# It’s been fight, fight, fight for three years

## Mental health provision and the experiences of parents of children with SEND in York

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## Introduction

Around 18% of pupils in the UK have been identified as having special educational needs and disabilities (SEND) and in York, 14.8% of children and young people in schools receive support for additional learning needs. Supporting a child with SEND can pose additional stressors beyond those experienced when parenting neurotypical children. These additional stressors have been linked to increased mental health difficulties in some parents and carers. However, mental health support is already difficult to access and the additional resources needed to support children with SEND may make access even harder for these families. This is especially important during the current SEND crisis, which is creating intense pressure on local authority funding and on schools, often leaving parents to fight for support. This means many families reach crisis point before they can access help.

Therefore, it is important to work with parents and carers to identify gaps and strengths in the current mental health support provided in York, with an aim to develop co-produced recommendations for what may best support parents of SEND in the local region and beyond.

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# The aims of this project

We examined parents' and caregivers' awareness of mental health services in the city of York and the surrounding areas, whether they perceive that current services adequately meet their needs, and how service provision could be improved. Specifically, we aimed to address the following research questions:

1. How do parents/caregivers of children with SEND living in and around York perceive their own mental health support needs?
2. What experiences of mental health support services in and around York do parents/caregivers of children with SEND report?
3. What, if any, are the needs/barriers to support faced by local parents of children with SEND in relation to mental health and well-being?

# What did we do?

We spoke to parents' and caregivers' about the current mental health provision in and around York and what they think could be done better. We did this using an anonymous online questionnaire and through interviews.

# Who did we speak to?

**Questionnaires**

- 66 parents/carers responded to our questionnaire: 7 (10.6%) reported that they identified as men, and 59 (89.4%) identified as women. The average age was 42.5 years.
- 68% of families had one child with a SEND diagnosis, and 28% had two children or more with a SEND diagnosis. Additionally 14 parents (21%) said they had another child at home awaiting a diagnosis, and four parents (6%) had two or more additional children awaiting a diagnosis.
- Eight parents confirmed they were neurodivergent themselves, 10 parents reported that they suspected themselves to be neurodivergent.
- Children were aged between 0-24 years; mean 11.3 years. Average age of receiving diagnosis was 7.2 years.
    - A breakdown of child diagnoses can be found in Figure 1.
- 44% of children had co-occurring diagnoses.

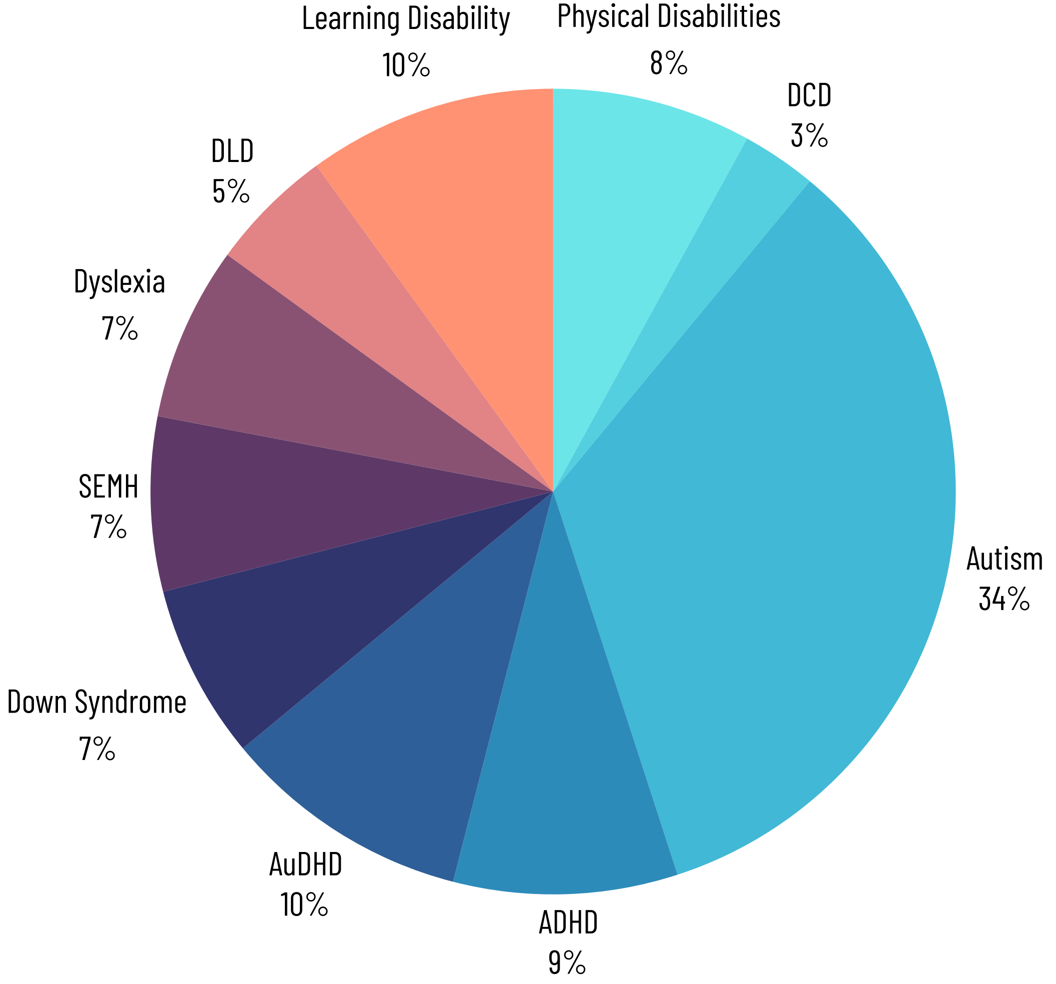
**Interviews**

- 12 parents who had taken part in the questionnaires previously: 8 (67%) identified as female. The average age was 49 years.

*Note: For readability, the term 'parents' is used to encompass all caregivers throughout this report*

# Breakdown of child diagnoses reported in survey data:

*Figure 1. Breakdown of diagnoses*



# What are the challenges faced by parents of SEND?

### ***The constant need to fight:***

Parents told us that their own mental health challenges were often a result of dealing with the extra demand on their resources: *"Everything to do with my mental health is not related to what's happening to me, it's what is happening to him."* One major stressor for parents was the constant need to fight for support, and the feeling of their child(ren) being burdens on the systems that were supposed to help them:

> *"Knowing that we are our child's only true advocate so he is treated fairly and his needs are met [is a challenge]. He is seen as a burden for the services that are in place to support him. We constantly feel let down and that* ***we have to work so hard to get what he needs to thrive in life****."*
>
> *"It is stressful, heart breaking and* ***so hard to fight to be understood and get support*** *for my child."*

## *A lack of appropriate provision:*

Many struggled with understanding their own children's needs, something which was exacerbated by a **lack of appropriate provision for children**. Families reported spending a huge amount of time, energy, and money chasing services which impacted their lives in significant ways. **50% of parents interviewed** had changed to part-time work or working from home/self-employment in order to have the flexibility to manage all the appointments and unexpected events that cropped up with their child(ren)'s needs:

> *"You can't look after him and also try and handhold all the services that are really meant to help you. You know, it's just not doable."*

A lack of suitable school provision played a large role in parents' distress. Those who had managed to find suitable alternative schooling provisions reported that their well-being as individuals and as a family improved dramatically after achieving the proper provision. However, access to provision was not always easy, and many parents reported having to fight to get their child into a suitable school, resulting in physical and mental health challenges in both children and parents:

> *"**We have battled for his EHCP** and now he has a place at a specialist school. Him going to mainstream caused physical and mental issues for him. He had seizures and couldn't cope. The care and right support wasn't there. I fought through the period to get him what he needed. But now he has his placement **I am dealing with the mental trauma of what happened.** PTSD symptoms from the stress and am in burnout."*

For those families who did not have an alternative provision in place, the emphasis from schools to make sure children attended their current placement had negative consequences on parents' mental and physical wellbeing:

> *"The school, the emphasis, "You need to get her into school." [...] So if I did get her into school, which was traumatic, she would erupt when she got home. And it gets to the point that I was being beaten up by my own daughter three or four times a week, and **it was like an abusive relationship that I couldn't leave.**"*

## Constantly on alert!:

Families spoke of the need for respite and their constant state of alertness to make sure their child was safe and that the rest of their family were looked after. Many felt like they had competing responsibilities, including making sure other children in the household were cared for was a cause of stress and worry:

> *"For me personally it's trying to split my time fairly between my other 5 children. My SEND child consumes a lot of my time and attention."*

This was especially the case for households with more than one child with SEND who found being on alert impacted their ability to care for themselves, impacting their well-being:

> *"So often things need immediate response, but I have this from both kids so* ***I am pulled both ways****, and then being told I need to take time for myself!* ***There's no time, no space.****"*

This need for constantly being 'on' had resulted in **many reducing their working hours or leaving their jobs completely**. This had a negative impact on parental mental wellbeing by placing additional financial stressors on families: *"I've had to give up my job due to insufficient wrap around care and my son's high needs. So I'm now only working 4 hours a week."*.

All of these points had led to many families calling for the need for respite, which was seen to be lacking:

> *"No respite. I'm 'on' all the time"*
>
> *"You* ***NEVER*** *get a break"*
>
> *"No free time. But also not being able to trust anyone to care adequately for my kids so I could have free time"*

## *Stigma in society and the social isolation that accompanies it:*

Parents reported breakdown in family and friend support after finding out their child needed additional support, and this had left many feeling isolated.

Parents expressed that caring for their children often resulted in social isolation from not only their friends, but their partners:

> *"My support network is tiny and I do most things myself even though I'm married."*

In some cases, this had led to estrangement with partners: *"We never really talked, you know, because by the time we sat down, we were just like zombies. You're just like, 'That was another fight.'"*

The additional challenges with taking their children out to socialise were also seen to impact parents negatively. Not only because they had had to change the things that they may have done before, but because others did not understand why these things were a challenge:

> *"It sounds really dramatic, but I suppose I've lost part of my personality. We can't go to the restaurants I want, because [son] won't eat that food. We can't go on the holidays that I would prefer or my husband would prefer, because [son] won't tolerate those type of holidays. We can't do the day trips that we really fancy because he won't tolerate the car journey or the type of activity when you get there, whereas friends of ours go, "Well, they just have to do it, won't they?" And it's, like, "No, because he has a meltdown and it's horrible and then we have to come home,* ***so no, actually, that's not how it works****."*

This feeling of their child's needs, and their needs as a family, not being understood by others, and the stigma attached to this, resonated throughout both the interview and questionnaire responses:

> *"When you have a child with a disability, you're just thrown into this whole other world where the people around you generally won't understand, won't be able to support you, don't really know what systems or help is available, so* ***it kind of feels like a really lonely place****."*
>
> *"Worrying about the outbursts when I take them out in public. It's very stressful. Worries about other people judging me for my son's behaviour."*

All of this fed into the worry parents had for their children, their children's futures, and their own emotional well-being: *"I think it's extremely consuming, you know, and we continually worry about him and his future and his wellbeing."*

## Who is accessing support?

Parents were asked about their experiences of accessing mental health support for themselves, and their awareness of services in the local area (see Figure 2). **Over 70%** of those who responded were accessing, or had accessed mental health support in the past, with a further 35% being interested in accessing support but not knowing what was available for them.

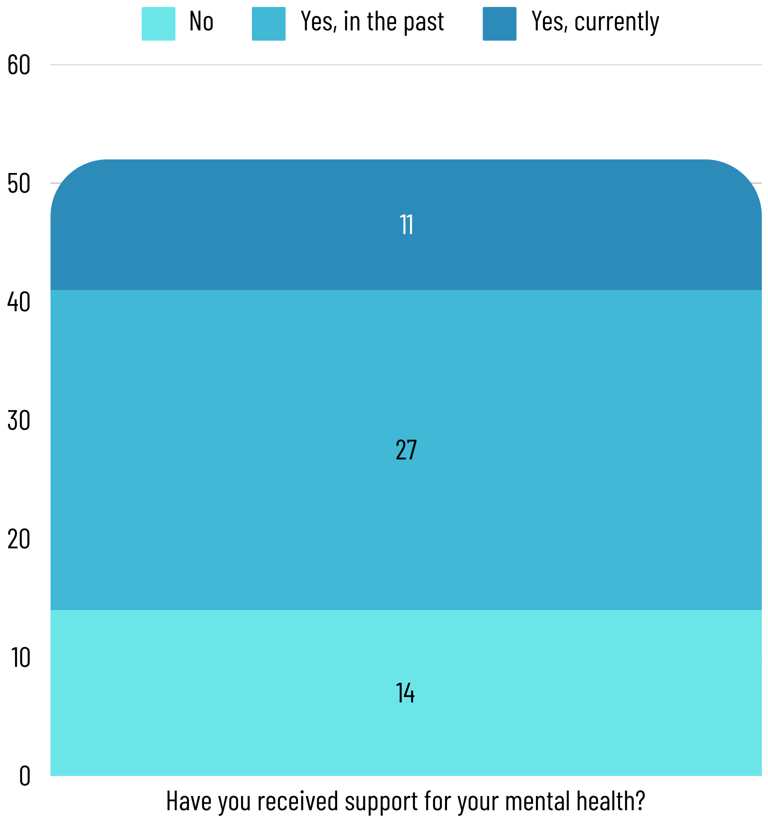


*Figure 2. Breakdown of parents accessing mental health provision in York*

# What’s working and what’s not?

We asked which **types** of services families felt were most and least useful to them. The majority of parents believed that **support groups**, such as parent-run WhatsApp groups, York Inspirational Kids, and drop-in sessions, were **most beneficial** to them. This was alongside more formal forms of support, such as **EIP and alternative school provisions. Portage** was also positively described by parents.

Families had **mixed experiences** of **CBT and NHS counselling** services. This was echoed by mixed feelings over private/workplace counselling and interactions with social services. **Of those receiving counselling, many were paying for the service themselves** due to long waiting lists for NHS services.

The majority of parents reported **GP services, York SEND Local Offer, CAMHS and crisis support services** to be some of the **least helpful** avenues of support. Many parents had had negative experiences with the services and felt that lack of communication between services had led to a breakdown in support. Some parents felt that group therapy via the NHS was also unhelpful, and some parents had difficulty access telephone or talking therapy.

**No participants reported that they felt mental health services were sufficient to meet their needs as parents of children with SEND.**

For the majority of parents, the focus of the support offered to them was too general, and/or the people delivering the support did not have sufficient understanding of what it was like to have a child with SEND to make the support useful. Although counselling services were often reported to be somewhat helpful, mixed experiences were linked to the generalised strategies counsellors and therapists suggested:

> *“You can't just go like “Well, I'll just go out for a walk.” That'll be some me time. **I'll set some time aside for self-care just as soon as the person that's completely dependent on me magically stops being dependent on me.**”*

For some, this had led to seeking out private counselling, paid for out of pocket:

> *“You get very general counselling or mental health-type support, it tends to be for things like depression and anxiety […] there’s lots of other factors that **we need someone who’s more specialist, so we just paid for it**. Which I hate doing, because I have a sense that it undermines the NHS, but I need to also make sure my family is fine.”*

Parents highlighted that support should be led by neurodiversity-affirming and SEND trained practitioners who are sensitive to the complexities of SEND families. This not only included the types of support being provided, but also understanding that the logistics of attending in person appointments might be a barrier to many households: *“Services that understand needs of carers especially around challenges with when they can get to appointments, that **caring responsibility might mean late cancellation** - not just 3 strikes and you’re out.”*

# What’s working and what’s not? (cont.)

Support services accessed through the GP were characterised as unhelpful, lacking in understanding of their unique challenges, and subject to prohibitively long waiting lists. For example, one parent reported walking out of a meeting with a GP who commented *“You’re a parent, what do you expect?”* when she described her challenges.

This lack of understanding was also seen in schools, with many expressing that it lead to increased stress on their own well-being:

> *“They’re [the SENCO] not experienced with children with disabilities, they don’t have their own children with disabilities, many of them, so they can’t empathise, they don’t understand the situation. One SENCO, my friend at a local school, [the SENCO] even said to her, “Well, if you looked at him within the classroom, you wouldn’t see that he was disabled, would you? So, he’s not likely to get an EHCP,” and my head just exploded.”*

Respondents reported that **fixing support systems for their children and increasing understanding of their needs would reduce the need for mental health support for themselves.**

It was clear that, for parents of SEND children, access to mental health support needs to be flexible and timely. The longer parents/families go without support, the worse problems become. Parents **struggled with basic accessibility of services, long waiting lists and convoluted systems**. There was a call for early intervention, with many parents only being able to access support once they were at crisis point: *“I want opportunity to get professional support quickly and before I’m completely in crisis.”* They also expressed a need for crisis support to be available more easily: *“Reduction in waiting times for diagnosis. Quick support offered to parents in crisis, **get the waiting lists down**.”*

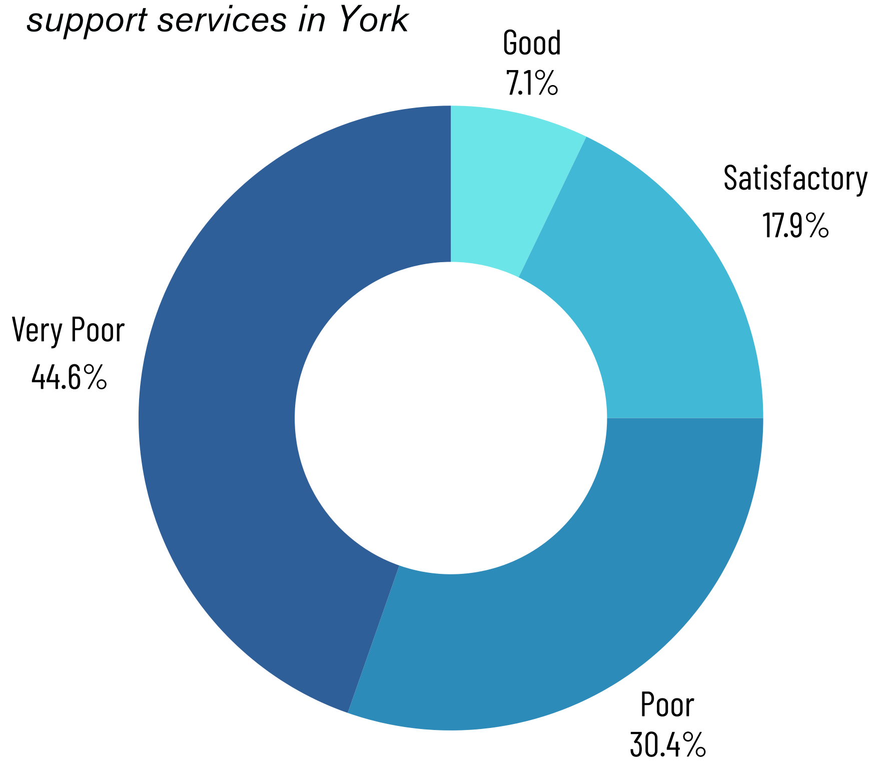
Others suggested that support pre- and during-diagnosis would have been helpful in supporting their well-being:

> *“Parents should be made aware of mental health services during the diagnosis process too. It affects you mentally and financially, for me it was hard to continue working full time due to appointments, parent courses, constantly picking my son up from nursery early and I just couldn’t focus on my work as I spent most days crying and worrying about the unknown and whatever spare time I had I would spend researching ways to help him.”*

Many parents reported that attempting to access the services that should help them, actually made their well-being worse: *“It’s a double bind really because the services aren’t adequate. **You have to push to get the right services but you’re being crushed at the same time by having to deal with it.”***

# What's working and what's not? (cont.)

*Figure 3. Breakdown of satisfaction with current support services in York*

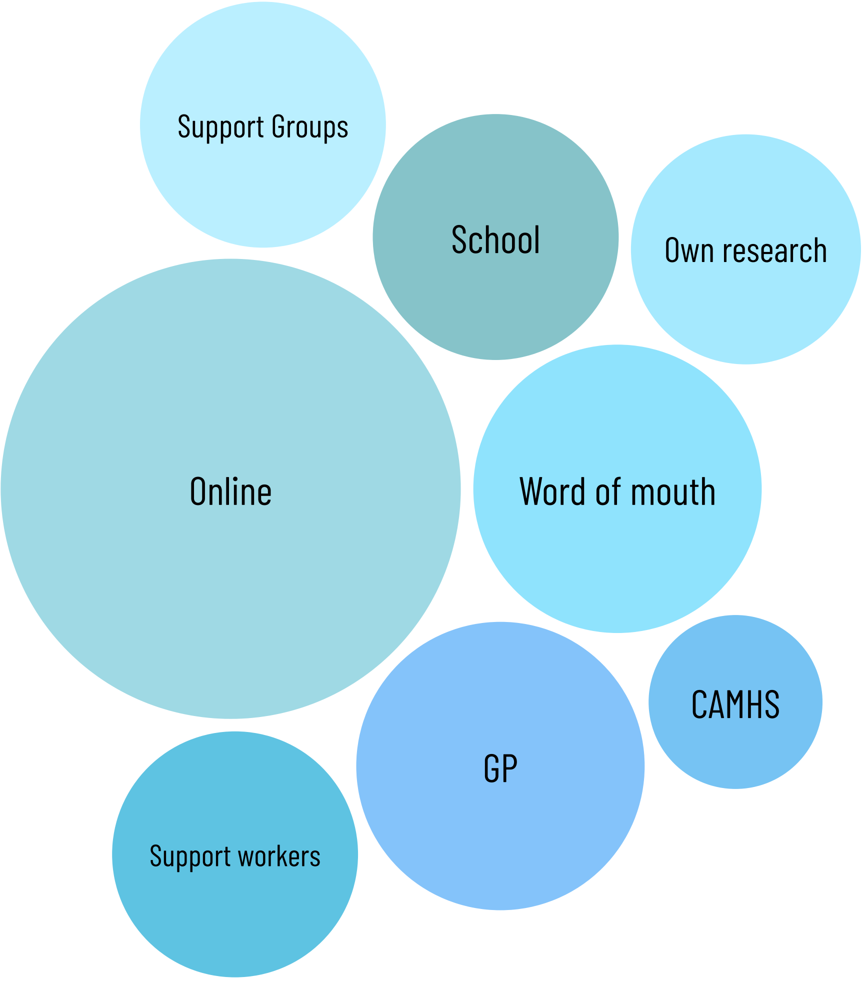


*Note: a fifth response category of "Very Good/Excellent" was available, but no participants selected this response*

Parents were asked if they thought there was sufficient mental health support available specifically for parents of children with SEND in York. **68% of respondents said no**, 25% were unsure and only 8% believed services could support their needs.

When asked what their current impression of the availability of support services was, **75% responded 'Poor' or 'Very poor'**. See *Figure 3* (left) for a breakdown of satisfaction rates.

We also asked **how and where** support was being accessed. The majority of parents found support **online**, including social media sites. Families also relied on **word of mouth** from friends and other parents or from signposting via their GP. It was clear across responses that if parents wanted support, they had to initiate this - parents sought out support from these resources as opposed to being offered them.



# What do parents want?

Parents want their children to be supported and for them to be supported well. It was clear throughout that reducing the stress placed on parents to fight for their children's access to appropriate education and specialist support was the main factor negatively impacting on their mental health. Fixing the state of SEND provision would in turn support the good well-being of parents.

> **"I don't want a different person every week, I don't want an agency, but someone who can become, like, I'd say a professional friend, a professional babysitter. They don't have to be mental-health psychiatrist level, they don't have to be, you know, they just have to understand, 'The reason I'm doing this is so these parents can have a break'"**

Parents wanted opportunities to meet other parents with lived experiences and to socialise in spaces that felt safe and accepting of their challenges and of their children. Some suggested that doing this along with professional support, for example a practitioner-led drop in session where they can receive support and ask questions. Parents are tired of having to find out all the information on their own and often at their own financial expense. These spaces would need to be inclusive of all needs, including children (and parents) with physical disabilities as it was noted that current social and support groups were more catered towards physically abled children with intellectual or behavioural disabilities.

> **"I just want support for [daughter], focus on that, because then that will offer me support by her getting that."**

Parents expressed that lack of time available for 'self-care' was a contributing factor to their mental health challenges and this was made worse by not feeling they could trust existing services. Parents called for practical support in the form of reliable respite and trustworthy childcare. Services need to be consistent and tailored for their children's preferences and they must take the family unit into consideration, not just the child or the parent in isolation.

> **"I think you need to have a lived experience and understanding because then I think you can have empathy, as opposed to judgement. And if you go at it with a 'I know how hard it is' and I understand that, that's a completely different footing from somebody who comes in without that and it does feel judgemental."**

# What do we recommend?

## 1

## Get services for SEND children right!

The mental health of parents is highly dependent upon the circumstances of their child and whether their needs are being met. This includes improving training for practitioners in existing services, including SENCO roles and mental health practitioners. **Get the services to support children right, and the rest will follow.**

> *“If my daughter’s happier and goes to school, I will be happy.”*

## 2

## Families are struggling with challenging and complex circumstances

Having access to “off the shelf” support isn’t enough. Parents are often managing complex needs of their children, with many having children with co-occurring SEND conditions, or more than one child with complex needs. Many parents have pre-existing depression; suspected or diagnosed SEND needs themselves; many are single-parent families or have relationships under strain due to the demands of raising SEND children. Half of interview respondents reported physical and mental abuse at the hands of their children and said that **they are afraid to reach out for support** for fear of being branded a bad parent or having their children taken away. Services which are **tailored, flexible, and understanding** to the complexities of supporting a child with SEND are crucial and must be led by kind and compassionate individuals. They must consider the whole family unit.

# What do we recommend?

3

## Make existing resources more accessible and robust

Parents are overwhelmed with options and possible resources including the SEND local offer website which was described as very difficult to access. Parents expressed a desire for a **reliable point of contact or a comprehensive and up to date directory** which can signpost to resources that meet their needs. They desired more proactive support to reduce the risk of reaching crisis point.

> *“I think sometimes the council can get inside their own little bubble of ‘Oh well, we have loads of things. It's all there.’ But actually they need to look from an outsider’s point of view looking into their bubble, going ‘Actually, is any of that easy to navigate? Is any of that easy to find out and is user friendly?’”*

## New services geared towards the well-being of parents should include parallel provision for children

4

Parents often lack opportunities for socialisation and struggle to access existing mental health provision due to childcare responsibilities, **new well-being services should combine opportunities for social contact/well-being support for parents with parallel activities for children.** Something like a play café would fit well with what parents report that they would find useful. Services which allow online or flexible ways of attending appointments would also support access to services for many families.

> *“What would be lovely was I can now get some support but there’s also a parallel children’s session where there’s someone running children’s activities at the same time.”*

# Contact us:

For further information, please reach out to us at **laura.fox@york.ac.uk.**

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