



Special Educational Needs and Disabilities

Mental Health and Emotional Wellbeing

Joint Strategic Needs Assessment

The Lived Experience of Families

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1. Executive Summary

1. Background

Cumbria received feedback from the Special Educational Needs and Disabilities (SEND) inspectors that senior leaders did not have a “*deep understanding of the needs of the SEND population*”. It was agreed via workshops that Mental Health and Emotional Wellbeing (MHEWB) of Children and Young People (CYP) with SEND, with a particular focus on Autistic Spectrum Disorder (ASD), was a topic that needed to be understood in further depth.

This document is part of the wider Joint Strategic Needs Analysis (JSNA) Deep Dive document and demonstrates what Cumbria knows about the MHEWB of CYP with SEND using the lived experience of parents/carers and CYP

The full JSNA Deep Dive document includes this section plus additional information from the data that is available to the Local Authority and NHS. The full document can be found here: <https://www.cumbriaobservatory.org.uk/jsna/send/> .

2. Summarising What We Know

The following is a summary of what we know as of July 2020 from the lived experience of parents/carers and CYP. Further detail is provided subsequent sections in order to provide a deeper understanding.

2.1. We have some data but it is not detailed, not always SEND specific, and does not tell us how we need to improve services. This means that Cumbria does not have an accurate or detailed picture of how families use services.

2.2. The greatest primary need for CYP with an Education Health and Care Plan (EHCP) is ASD (33% of all EHCPs). The fourth greatest primary need for CYP with an EHCP is Social Emotional and Mental Health (14% of all EHCPs).

2.3. Parents/carers have told us via the Cumbria’s 2019 SEND Parent and Carer Survey that their experience of MHEWB services in Cumbria was poor. 42% of parents/carers agreed that their child has been able to access provision, and 48% agreed that provision is currently meeting their child’s needs. Priority areas for improvement included early intervention and quicker access to services.

2.4. Parents/carers have told us that they may be unaware that MHEWB support is available to them and that they find the support system complicated to navigate. There are also gaps

in services particularly for CYP with ASD and no learning disability (LD), and those who are showing violent and challenging behaviour.

2.5. Parents/carers have told us that we do not have the basic service processes right (referrals, appointments, transitions, discharges) and that when these breakdown, the needs of CYP with SEND go unmet and this can lead to issues with MHEWB.

2.6. Parents/carers have told us that multi-agency working (including schools and families as part of the multi-agency team) is not always effective and that there is / can be poor communication among the team. Often MHEWB partners are not included in the EHCP process and are therefore missing from the team.

2.7. Parents/carers have told us that services and schools are not always flexible enough to meet CYPs with SEND MHEWB needs. They expect us to flex the service to fit the child, not the child to fit the service.

2.8. CYP have told us via the 2019 Survey for Children and Young People that they feel the people who help them learn and stay healthy know what they need and listen to what they want.

2.9. CYP have told us that addressing bullying and teasing due to SEND will improve their MHEWB.

2.10. Cumbria has more information about the needs of CYP with SEND and MHEWB from the lived experience of parents/carers than it does from the lived experience of the CYP themselves.

3. What Next?

Understanding the needs of families is a continuous process. This document should be viewed as a snapshot in time and will be the basis upon which Cumbria grows their understanding of needs of this cohort. The intention is to use this understanding to commission and improve services to better meet Children and Young People (CYP with SEND and MHEWB needs).

This chapter forms part of the wider Special Educational Needs and Disabilities - Joint Strategic Needs Assessment accessed here:

<https://www.cumbriaobservatory.org.uk/jsna/send/> .

2. Qualitative Deep Dive - The Lived Experience of Parents/Carers

SEND and Mental Health Emotional Wellbeing (MHEWB) – Qualitative Deep Dive What have parents/carers told us about their lived experience?

Introduction

The purpose of this qualitative deep dive is to understand the lived experience of Cumbrian parents/carers where CYP with SEND, particularly autism, have MHEWB needs. A number of documents, reports, case studies, surveys and interviews have been synthesised, (for the full list see Appendix 1) and the key themes and insights have been analysed and outlined below.

Readers are able to get an at a glance insight into to the voice of families simply by reading the **bold headings** and *italic subheadings* only. Further details and real life examples are included below the headings and subheadings with the aim of giving the reader a richer picture of the inner world of these families. Please note that these views have originated from a sample of Cumbrian families and therefore they may not be representative of all Cumbrian families.

1. Parents/carers have told us that they may be unaware that MHEWB support is available to them and that they find the support system complicated to navigate.

1.1. Parents/carers are not clear where or how to find the information they need.

Parents/carers have commented that the quality and effectiveness of services is on the whole good once they have access to them, the difficulty is in knowing that they are available and getting access to them - "When you know about it, it's great!" Parents/carers have fed back that the Local Offer is not intuitive or easy to navigate and that they are often reliant on other parents/carers or word of mouth.

Families have told us that they want to see clear packs of information explaining what services and support are available in Cumbria (and nationally). These should be organised as directories of services relevant for different age groups, and families should be given these at key points e.g. birth (where a child has a genetic condition), diagnosis and key developmental points e.g. starting school, year 9 review). Families have said that they also want to be able to talk to someone who can give signposting advice.

1.2. Parents/carers would benefit from help to navigate the system.

Parents/carers have expressed that the system is confusing and complicated and that they would like a key worker to help them understand, access and coordinate the support they are entitled to, as well as to offer practical and emotional support. It is a requirement in the NHS Long Term Plan that CYP with ASD and/or a learning disability with complex needs will have a keyworker by 2023/24. It should be noted that the SENDIAS (SEND Information and Advice Service) service and DCO (Designated Clinical Officer) may be able to help with system navigation; however parents and carers are not always aware that these services are available.

1.3. Example of the difficulty of finding information and the impact of receiving the right information at the right time.

One case study illustrated how difficult and non-intuitive it is to find information and support as a parent/carer even when you work with adults who have learning disabilities and therefore interact with the SEND system professionally. This parent/carer's child was diagnosed with Down's syndrome and had started to display some challenging behaviour. The parent/carer only found out that there were services available to support them and their child by chance through a work related encounter.

Although the child was under Paediatrics, there were long waiting lists to be seen and locum doctors, "we've not seen the same GP or Paediatrician twice". Now the child's needs are met and the family are well and thriving, but the parent/carer believed that this happened only through "luck and good timing" because they didn't know what to ask for, or from whom. Without the right services at the right time, the child would have been increasingly distressed and the family would have struggled to cope because they did not understand their child's world or behaviour and therefore could not meet their needs.

2. Parents/carers have told us that they may have emotional barriers which prevent them from accessing MHEWB support for their CYP when it is needed.

2.1. Parents/carers may find it difficult to say that they need support.

It can be difficult for parents/carers to seek support and understand that it is okay to ask for help. Parents/carers, particularly early on in their support journey, may be reluctant to seek out services because there is a perception that "I should be able to look after my own child".

Parents/carers are also in a constant high level of stress just from activities of daily living. On top of this, getting their children to appointments is a huge additional difficulty, for example one parent/carer said that they must bribe their child with treats to attend. That parent explained that they also have to arrange for their other children to attend breakfast club at

school in order to be able to take their child to the appointment. This causes the siblings distress because they also have additional needs and this is a disruption to their routine.

2.2. Example of the impact of difficult in seeking support due to emotional reasons.

In one case study, a professional talked about their role in encouraging parents to initiate the diagnosis process. Parents were reluctant to seek a diagnosis because they were worried about the consequences that their child receiving a label might entail. Without sensitive support and education from this professional, parents may have delayed seeking help, their child could have had their needs unmet, the child's development could have been delayed and the family situation may have deteriorated into crisis.

3. Parents/carers have told us that multi-agency working (including with parents and education as partners) is not always effective but it is crucial to ensure that MHEWB needs of CYP with SEND are met. This is both early on in the journey of support, and especially in times of crisis.

At both a service and individual level, when professionals work more closely with each other, they better met the needs of CYP with SEND.

3.1 Multi-agency working can form an effective team around the child to meet MHEWB needs.

Structures like the Early Help process, EHCP reviews and Children Looked After (CLA) reviews were helpful in bringing together agencies and there were a number of positive case studies demonstrating the effectiveness of these. The Clinical Commissioning Groups' (CCG's) Dynamic Support Register processes also facilitated, albeit in a time limited way, effective multi agency working for those children with LD and/or autism facing crisis and admission to hospital. There was however a perception that EHCP reviews were not always conducted in a timely manner and often focused on educational needs rather than the child's holistic needs.

3.2. Multi agency working is most effective when led and coordinated by a key professional, without this the team is fragile and can break down leading to gaps in meeting CYP's needs.

If one professional did not take ownership in leading the team around the child and advocating for the child, multi-agency working was fragile and easily broke down. Other examples of causes of multi-agency breakdown were:

- Professionals on extended sick leave or who had left their role
- Children not meeting criteria for support from a service and no alternatives being offered
- Delay in scheduling of multiagency forums to address issues

- Professionals uncertain how best to meet the child's needs, due to disagreement or complexity, and uncertain how to escalate this, or escalation is ineffective
- Professionals unclear how other agencies processes work, e.g. understanding risk, becoming a child looked after, going into residential accommodation, being sectioned under the Mental Health Act
- Professionals received insufficient training in working with high risk children in crisis situations
- Families are unable to engage with services and are therefore are discharged from caseloads

3.3. Services must continually improve their processes to work more effectively together.

CAMHS and LD services gave positive examples of how they are working more effectively together. Training and support has been taken up jointly between teams. There are weekly referral discussions for any new referrals where it is unclear which service would best meet the need. This has led to individualised assessments, joint appointments, and joint working with psychology, psychiatry, CAMHS practitioners and learning disability practitioners. This reduces the time that families are waiting for support and can reduce anxiety as families do not have to re-tell their story to new professionals.

Parents/carers gave negative examples of where the system contradicts each other resulting in a delay in meeting CYP's MHEWB needs. These included the use of the term "Pathological Demand Avoidance" which education recognises as a sub-type of autism but health do not. Similarly the terminology clash between the phrases "Learning Difficulties" that education use, and "Learning Disabilities" that health and adult social care use. When the system does not use the same language, the CYP's needs and the approach to support them can remain unclear.

3.4 Example of the impact of a breakdown of multiagency working.

In one example of multi-agency breakdown, the team were unclear how best to meet the child's needs and were not able to agree a shared understanding of how to manage the risk that the child presented with. Upon escalation to senior managers it became apparent that there was a lack of understanding between professionals of both health and social care processes which meant the system did not work as a united front to support the child and family. The breakdown of the multi-agency team meant that the child had a longer than necessary stay in the local District General Hospital while a discharge plan was agreed which was distressing to the child and family.

4. Parents/carers have told us when standard service processes breakdown, the needs of CYP with SEND go unmet and this can lead to issues with MHEWB.

In addition to understanding and meeting SEND specific needs, services must ensure that basic processes from referral to discharge are effective, inclusive and high quality. The following specific issues were mentioned as problematic:

4.1. There is poor access to services.

There can be lengthy waiting lists and it is not clear how long parents/carers will have to wait for a first appointment. Regular communication throughout the waiting process would be helpful, e.g. phone check ins to get advice and information as parents can think that they are on a list when they have actually been discharged.

4.2. It is unclear what to do next when a referral has been declined.

Services do not always explain why a referral has been declined and they do not always suggest or signpost to other services. Parents/carers said that in these instances a courtesy call explaining other options available would be helpful.

4.3. Support can end prematurely when staff members leave.

When a professional leaves the organisation, there is not always a handover to another member of the team which means that support can end abruptly and prematurely.

4.4. Support can end prematurely because service policies are not flexible.

Service discharge policies should not be one size fits all as this does not always take into account the additional adjustments that may need to be made for CYP with SEND. This means that support can end prematurely and needs go unmet.

4.5. Universal services can end prematurely when specialist support steps in.

In the Cumbria Early Intervention Pilot families reported had not had their health visitor check when their child was two years old. This reflects a perception that universal services step back and hand over to specialist services when indicated, even if specialist support is not received.

4.6. Individual professionals may be unclear what to do when other parts of the system break down.

In a case study submitted, one service worked exemplarily to meet the child's needs; however other parts of the system appeared to not be as effective. An example was given where health visiting checks ended prematurely. The service that continues to work with family noted this, but did not follow it up with the health visiting service directly. Professionals may need to be educated and/or empowered to address issues where CYP's needs are not met in other parts of the system.

4.7. Examples of the impact of standard service processes breakdown on families.

An example was given where one family did not have access to community paediatrics for a lengthy period of time due to staff leaving and long waits. This meant that they couldn't get the blue badge they needed for their daughter who couldn't walk for three years.

Another example was given where one the health visiting service ended prematurely. The narrative that the family ascribed to this event was that this was due to the child's challenging behaviour that was displayed during the visit. It is likely that the process broke down due to another reason; however this perception may contribute to a reduction in the parents' confidence and willingness to ask for help because they may believe that services are unable to help.

5. Parents/carers have told us that services are not always flexible enough to meet CYPs with SEND and MHEWB needs.

Services need to ensure that they are making reasonable adjustments where appropriate, but they may also need to go beyond reasonable adjustments to meet the needs of CYP with SEND. Examples of ways that services have successfully tailored/could tailor their approach are:

5.1. Undertaking home or school visits so the child is in a comfortable, familiar environment.

5.2. Building up a child's confidence to attend appointments and become familiar with new venues and professionals.

One parent/carer explained that out of the 10 appointments that they were entitled to, two of those were wasted because in the first one, all that the child could manage was to look at the room, and the second one all that could be managed was to say hello due to their anxiety.

5.3. Having number of appointments based on need, not a pre-set quota.

5.4. Offering a variety of approaches to support parents/carers, for example holding groups and courses online.

Parents/carers may not have been able to attend face-to-face sessions (when they were previously operational) due to other commitments. This would have had a negative impact on meeting their child's needs and could have contributed to deterioration in the family situation. In one example, a mum was unable to attend a support course aimed at preventing and managing challenging behaviour because her child was being sent home from school so frequently. In another example, a parent/carer said that there needs to be one place to go to online for resources and that these should be easy, implementable videos. In her words,

“people can’t afford to spend the time or money reading books and they can’t get to face to face workshops, doing everything face to face is not scalable.”

5.5. Working with what interests the CYP to maximise their motivation to engage.

A number of case studies mentioned doing activities with CYP when working with them, e.g. football, baking, going for walks and playing pool. This can particularly benefit CYP with autism who may struggle socially with a 1:1 session in a meeting room.

5.6. Using online chat services or videocalls to engage and interact with CYP.

These may help CYP, particularly with autism, to engage with support. There were case studies highlighting professionals successfully build supportive and helpful relationships with CYP entirely through online chat.

5.7. Understanding how individual CYP, particularly with autism, communicate and using this to adapt service processes.

For example, because it can take time for a child with autism to develop a trusting relationship with professionals, the child is unlikely to want to talk on the phone to a stranger (e.g. in CAMHS crisis team) about their feelings. Similarly CYP with autism can struggle to understand and articulate their feelings and when confused they may give what they believe is socially expected response. One child with autism was discharged from a service because they said that they were fine in appointments, but there were clearly unmet mental health needs. Furthermore CYP with autism may not accurately fill in forms, for example one child said that they could not write down that they hate their teachers. Professionals may therefore not fully understand the CYP’s lived experience and thus be able to help them

5.8. Example of the impact of having a flexible approach to meet one CYP’s unique needs.

CYP with SEND have unique needs and what works for one CYP may not work for another. Services need to take time to understand the CYP’s world and have a toolbox of approaches that could be used to support them. Without this CYPs MHEWB needs will go unmet. One case study showed the level of complexity and the type of intervention that was required in order to build rapport and trust with one child. An Educational Psychologist explained that they worked with the child for more than five years and up until the last few months, they had been in separate rooms and communicated through a door which was just open a crack so they could hear each other. Without this patient and person centred approach, this child would not have received the support they need and their situation and functioning could have deteriorated into crisis.

6. Parents/carers have told us that crisis services could better meet their CYP’s MHEWB needs.

6.1. Parents/carers should not experience a gap due to service handover when their CYP's MHEWB needs have escalated.

Some examples were given where a CYP was working with a Tier 2 MH service and the child was beginning to build a good relationship with the professional. The child then said that they were thinking of killing themselves and because of that, the Tier 2 service said that they couldn't see the child again and would refer to Tier 3 MH services. There was then a waiting list to access the Tier 3 service leaving the child and family without support in a critical time.

6.2. Parents/carers want more advice on how they should help manage a child who self-harms.

Parents/carers said that they were given an advice sheet, but want to speak to someone and ask questions. They explained that they are worried and scared and don't know if what they are doing is correct.

One child of eight was told that they needed to have three suicide attempts before Tier 3 services could see them. It was later confirmed that this information was given incorrectly by a locum who has now left. Although the professional was well intentioned, this caused a delay in the child's MHEWB needs being met and additional stress and distress within the family.

6.3. Example of the impact of crisis services not meeting the needs of families.

When families hit crisis due to a CYP's MHEWB needs not being met, and crisis services are not coordinated, there is an enormous impact on families. One parent/carer explained how her marriage is strained as the husband and wife take turns having night and day shifts so that one person is watching their child all the time to make sure that their child is safe. This parents/carer had seriously thought about putting their child into care because of the failures of the system.

7. Parents/carers have told us that GPs are not always involved in their child's care, but when they are can be a great advocate and help to progress the journey of MHEWB support.

There were some case studies which detailed how the GP was able to progress problems and resolve barriers to accessing support. Where GPs were involved and were aware of the CYP's needs, parents/carers said that they provided much needed and appreciated support.

GPs are not always involved in the team around the child/family and not aware of CYP's needs, particularly if the CYP has complex needs and are seen in paediatrics or other specialist services. Some parents/carers commented that their GP didn't have much

understanding of challenging behaviour and were not always clear where to refer CYP with learning disabilities and/or autism.

7.1. Example of the impact of GP involvement in supporting a family.

After one CYP was brought to the CCG's attention due to their complex needs and rare diagnosis, the GP actively stayed involved and joined the rest of the professionals in multi-agency meetings until they were satisfied that there was a robust plan to meet the child's needs. The GP also continued to offer ongoing support to the family during this period which parents/carers found invaluable in helping to navigate the system and providing emotional support.

8. Parents/carers have told us that when schools understand the individual CYP's needs and have a flexible approach, they can effectively meet the needs of CYP with SEND. Schools are not always able to do this however which results in significant negative consequences on the CYP's MHEWB.

8.1. Schools need to understand why CYP with SEND might be disruptive in class and respond appropriately.

Parents/carers thought schools did not always understand why CYP with SEND might act inappropriately in class or display behaviours that challenge. What could look like naughty or disruptive behaviour can be a way to signal unmet needs and parents/carers thought that CYP should not necessarily be punished in the usual way. They felt that schools needed more education in the functions of behaviour and positive behavioural support to better understand CYP with SEND.

8.2. Schools need to be flexible to meet the needs of CYP.

Schools can play an important role in enhancing the MHEWB of CYP with SEND, particularly if they can adapt the environment to meet the CYP's needs, e.g. provide smaller classes, ability to leave class early to prevent sensory overload from noisy classroom changes, allow CYP to use their phone in class if it is their coping strategy. Parents/carers were dissatisfied with school's approaches when "they expected the CYP to adapt to school instead of school adapting to the CYP".

8.3. Schools can play an important part in addressing bullying which is very important to CYP with SEND.

Specialist Advisory Teachers can also play an important role in addressing isolation, exclusion and bullying which CYP have told us is of significant concern to them and impacts their MHEWB.

8.4. Schools can benefit from training and specialist advice.

Educational Psychologists can play an important role in helping schools to understand CYP's behaviour on an individual basis and work with the school to develop strategies to

prevent and manage challenging behaviour. In one case study a child was markedly less distressed and engaged in fewer episodes of self-injurious behaviour after some advice and consultation from an Educational Psychologist.

8.4. Education can do more to support parents when their CYP are out of school.

Parents/carers felt dissatisfied and unsupported when their CYP were out of school for significant periods of time. It was felt there was disparity between CYP with SEND and CYP without SEND and that “it was seen as acceptable for a CYP with SEND to be out of education for seven and a half months compared to if a typically developing child were out of school for this long.”

8.5. Parents/carers need to be able to trust schools.

Parents/carers have told us that this is particularly important if CYP is non-verbal and not able to explain what their experience at school is like. Parents/carers told us that this often made them feel vulnerable and powerless.

8.6. Example of the impact of class intervention to address exclusion.

Taking a flexible and holistic and person centred approach helped one child with autism who was having problems with exclusion in class that was affecting his self-esteem. While the child could have feasibly been referred to Mental Health/Emotional wellbeing services to improve their self-esteem, a Specialist Advisory Teacher conducted a whole classroom intervention working with the class to get them to better understand, support and appreciate the strengths of the child. This intervention effectively addressed the root cause of the problem and the child’s self-esteem and mental health improved. This example illustrates the complex interplay between the CYP and the environment and that difficulties can arise when children with additional needs are made to “fit” into a neuro-typical world.

9. Parents/carers have told us that they are concerned about their CYP’s MHEWB needs being met as they enter adulthood.

Often there is no adult equivalent for children’s services. CYP who have been on the caseload of child mental health services are not always eligible for adult mental health services. Those that are eligible may need additional support to access and engage with adult mental health services particularly if services do not have a flexible approach. (See point 5).

10. Parents/carers have told us that there are a number of gaps in commissioned services which means that a CYP’s MHEWB needs are not being met.

10.1. Occupational Therapy can better meet the MHEWB needs of CYP with SEND

Occupational Therapy (OT) services are only commissioned to work with CYP who have

complex physical difficulties and not CYP who have difficulties with functioning due to neurodevelopmental differences. One CCG commissioned a pilot project where OT services worked with CYP with autism at risk of hospital admission and demonstrated that OT have an important role to play in helping CYP with autism to improve their daily functioning skills, ability to self-regulate and cope with anxiety and understand and interpret their sensory world. All of which led to better MHEWB outcomes.

10.2. Speech and Language Therapy can better meet the MHEWB needs of CYP with SEND.

Speech and Language Therapy can better support CYP, particularly with autism, to improve their communication, social skills and understanding. If CYP struggles to communicate and fit in with their peers, this can lead to isolation which in turn can lead to problems with MHEWB.

10.3. Local autism assessment services need to be improved.

The process is too lengthy and there is insufficient support for parents/carers prior to assessment commencing, and after diagnosis. Parents/carers also feel the decision making process is subject to financial conflict of interest and that their opinion and experience is not valued as they are not allowed to be a member of the decision making panel. There is also insufficient support explaining autism and its impact for the CYP themselves and the relationship between autism and anxiety and other MHEWB issues.

10.4. Access to specialist autism services need to be equitable across Cumbria.

There is a gap for second opinion autism assessment services and specialist neurodevelopmental assessment and intervention services in south Cumbria specifically. North Cumbria have access to these services and parents/carers have spoken highly of them. This is a clear inequity across Cumbria that needs to be addressed.

10.5. There is insufficient support for CYP with autism and their families, particularly when their autism negatively impacts their mental health.

While Tier 2 and 3 MH services can meet the MHEWB needs of CYP with autism, the professionals in these services are often not autism specialists and the complex interplay between autism and mental health may therefore not be effectively addressed. Services which are commissioned to develop positive behaviour support plans (a recognised framework to support people with a learning disability, and/or autism, including those with mental health conditions, who have, or may be at risk of developing, behaviours that challenge) are not commissioned to develop plans for CYP with autism aged over 11 years old leaving a clear gap. Furthermore a LD Specialist Psychiatrist is not commissioned as part of the children's LD team, which is not optimal in meeting the MHEWB needs of CYP with LD.

10.6. Early intervention services need to be commissioned for CYP with SEND.

It is important that services for CYP with SEND meet their MHEWB needs but anticipating these needs before they arise and giving parents/carers the skills and confidence to meet them, can reduce the likelihood and severity of MHEWB needs developing.

10.7. There is insufficient support for CYP with violent and challenging behaviour.

Parents/carers do not have a dedicated service to support them if their child has violent and challenging behaviour. Access to CAMHS is poor and even when CYP are seen by CAMHS they are unable to help with this and can often only provide medication which does not address the underlying factors. If CYP have a LD, then parents receive good support from the LD Team. If CYP have autism and no LD, then there is no support for parents for violent and challenging behaviour. Parents say that these are “forgotten children”. Parents have also told us they feel blamed by professionals and ashamed.

10.8. Parents/carers want to be paid partners.

Parents/carers have told us that they want to be commissioned as paid partners and have a role in helping families meet their CYP’s MHEWB needs.

10.9. Parents/carers are dissatisfied with the “Episodes of Care” model in health services.

Parents/carers think that episodes of care is inappropriate for CYP with SEND who can have long term, if not lifelong conditions, known to be at risk of poor physical health, MHEWB and social outcomes when they have don’t have the right support in place throughout their development.

10.10. Parents/carers want independent key workers commissioned.

Keyworkers would play an important role to coordinate support, navigate a complex system and be available for families throughout the course of the CYP’s development (i.e. not following episodes of care model). This is in line with the plans set out for keyworkers in the NHS Long Term Plan to be achieved by 2022/23.

10.11. Parents/carers want gaps in services and unmet needs to be routinely fed back to commissioners.

Parents/carers have suggested that services initiate a system to log when needs cannot be addressed/are taking too long to be addressed (e.g. there is no one in post/a long waiting list). This intelligence should be escalated to commissioners to make them aware of the impact that these gaps are having on the MHEWB of CYP with SEND. Parents/carers want reassurance that these gaps will be addressed.

11. Parents/carers have told us that they experience significant negative impacts on their own MHEWB when the MHEWB needs of their CYP are not met.

11.1. Living in a household where a CYP’s MHEWB needs are not met can be stressful and
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anxiety provoking.

To illustrate the lived experience, the following quotes have been taken from parents of CYP with SEND before they attended a parenting programme:

“I’d like to wake up without dreading the day with child and go to sleep not worried.”

“I’d like to be able to take all 3 children out.”

“I’d like to see her smile more often and generally be happy without repercussions.”

These parents/carers were struggling to get through the day and survive, let alone think about helping themselves or their families to be healthy, well or thriving.

Parents/carers have told us that they are also worried about the consequences of the system failing their CYP. There is an enormous impact on children, not only in the short term because they are not getting their needs met, but their future opportunities are being affected too. For example, one parent/carer said that their child now cannot be in the top set of lessons at school due to the absences from medical appointments. Another said that their children are losing their respect and trust in the NHS which may affect their health behaviour as adults.

Research has shown that parental stress can affect their child’s behaviour and contribute to an escalation in behaviours that challenge and a reduction in cognitive and skills development. The more resilient and supported a parent feels the better they are able to advocate for their which directly supports health outcomes.

11.2. Interacting with the SEND system causes additional stress and distress to families.

Parents/carers feel that there is often a basic lack of kindness and an unwillingness to help from professionals. They would like professionals to acknowledge that they are struggling and to be honest and realistic when they talk with them. They have also said that they have felt blamed by professionals which negatively impacts their confidence and creates antagonism with the system.

Parents/carers want to be respected and have their opinions valued, they feel that in meetings they are dismissed as “just a parent”. One parent/carer said that they were doing an MSc in Autism just so that they can be taken seriously.

Parents/carers are expected to navigate the system in addition to these highly stressful activities of daily living. They feel that everything is a battle and that they have to go into meetings with a “tactical plan”. They feel that all the people who work on their behalf (e.g. EHCP keyworker, professionals in services) have a financial conflict of interest because if families get what they need, then services suffer financially. The result is that families do not

get what they need. Being called a “difficult parent is a badge of honour” but sometimes parents/carers don’t have the energy to fight or complain.

3. Qualitative Deep Dive - The Lived Experience of Children and Young People

SEND and Mental Health Emotional Wellbeing (MHEWB) – Qualitative Deep Dive

What have children and young people told us about their lived experience?

Introduction

The purpose of this qualitative deep dive is to understand the lived experience of Cumbrian CYP who have SEND, particularly autism and MHEWB needs. In comparison to the understanding the lived experience of parents/carers, there were relatively fewer sources from which to draw upon, however the key themes are outlined below (See Appendix 1).

All of Us Forum - May 2020

What has helped during lockdown?

- Starting A Level bridging courses
- Getting out for walks
- Quiz
- Gardening/Wildlife
- Walking dogs on beaches
- Jigsaw puzzles
- Making funny films
- Crafts: Making Summer wreaths
- Doing Exercise
- Baking
- Rock Painting
- Having Dad at home
- Being with dog

What would you change about lockdown?

- I wouldn’t change anything as I’ve just got used to the changes and if starts changing all of time I wouldn’t like that.
- Going out to bars, pubs and restaurants
- Not sure what going back to a job will be like

- It not being so boring
- Missing family, Aunties
- Queues at the supermarket and going into shops
- Missed friends a lot and it would be nice to chat more

Key Quotes from CYP with Autism at an Open Space Event - 2016

“I’m bullied and teased because of autism.” – Bullying was the number one issue to address to improve MHEWB as voted by CYP.

“Work with us, not for us”

“Don’t patronise me”

“I feel my input goes nowhere”

“How do you know what is best for me?”

“It’s scary doing health things like going to the dentist or taking medication, don’t like feeling of creams.”

“Hard to know how we feel.”

“Small groups and 1:1 is better”

“I need time to understand”

4. Appendix 1

Resources Used: Qualitative Deep Dive

- Cases studies submitted via the SEND Improvement Programme – June 2020
- All of Us Forum – May 2020
- Autism Open Space Event – 2016
- Morecambe Bay CCG Occupational Therapy Pilot
- Cumbria Early Intervention Pilot with Challenging Behaviour Foundation – August 2019
 - Focus Groups
 - Parent/Carer Survey
 - Presentations delivered to SEND Improvement Working Groups
- SEND and Mental Health Event, Barrow - September 2019
- Conversation with parents/carers of CYP with Autism, Kendal – December 2019
- SEND Witness Statement – North Cumbria – March 2020
- YouTube video with Triple A - <https://www.youtube.com/watch?v=bQzhpnXgO2s>
- Violent and Challenging Behaviour Parent Carer Survey – July 2020
- Conversation with Shout Group in Maryport – January 2020
- Lessons Learned from a Morecambe Bay CCG CYP