



healthwatch
Stoke-on-Trent



“While We Were Waiting”

A Story of Special Educational Needs in Stoke-on-Trent

August 2017

The Healthwatch Stoke-on-Trent Mental Health Sub-Group and
Partners.

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(<https://creativecommons.org/>) -



Stoke on Trent's Parent Carer Forum - we work in partnership with all services to better shape the service for children and young people with disabilities and/or additional needs 0-25years



Healthwatch Stoke is a local consumer champion, empowered with statutory powers to strengthen the voices of health and social care services.

It's website can be found at: www.healthwatchstoke.co.uk

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Introduction

Through the latter part of 2016 and early 2017, Healthwatch Stoke-on-Trent devised a project called 'While We Were Waiting'. This project aimed to better understand the experiences of people and their families whilst waiting for Child and Adolescent Mental Health Services (CAMHS).

The methodology for this project was informed by the voices and opinions gathered as the programme moved forward. The most common of these themes was SEN (Special Educational Needs).

This report presents themes derived from conversations with various participants including educational staff and parents. These themes are then analysed to present findings and recommendations.

This report finds that there is a focus upon diagnosis in SEN. However, this may also be perceived as meeting thresholds for support. Staff describe how this can mean a loss of focus upon the actual needs of the child. Indeed, parents describe little support whilst waiting for a diagnosis, much to the frustration of some education staff spoken to.

Participants describe how agencies could work together better. Education staff describe how there is potential for greater information sharing between agencies. Without this sharing, opportunities are lost, such as the ability to coordinate interventions. Parents may also become disillusioned when things aren't joined up.

Relationships between schools and parents also feature in this report. Questions are asked about changes to the school nurse service and how this might impact. Both parents and staff describe a need for consistent relationships and a familiar face.

The report makes recommendations that may address many of the themes raised by participants. It is hoped that this paper encourages the open conversations needed between providers, staff and service users.

Healthwatch Stoke-on-Trent would like to thank its partner organisation, Stoke Parent Carer Forum and all participants for assisting in this work.

What We Did

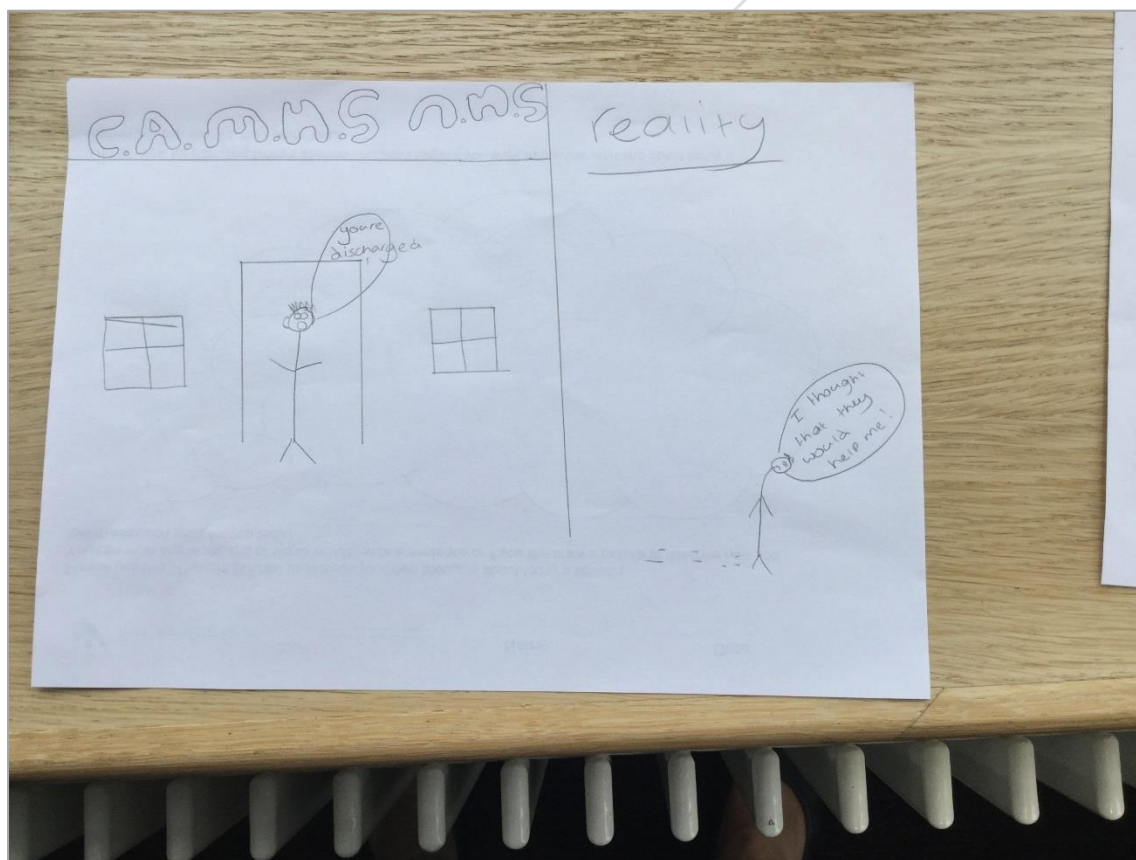
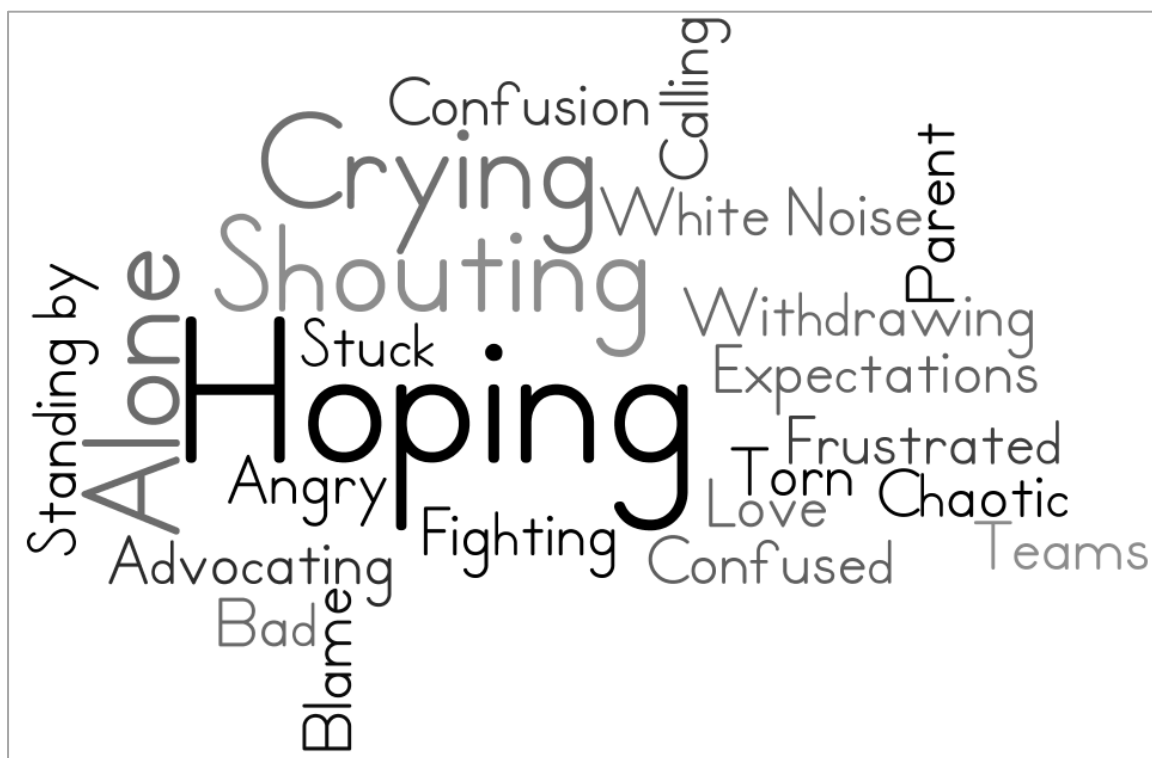
Healthwatch Stoke-on-Trent exists to make health and social care services better for ordinary people. It believes that the best way to do this is by designing local services around their needs and experiences. Healthwatch also believes that the design of those services should put the service user at the centre of the process.

To raise awareness of the project a web page was built along with a social media stream, a family event was held at the Mitchell Arts centre, leaflets and posters were distributed across the city and the project was advertised in various newsletters and on the Stoke-on-Trent school intranet.

The data received was from the following sources:

Focus Group	CAMHS Staff (4), Education Staff (16) (20 attendees total)	Jan 2017
Semi-structured interviews	Parents of children (4) who are service users.	July 2016
Semi-structured interview	Professional working in the field (1)	Jan 2017
Cultural Animation	Session with Borderlines theatre group using Cultural Animation to explore experiences of waiting (13 attendees including 6 parents of service users)	June 2016
Web Page	A web page that received 8 responses to an online call for comments	Winter 2016

Emotions (from Borderlines Cultural Animation workshop) Larger text indicates higher frequency.



Drawing created by participant in the Borderlines Cultural Animation workshop (June 2016)

Story Sharing - Family Event

This event offered up a variety of activities for attendees, from Minecraft for children to a series of 20 minute presentations from a variety of providers such as Changes YP and NYAS.

Representatives also attended from North Staffs Combined NHS Trust who presented the work that had recently been done to listen to patients (<http://www.slideshare.net/healthwatchstoke/north-staffs-combined-nhs-trust-camhs-presentation>).

The event culminated in a workshop where service users expressed their experiences of waiting through performance (below);



Video from Family Day (https://www.youtube.com/watch?v=j_FSrmR9jgY)

Key Findings

Amongst the key findings, Healthwatch found that:

- In some SEN, a focus upon diagnosis may detract from understanding and delivering for the needs of the child (p19 and throughout);
- Participants describe communication between education and health services as inconsistent (p12 onwards);
- There is great potential to build cooperation between services (p14 and others);
- Consistency provided by services such as school nurses aid the maintenance of relationships (p22);
- Some education staff describe a lack of confidence in dealing with mental health and wellbeing issues. They would appreciate more access to specialist advice (p24);
- Parents may have pre-existing unidentified needs such as SEN, mental health or emotional that may contribute to prevalence or outcomes. This is sometimes identified through relationships with schools (p21);
- The effects of stigmatisation cannot be underestimated in this group. Parents describe being affected by stereotyped ideas (p17);
- More can be done to improve signposting services (p24 onwards);
- There remain questions around the support available to parents and who should deliver it (p23 and throughout).

Recommendations

- Although the data gathered is useful, there are still data gaps. Further engagement is advised, perhaps through Educational Psychology or early help champions to further understand expectations of the service.
- Stigma & Effects:
 - There is some good practice in Wellbeing and Mental Health support for parents in schools. This should be shared;
 - There is some good practice in building relationships between schools and families. This should also be shared;
 - There should be more promotion of routes into tier two services for staff and parents.
- SENCO's suggested having specialist support from CAMHS for mental health issues (in addition to the NSCHCT referral advice line). Healthwatch feels that this area should be further considered to what benefits may accrue.
- Work in partnership with parents and families, moving away from a tiered system that encourages parents to evidence need:
 - Align with the proactive 'staying well' sentiments of Together We're Better and the Sustainable Transformation Plans¹;
 - Explore collaborative approaches to working.

¹ <http://www.twbstaffsandstoke.org.uk>

- In order to help facilitate a more coordinated service:
 - all staff to be supported in terms of the data protection act;
 - simple consent boxes on CAMHS forms so that SENCO workers can be informed when an assessment has taken place;
 - SENCO's copied into letters from other agencies where relevant;
 - SENCO's to be informed regarding outcomes of assessments?
 - SENCO's to be made aware of any strategies that are in place for the child;
 - an effort should be undertaken to understand the linkages between Education and Health in light of recent changes to the School Nurse service.

- More work to be done around the preventative agenda in schools, such as emotional literacy:
 - further promotion of services that already exist;

- The Local Offer:
 - parents could be systematically made aware of what they can expect in terms of service;
 - further promotion of the Local Offer;
 - Online resources about mental health, coping mechanisms and others to be made available so that SENCO's and the public can easily access them via the website.

- **Ensure consistent channel of communication between parents and staff for the long term.**
- **Build community capacity to empower parents to engage with schools.**

Themes -

What follows is the stories and comments gathered as part of this project broken down by theme and presented as a narrative. The content should not be taken as statement of fact but collection of opinions.

Communication

Confidentiality

Education staff reported how sometimes information about the status of a child is not reported to the school, for example, when an assessment has taken place. Indeed, a school may not know that a child is already receiving support from CAMHS. An education worker described this as being 'kept in the dark'. Sometimes they only discover information such as this at parents evening for example. This may not happen at all if the parent does not engage well with the school.

'It seems an awful long time since the referral so we will check up with CAMHS to see where it is and we are told that they (CAMHS) can't tell us because of confidentiality' We don't know if they've missed an appointment, are they on the list etc.' - Education Staff

Parents expressed feelings of feeling disempowered and stuck (video) -

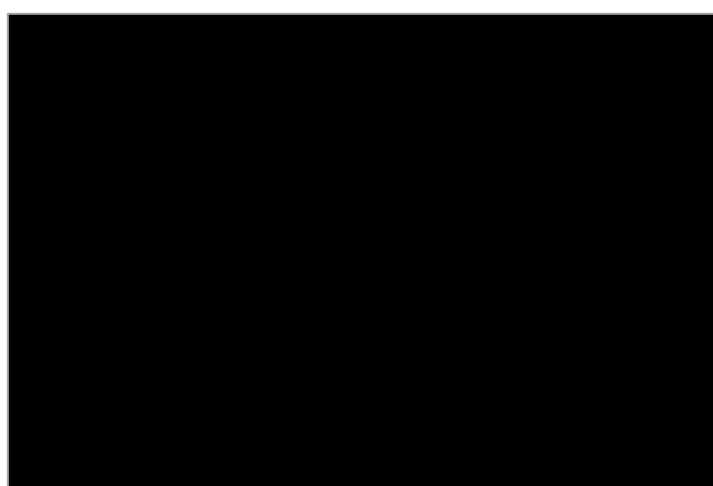


Figure 1 - Parents describe what it's like to be waiting for services, expressing feelings of being tied and stuck, waiting for somebody but not sure who. Feeling 'all at sea'. Unsure when things will happen. - <https://youtu.be/bCl-lqZK0ms>

Contributors reported that sometimes parents will ask the SENCO to contact CAMHS on their behalf but due to confidentiality the information cannot be discussed. Even after making the referral to CAMHS and sending in support information, SENCO's may not be informed regarding outcomes. It was described how service users may not necessarily perceive borders between services.

“There may also be a presumption from the parent that as we make the referral we may get automatically copied in. They may not necessarily realise there is a confidentiality issue”- Education Staff

One SENCO described taking matters into their own hands and that when the process first starts with the parent they get written consent to discuss their case with CAMHS.

There is sometimes difficulty in gaining consent. One contributor described how currently it is difficult to progress regards communication without buy-in from the parent.

‘So much talk about working together in partnerships with other agencies but we keep on coming up against glass walls’ and if you haven’t got the parent on board how do you get round that?’- Education Staff

SEND CODE OF PRACTICE 9.32

“Information sharing is vital to support an effective assessment and planning process which fully identifies needs and outcomes and the education, health and care provision needed by the child or young person.

Local authorities with their partners should establish local protocols for the effective sharing of information which addresses confidentiality, consent and security of information (see the References section under Chapter 9 for a link to the DfE advice ‘Information sharing for practitioners and managers’).

Agencies should work together to agree local protocols for information collection and management so as to inform planning of provision for children and young people with SEN or disabilities at both individual and strategic levels.”

Working Together

There is scope for agencies to work together more closely. Participants describe how things can work as well as how improvements could be made.

Contributors reported that they felt there are not enough opportunities for education to discuss individual cases with health. A SENCO described an example of this as needing a contribution towards an Education Health and Care (EHC) Plan. Without the needed information, the SENCO may have the expertise to set out the advice but feels this is a missing, crucial contribution.

Staff describe how poor communication can impact upon uniform delivery of advice.

“We all want the same goals. If there was any way that we could talk to CAMHS - and they could talk to us this would be so beneficial to the parents.....we have parents who are getting so frustrated saying ‘CAMHS have said this’ and I don’t know if what the parent is saying is accurate”- Education Staff

“Can you include us in the process when you are working with the family so it’s all joined up working together. We have a system with speech therapy - they will send to us a copy of the same strategies that have been given to the parent to use at home - singing from the same hymn sheet” - Education Staff

There appears to be a willingness to work in partnership. An education worker described how, before Christmas (2016), they had received a detailed progress letter from CAMHS describing where a child was and what was in place. As well as imparting empowering information, staff described feeling valued as part of that collective contribution.

“This type of response from CAMHS. This had never been seen before but it was really valued by our SENCO team.”- Education Staff

SEND CODE OF PRACTICE 9.33

As far as possible, there should be a ‘tell us once’ approach to sharing information during the assessment and planning process so that families and young people do not have to repeat the same information to different agencies, or different practitioners and services within each agency.

The cohort described further how things can work;

“It felt good to talk to the hub (CAMHS HUB²) this morning - to discuss a particular case - and talk about our concerns and safeguarding issues and feel vindicated that they had similar concerns and recognising our value as a school. The frustration for me was that I wasn't included in the what happens next stage.”- Education Staff

A teaching professional from one of the attending schools discussed a situation that had arisen that very morning. It was described how, after a lengthy conversation with CAMHS on the telephone discussing the concerns the school had about an individual, the person was then informed that it would go to a panel. He asked when he would be made aware of the decision and he was told he wouldn't as it was confidential - the contributor described this as very frustrating:

“The parent would expect a response from me as I did the referral and they would not be happy with ‘I don't know’.”- Education Staff

Parents may also become frustrated:

“I needed to know what was going on with my child, I was confused. I had everyone giving me lots of different opinions.” - Parent

This may indirectly lead to further pressure on services:

“The parent will ask ‘What's happening?’ and feel the school isn't dealing with it effectively. The parent will then go back to the G.P for another referral to CAMHS. It's very frustrating. At times we will sit round the table with other professionals and try to figure out some other support signposting”- Education Staff

A SENCO informed the group that the speech and language therapist now informs them what has occurred at the meeting and what strategies have been put in place. She felt this was useful and could this be repeated with CAMHS. Cooperation can work.

‘I have a parent who is coming up with something new every week - I heard via the paediatrician that the parent had been offered parental support but wasn't happy about this. At least I was kept in the loop about what was happening’- Education Staff

² See here - <https://www.camhs-stoke.org.uk/>

Diagnosis.

Labels

Much is said in literature about stigmatisation, it is seen to go hand in hand with labelling. Labelling an individual can be seen as a negative thing, impacting upon self-esteem which may limit the extent to which an individual is enabled to fully participate in society³. Indeed, this was recognised as an issue within special education back in the 1980's.⁴

In the context of SEN, labels are sought or avoided. Some will seek a diagnosis whilst others are harder to reach as they would rather not be labelled. The British Institute of Learning Disabilities (BILD) describes its understanding of this:

“ . . . when we talk about people with learning difficulties, we mean ‘people labelled as having a learning difficulty’. This is one of the labels that society puts on us to mark us out as not being able to understand things the same as other people... We believe that people labelled as having a learning difficulty are disabled by society” - BILD⁵

Education staff had various perspectives on the drivers for diagnosis seeking and how best to support parents. Indeed, they mention how stigmatisation can be understood as a driver too:

“Some parents need a label - just to makes sense of things, (they) don't want to be seen or feel like crap parents”- Education Staff

³ See here for example

<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.336.9967&rep=rep1&type=pdf>

⁴ Tomlinson S, 1982, A Sociology of Special Education, Routledge

⁵ <http://www.bild.org.uk/EasySiteWeb/GatewayLink.aspx?allId=3961>

STIGMA

Mueller et al describe how “Mothers appeared to be particularly vulnerable to self-stigma. Statements by other parents, friends, as well as family members led many mothers to engage in internalising feelings of shame and accusation.”

Also, “the criticism by others has been found to have negative consequences on the mother’s wellbeing as reflected by moderate to large significant correlations between criticism of parenting style on both depression and perceived social support”

Mueller et al, 2012,
Stigma in ADHD,

In an environment when one feels the need to negotiate between being labelled a bad parent and not receiving support, or having a label but receiving support, one is forced to make choices.

"I needed to know what was going on with my child, I was confused. I had everyone giving me lots of different opinions, (ranging from) he needs disciplining, he just needs a good smack to maybe he is autistic . . . different opinions. I just started blaming myself as a parent" -

Parent

"I asked a parent once what do you think you would get if the child had a label? 'The parent said to me 'it will make it not my fault'- The child's father was derogatory to the mother." - Education Staff

Another suggested a similar view:

'I had a parent who had one not out of the ordinary child and then her second son had issues for her. It was about him not being labelled in high school as a naughty boy' I just want an answer. An answer that will support that he

isn't a naughty boy' - Education Staff

One parent had experienced this:

"you could just tell something wasn't right and I'd go into school and I'd say, this isn't right, please help me? They'd say, but she's doing it here, she's doing this . . . are you sure it's not you, are you not tough enough with her, is it because you're a single mum? . . . I got called an overreactive negative mum which didn't help . . ." - Parent

"I think giving other people, like parents that don't have children with especially ADHD and autism . . . you get a lot of "that wouldn't of happened in my day" and educating the parents of children who haven't got additional needs would help because I think they would have an insight of what it's like." - Parent

This sort of interaction could risk stigmatising and result in further difficulty with relationship building. Other school staff also recognise that sometimes it can be difficult to get schools and parents engaged.

SINGLE PARENTS STATISTICS

Research on single mothers shows that family structure in itself has little effect on children's cognitive and emotional outcomes once other factors such as parental education are taken into account.

Children in single parent families are twice at risk of living in relative poverty than those in couple families.

Source - Gingerbread

<https://gingerbread.org.uk/content/365/Statistics>

“Some parents find the word CAMHS a barrier for example ‘what are you trying to say about my child’s mental health. They see it as a reflection of their parenting skills.” - Education Staff

“Some parents won’t ask for help”- Education Staff

One wonders then how conflicting opinions upon the drivers for label seeking behaviour might further drive ‘hard to reach’ parents away.

This lack of understanding was contextualised by a third sector professional who explains how staff may not see the full picture;

“There are some very good schools that meet that needs of every young person very well. Children can behave differently in different places so, at home it can be challenging. Practitioners don’t often see the whole picture “burn out’s” are often in the evenings and at home because the child has conformed all day to that very structured environment of school. It isn’t always a parenting issue, it’s just that when they are at home they can be themselves and display the behaviours that have built up all day. Parents need support/techniques to deal with these behaviours and anxieties consistently. - 3rd Sector Professional.



Borderlines Workshop - Emotions Once the Wait is Over. Larger text indicates higher frequency.

Need or Label?

Some education staff suspect that a focus upon diagnosis could result in missing opportunities to address need.

“For some parents, they don’t even think about them (child) achieving and how they can be helped to achieve, it’s just about getting the label” - Education Staff

‘I find it really sad that some parents think they really need to get a diagnosis before they get the right support in school. It’s our duty in school to give that child the support it needs to achieve regardless of if they have a label or not’ - Education Staff

A group participant noted that perhaps there is some confusion about what help is available in any case;

“There’s a big myth that with that label this will happen and that’s going to happen. I don’t know if CAMHS can myth bust?!” - Education Staff

One staff member suggests that parents may be so desperate for a label that they identify behaviours that aren’t there,

‘It’s frustrating for me when a parent is seeing things that aren’t actually happening’ - Education Staff

This focus upon attaining a diagnosis or label could be an impediment to receiving help;

‘There is big expectation from the parent and they wait for that referral and nothing is done in the interim. Other things can be done before the referral’- Education Staff

“Sometimes the referral is a ‘get out’ clause an easy option - someone has suggested contacting CAHMS after one bad day at school. Sometimes there are other options it doesn’t have to be a referral into CAMHS there are often other options before CAMHS. CAMHS can’t always be the magic wand.”- Education Staff

Social & Environmental Factors

It is worth considering the social factors that may impact upon diagnosis seeking over need. There are reasons why SEN may lead to the higher rates of child poverty. It may not be that SEN causes child poverty, but the opposite as described by a third sector worker.

“ I know parent carers that have had a loss of income into their households due to the awaiting the diagnosis of their child. Many have had to give up or lost their job during this time. They were functioning working adults with a child but with all of the issues such as not joined up services and coordinating time like meetings outside of school for the child, parent carers have to stop working really or have time unpaid leave which often leaves parent carers becoming depressed or lonely in various different ways after losing their job.

By the end of the assessments and waiting times I do know a few families that are cutting their working hours because of their child's needs. Lack of sleep is the big one really. The impact of having no sleep through either your child's behaviour or worry of where your child is going to get support or (the) daily judgmental attitudes towards the child or yourself as a parent. Parenting skills can be squashed at that time when you are feeling like you are useless, the blame will with have a weight on how you function as a parent and as an adult that can lead to being unemployed, which obviously leads to having less income in your home relationship difficulties etc .

Parents often won't go for the promotions either if you haven't got the childcare support around you.” Third Sector Worker

Some staff identified how it can sometimes be difficult to understand problems in school without setting them into context by acknowledging social and environmental issues and the impact these can have.

“It is hard being a parent and it is even harder being a special needs parent and what I have noticed is that, from my meeting with parents is the impact on the parents' health. I've noticed talking with different parents, similar things, perhaps in their own mental health or wellbeing and of course while you are going thought that, you still have to look after your children, it's a problem.” - Education Staff

Mental health issues can sometimes be picked up, this offers positive outcomes for the whole family;

“I had one child who came through as a referral. The CAMHS team realised that there was anxiety for the parents that was then having an impact on the child. They took the time to work with the parents that then had a positive impact on the child.” - Education Staff

“. . . it can be difficult because parents themselves can be undiagnosed, I have known parent carers that have themselves been diagnosed through the child’s process of being diagnosed. This can help parents to understand why they are unique and struggled with different elements of their own lives. Support at this time needs to be increased parents often blame themselves and this can cause a lot of strain on relationships within the family unit and also the extended family” - Third Sector Worker

“We are not seeing the root causes of the issues at home and likewise the parent isn’t seeing the root cause of the issues at school’. Some parents aren’t in the best place in their area of their life and this has an impact on the child” - Education Staff

There appear to be opportunities for initiatives such as Cooperative Working⁶;

“It’s frustrating I can be working with a child for 6 hours but I am aware that there are other factors impacting on this child’s life. For example, drug/alcohol use at home.” - Education Staff

“I spent 80 per cent of my time working with parents outside of the issues of the child” - Education Staff

⁶ <http://www.stoke.gov.uk/ccm/navigation/community-and-living/cooperative-working/>

Relationships

Education staff made mention of changes to the delivery of school nursing in Stoke-on-Trent.

“We had a named school nurse we could just call up and ask can you check if there is an appointment coming up etc. We haven’t got that now. We don’t have a link with health”

- Education Staff

“The school Nurse would prompt if parent missed an appointment at CAMHS” - Education Staff

For others, continuity is key as it helps build relationships;

“Services are stretched and reduced meaning more demands on people like teachers, educational psychologists. In an ideal world every school would have an educational psychologist, occupational therapist, a school nurse at least part time ... one day a week, one day a month? Schools just don’t seem to have the budget for this.” - Third Sector Professional

“ . . . there is a referral system for most services now. There isn’t that familiar local face that you trust. People want relationships. Building relationships with familiar professionals helps people to engage with community which must improve outcomes for the child and families” - Third Sector Professional

“Changes with the school nurse service hasn’t helped - previously the school nurse was the one who would advise staff regarding a student. Parents knew the school nurse they trusted her. That consistency is no longer in school” - Education Staff

“Parents want that familiar face- the school nurse was that familiar person. Most of our parents wouldn’t go into a drop-in session” - Education Staff

Some schools take a proactive approach. In one example a school invested in three family support workers. Contributors commented that this is not always financially viable. There is good practice that goes on though, devised locally.

“School can be the key place for support to happen . . a lot of schools have been doing nurture rooms for the young person with various needs and different classroom environments. Schools are investing in parenting rooms and delivering self-esteem classes

such as the “Sparkles” course at the Meadows Academy, Blurton, not only home/school link workers but acknowledging that there is a need to give more support for parents to gain better outcomes for their pupils. There is other academies/school doing this kind of support.

<http://www.stokesentinel.co.uk/unique-wellbeing-centre-officially-opened-at-the-crescent-academy-in-meir/story-30115931-detail/story.html>

Some high schools have got a sanctuaries with bean bags, music etc where young people can go and chill if feeling emotionally unstable for example if they have suffered a bereavement . Emotional wellbeing needs to be prioritised”. - 3rd Sector Worker

Staff spoke about how they have innovated;

“It’s hard to break down the barriers we have many parents who have gone through the system and their needs haven’t been met. We try and work on parents self-esteem in small groups. We had a small coffee morning and parents had time to do things with their child and an opportunity to speak in an informal way about their child. It was very positive.” - Education Staff

There isn’t always the time to deal effectively with issues;

‘less resources - parents in tears and I try and give them support. I feel sorry for those parents who don’t feel they can come to us but I’ve also got less time to deal with things’- Education Staff

“If I see that there is a parenting need I will tick a box to recommend Triple P⁷, but we’re making a judgement about their parenting style.’. The parent may not turn up for the course may not want to know. I have just started a project in school where I have targeted individual parents who I know need support and skills. I’ve called it positive parenting I’ve taken the stigma out of it.’ As soon as I’ve spoken to the parents I’ve started a relationship and they’ve come on side” - Education Staff

⁷ <http://www.triplep-parenting.uk.net/uk-en/find-help/triple-p-online/>

Information Provision

Skills and Signposting

Some staff described how in some cases they feel they are “plugging the gap” as parents wait for other services. They understand how additional training can help to do this. For example, one Senco attended training that taught coping strategies. She was then able to share these with a parent who was struggling. Perhaps, had the parent not learned these strategies and had the SENCO not had the training perhaps the only option would have been to refer to CAMHS because there was nowhere else to go.

Without training, one SENCO described how;

“I felt I was put into a position to make medical statements that I wasn’t qualified to make - but there was no input” - Education Staff

*“At school I am worried about doing the wrong thing because it is mental health I’m scared of doing the wrong thing that will do more harm. If we could get strategies in the first place from the those with the expertise from the professionals that would be great”
- Education Staff*

Another gave an example of how training would help;

“a seven yr old child was self -harming both at home and at school. The referral was rejected. This was very hard - as the Senco had gained the trust of the parent and encouraged a referral was necessary only to be told that this wasn’t an issue for CAMHS it was a school issue. It’s a demoralising time for staff I’m not a mental health expert I don’t know what to do next’- Education Staff

“we are trying to plug the gap”- Education Staff

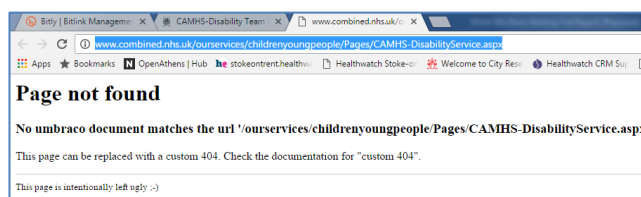
One interviewed parent explained how all benefit from training.

“Having teachers that have attended courses. The teacher that I dealt with had an interest in SEND and she kept up with her reading. I think that everyone who is a practitioner should keep researching. Sometimes I get the feeling that when I attend meetings with other people that level of training and developing isn’t happening and they are sticking to stereotyped ideas, that makes me question.” - Parent

Some contributors were aware of courses that could support, such as one delivered by Changes, another by Young Minds or the Mental Health First Aid program⁸. Where there is a cost, this is described as a barrier to access.

Another described how they were unclear what training is available and recommends more proactive delivery of information;

“. . . it would be really useful for professionals, giving us information about what courses information is out there. Instead of having to ask do you do or is there?”



The CAMHS Disability website accessed via the Local Offer (March 2017)



Banner on the Local Offer website accessed March 2017

⁸ <https://mhfaengland.org/youth-mhfa/>

THE LOCAL OFFER

“The local offer should not just be a list of services. It should give a broad range of information about the support that the local authority expects to be available across education, health and social care. The information should be clear and easy to find.”

“By 1 September 2014 local authorities must publish the first version of their local offer on their website. This must be developed and improved over time.”

https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/send_reforms_-_the_local_offer_explained_august_2014.pdf

Another described designing her own intervention;

“I write everything down that I do because I find chunks of my time is doing things not under my remit. E.P’s are recommending the 5 point scale⁹, there is no training for it. I do training around the 5 point scale using resources from Changes. I mix it up to do my own package ...but there is no training to do this but it is recommended that we deliver it” - Education Staff

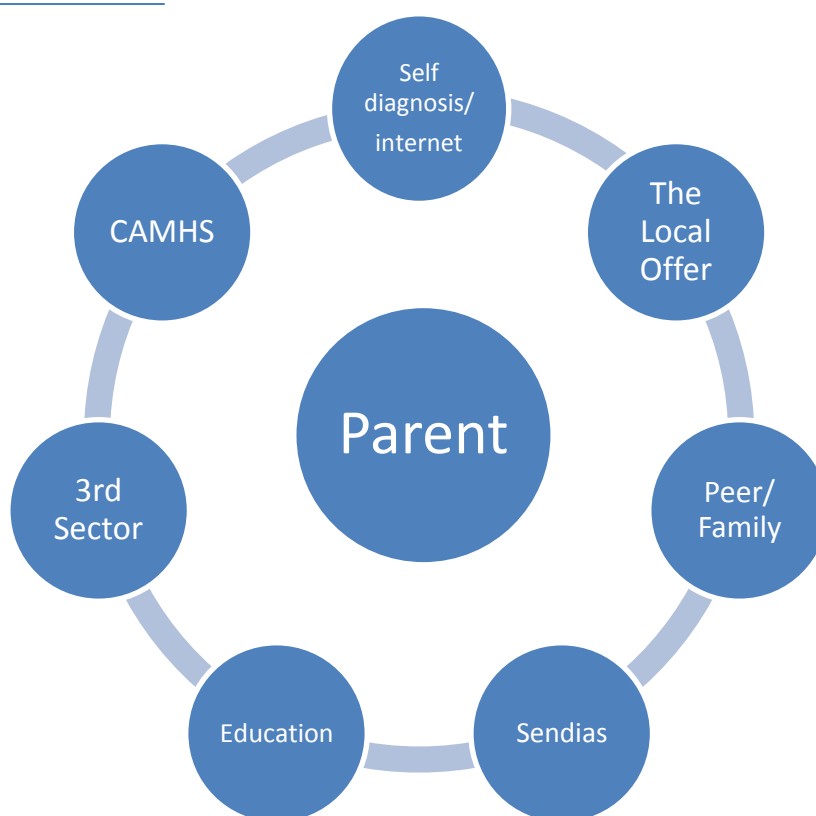
Other resources also present barriers to access;

“STRENGTHS and DIFFICULTIES¹⁰ questionnaire. To check the questionnaire was free but now they will charge for this service. We use it when we’ve got to our threshold of understanding/parents are struggling new behaviours, (it’s the) first tool in our toolbox.”
– Education Staff

⁹ <https://www.5pointscale.com/>

¹⁰ <http://sdqscore.org/Amber>

Parents



Sources of information for parents

“I’ve been signposting to Barnardo’s Upside¹¹. It says for 11 - 18 but I’ve been doing it for parents of children younger. They have got lots of tip sheets on.”- 3rd Sector Worker

A staff member said that she had been to CAMHS and had found self-help leaflets, for example, on headbanging;

“This was very useful for parents, it gives them more tools in their toolbox -strategies/ techniques.” - Education Staff

‘I think for some parents its understanding their child’s need and what is needed to support those needs’ - Education Staff

“Signpost people, give them places to go, give them ideas of places you could go to, services you could find that would help you with your child, help you with your mental health or help you keep your family a family” - Education Staff

¹¹ <https://www.upsideonline.co.uk/>

“As a school I would love to offer support groups and training to parents but the agenda of the L.A, their priority is developing IT, Basic English/Maths. They would frown on a parenting course for Children with ASD they would say well where is your IT where is your Maths etc.”- Education Staff

“Many parents have said that they have done the Triple P course several times.”- Education Staff

“Triple P is a hurdle if they have done it to get referred.” - Education Staff

“We try and encourage the parent to attend (ppp) as they will be with the child for the most part and it is to empower them and give them support. If it is a tailored need we will give individual sessions. Sometimes it isn’t a tier 3 mental health issue it is an environmental issue which we can’t control” - CAMHS Staff

Parents described barriers to the signposting and advice needed to build specialist skills that would help them cope while they were waiting. In particular, it may be difficult to access advice without a diagnosis.

“When you are on a waiting list you don’t get no (sic) support”- Parent

Without formal or reliable informal support, parents turn to the internet. As well as being popular (all parents mentioned it) it is importantly, accessible even to people who are socially isolated (provided they have the IT skills of course).

“If you don’t know how to access a computer or you don’t know what services are available when you look (what do you look for?). I was, at one point, I couldn’t use a computer so if you had asked me to google somewhere that would have made me worse! (more anxious)” - Parent

This is not something typical to this cohort. A recent publication by the Office for National Statistics¹² showed that more people use the internet to search for health information than information about education (2013 up from 2007).

¹² Retrieved from http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171778_322713.pdf

The sources of information available are varied in terms of quality. Some found peer support through forums.

“You look on lots of forums, looking on the internet for different things, so Netmums and MSAAA, National Autism Society. You become like a researcher because you are constantly looking for different support groups to support you.” - Parent

Cole et al (2016)¹³ found that the nature of forums is quite different from other sources of health information on the internet. They found that,

“discussion forums (are) more conducive to the transfer of good quality information than other types of websites.”

This is primarily because of the value of peer support, as well as the way in which users are able to comment on each other’s contribution, correcting them as necessary. However, parents may still need to learn how to best navigate these sites and be able to differentiate between those that are, or are less useful.

“There is a lot of support online. However, how useful some of that support is, is questionable. There is (sic) a lot of extreme opinions online. So you could a nice official one (like Face2Face) and its monitored and great and there are lots of unofficial ones out there. Again, there are lots of people telling them how to look after their kids, very opinionated people, you get trolls online. There are perhaps groups that parents need to steer clear of.” - Parent

“. . . what you do need is coping mechanisms and management techniques.” - Parent

“. . . strategies around anxiety techniques.” - Parent

The sorts of information that parents seek will vary by condition, but amongst our parent group people were looking for skills that would address the immediate need.

Considering the context that this information seeking is occurring in, one participant suggested that the need for information could become overwhelming. It is easy to understand how this could happen when you are both concerned for you child and perhaps stigmatised.

¹³ Cole et al, 2016, Health Advice from Internet Discussion Forums: How Bad Is Dangerous?

There seems to be some evidence that diagnosis is perceived as a barrier to help and advice that could perhaps be delivered without it.

“ when seeking information, people shouldn't get overwhelmed and look for other things in your life, look for other interests. Don't let that become the focus of your life because your child isn't sat there thinking about their autism, they are just thinking about their life. You need to get out there and enjoy life although it's very hard to when you are feeling not well. That's when you need support.” - Parent