Services who are all experienced in mental health. The young person will then be offered the advice or support that best meets their needs.

We aim to:

- Offer advice and guidance to accessing support
- Simplify the referral route and reduce duplication of referrals
- Offer timely and easier access to the 'right service'

ESPCF parent carer feedback indicates that SPoA itself **does not always meet those aims**.

Social care support

SPoA is the first point of contact for families who need to access social care support. Some of those families would be referred to the [Children's Disability Service](#) (CDS). Its website states:

The Children's Disability Service helps children with severe learning disabilities. We assess children up to age 16, and their families, for social care support.

We'll do a family assessment if a child:

has a severe learning disability
is on [level four continuum of need](#): and
other services are not appropriate or have not been effective
We normally decide within 24 hours if we'll do an assessment.

The CDS criteria is very specific and **does not offer support to families in need** where the child or young person does not have a severe learning disability.

ESPCF was told that families in need of social care support who do not meet the CDS criteria need to contact SPoA. However, for some parent carers **this has not been at all helpful**.

Early help keywork service

ESPCF also understands that SPoA is the first point of contact for other services such as the [Early Help Keywork Service](#). Its website explains:

As part of our Early Help Service we offer a Keywork support to families. Our keyworkers work with families with many or complex needs.
This can include support around mental health, domestic abuse, substance misuse and housing.

Conclusion

Currently there is no single webpage/website that accurately explains which services can be accessed via SPoA and specifically which services can **only** be accessed via SPoA. ESPCF has on several occasions outlined these concerns and has requested precise information about when to use SPoA and asked that the local authority SPoA webpage is updated and made accessible.

ESPCF understands the following information is correct but will continue to request clarification.

The following services can *only* be accessed via SPoA:

- A referral to CAMHS
- A referral to CDS
- A request for a social care assessment
- Early help keywork service

However, for those families in need of specialised support including overnight respite, one of the following assessments will be required:

Carer's assessment: parent carers who are looking after someone who cannot manage without their help can approach Adult Social Care and ask for a carer's assessment. If the caring responsibilities are shared with another person, including a child under 18, each person can have their own carer's assessment.

A carer's assessment can be completed as a self-assessment [here](#) or via [adult social care and health services](#).

Social care needs assessment: this is an assessment of an individual's care and support needs and might be helpful for parent carers who have a disability and/or where caring responsibilities are having a serious detrimental effect on the parent carer's wellbeing.

A social care needs assessment can be completed as a self-assessment [here](#) or via [adult social care and health services](#).

ESPCF has received feedback from parent carers who have been assessed as not eligible for support as well as those who are eligible but have then discovered that the support is not available. It is evident that these assessments will not always provide the help needed, but it has been successful for some families and is therefore a potential means of accessing support.

ESPCF parent carer feedback is varied on whether contacting SPoA has been useful, but even when it is, the criteria for support is high and there are gaps in services, leaving some families struggling and heading towards risk of breakdown. The information and signposting provided for those who do not meet the required criteria is not consistent and sometimes signposts families to services that have long waiting lists.

Respite services

In September 2022 following a local authority increase in funding for short breaks provision, ESPCF held two focus groups with Andrew Stowell, Commissioning Manager at East Sussex County Council, to ask parent carers what would be needed to improve services in East Sussex. The focus groups were initially about short breaks as the Commissioning Manager does not oversee overnight respite services, but we did hear from several families in urgent need of specialist respite services, including overnight provision.

In March 2023, ESPCF met with the Head of Service for Children's Locality Social Work Services with responsibility for the Children's Disability Service (CDS). The CDS is responsible for:

children who have severe and long-term cognitive delay and severe learning disability, low functional abilities and who may also have physical disabilities.

There was acknowledgement at this meeting about the lack of overnight respite services and ESPCF was told that plans were being developed to rectify this. Since this meeting there has been an increase in available overnight provision, although there is still a waiting list. ESPCF's concern is that the waiting list is not fully inclusive.

ESPCF raised its concerns about those families where a child or young person does not have a severe learning disability but has a high level of need which often has an exhausting impact upon the family.

ESPCF was told those not eligible for CDS should contact SPoA as they would need an allocated social worker to access social care support. As this report has already noted, **this is not as straightforward as it seems or as it should be.**

“(Name) has level 4 cerebral palsy, is partially sighted, has low IQ, is incontinent and does not sleep well. ESCC say we are not entitled to any help. If we are not getting help then I wonder who is? They said it’s because he doesn’t have a ‘classified’ learning disability as his IQ is 74 and it would have to be below 70. No respite and no direct payments which would have meant some of his school 1-1’s could possibly take him out in school holidays. Nothing. We are loving parents but we are exhausted. Social services these days is all about crisis response, there are no preventive measures for families of disabled children. I already know one family whose child is now living in a residential home because the family couldn’t cope in the end without a break. How does that save money? I wish I hadn’t even asked for an assessment; the whole process left me anxious and depressed and angry.”

The difficulty for families trying to access vital support not provided by the CDS was also highlighted in a [report](#) published by ESPCF in March 2023 about the NHS commitment to provide designated keyworkers for children and young people who are autistic or have a learning disability, or both, with complex mental health needs. The report focused on feedback from parent carers with lived experiences and showed the alarming lack of support for families living with an unacceptable level of risk. None of the families we spoke to had any access to overnight respite despite the most troubling of circumstances:

“My son has additional needs and multiple vulnerabilities. Services have failed and he has come to the attention of the police and yet we have been unable to get an EHCP, a personal budget or any respite care. I have referred myself to social care, got safeguarding involved

several times as younger child is at risk. MASH calls and says I am doing everything they would tell me to do so they cannot help."

ESPCF has **repeatedly requested more information about what overnight respite support is (or should be) offered to families who do not fit the CDS criteria and has not had adequate answers.** Some families told ESPCF that even a few hours of respite would help, providing a momentary break to help relieve the exhaustion they are experiencing. Although it is broadly positive that the availability of short breaks has significantly increased, they do not provide the specialised care and support needed for children and young people with complex needs.

Parent carer feedback on respite and social care support

The feedback ESPCF has received from parent carers about the difficulty accessing support and services via SPoA is quite extensive and very concerning. The long waiting lists to access CAMHS (for mental health support and for neurodevelopmental assessments) is already well documented but the data is lacking on social care support and services in regard to unmet need.

ESPCF has received significant feedback from parent carers who have sought social care support. These are a few examples:

"Our family is in crisis but there is nowhere to go for help. We are battling for the right school. We are battling for mental health support. We are battling for an ADHD assessment in the hope that medication helps. We have no respite. I am broken by it all and I feel that the people who are meant to help us are instead crushing us even more."

"We get told our home is unsafe for our disabled child (which we already know) but no financial support to change it. This means our son requires 1 to 1 support. We get promised respite but the carers are paid so little we can't recruit one."

"This (supporting CYP with complex needs/years to get EHCP and specialist school) has near enough broken our family. His brothers haven't had the time they deserve from us, and none of us can get any respite except sibs club which is lovely but not enough. I have lost my job, given up my career, have my own mental health concerns as a result."

"We have recently for a second time asked for a full assessment by social care and they are telling us we don't qualify for any respite or direct payments as they say our son's IQ would have to be below 70 to meet their threshold, He doesn't sleep he needs turning at night, he struggles to eat and we also manage his dysfunction bladder and bowel daily. He has catheters. We are

just very tired and we see other children with less needs get support in the form of direct payments and respite yet we are being ignored. We want to be able to continue to give him excellent care but I am only one person and it affects his brother too.”

“After just having yet another family meeting and being told yet again that there is not going to be any overnight respite provision in the foreseeable future for the families who reach the high criteria for this due to East Sussex’s lack of provision, I just wanted to mention the urgent need for the local authority to provide some services of its own.”

“We are a family who is being told that we are at risk of family breakdown (due to our son’s very high care needs) without regular respite but the local authority has no real services to offer. We have had to have serious discussions about whether we can continue to provide for our son and feel that it is completely unfair that we may be forced into a decision whereby we can no longer care for him due to a lack of respite.”

“Currently the criteria are very problematic. An assessment that considers the whole family impact of needing/not having access to respite would be helpful.”

“No nights off from caring for 10yrs. Despite very complex needs of CYP, still almost impossible to get respite.”

“I have been told we are at risk of family breakdown but still the resources are not available.”

“Had respite but now closed. Young Person doesn’t sleep and needs constant support. Need time to get housework done, take a break and get energy back. Single parent with own health problems, essential to have a chance to recuperate and have enough energy to caring on caring role. Having no break makes health worse so constant vicious circle.”

“It is really hard to access an initial assessment.”

“Criteria for support is too high when YP has very complex needs and requires constant support, but not eligible.”

“There is a stigma that comes with asking for help from social services, especially when told that parenting skills would be looked at and asking why other family members can’t help.”

“Direct Payments need to be more realistic – pay allocated for PAs is demoralising. It’s a specialist caring job for vulnerable children and young people and should be more than living wage. People can earn more in a supermarket with much less responsibility.”

East Sussex Special Educational Needs and Disabilities (SEND) Strategy 2022-2025

ESPCF attends monthly meetings with the local authority, health, and social care managers to assess how the SEND [strategy](#) is being implemented. Some of the areas for improvements within the strategy were documented in the Joint Strategic Needs Assessment (JSNA) review 2021, including the following ‘challenges and opportunities’:

- Challenges across the social care system relating to the availability of respite opportunities, especially for young people with the most complex needs.
- Waiting lists, eligibility, knowing how to access services identified as barriers.
- Lack of clubs, including holiday activities resulting in negative impact on the whole family, including parents/carers and sibling carers.
- Professionals need to understand the impact of lack of resources and support. The alternative of no respite can end up being long term residential care for a young person.
- The whole family need to be considered to help them avoid exhaustion and breakdown.

This report has already referred to the shortage of overnight respite provision and ESPCF has raised concerns that there is a lack of discussion and data on those families needing respite who do not meet the CDS criteria. ESPCF has asked that this data is captured and acknowledged.

ESPCF will continue to request information, to highlight the gaps in services, and try to influence services to meet the needs left by these gaps and keep parent carers informed.