NHS North Cumbria Integrated Care NHS Foundation Trust

NHS Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

NHS Lancashire & South Cumbria NHS Foundation Trust

NHS North Cumbria Clinical Commissioning Group

NHS Morecambe Bay Clinical Commissioning Group

Cumbria County Council

Special Educational Needs and Disabilities

Mental Health and Emotional Wellbeing Needs

Deep Dive Joint Strategic Needs Assessment

Cumbria County Council, Performance & Intelligence

Contents

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 Joint Strategic Needs Analysis (JSNA) deep dive demonstrates what Cumbria knows about the MHEWB of CYP with SEND using:

i) the data that is available from the Local Authority and NHS
ii) the lived experience of parents/carers and CYP

2. Summarising What We Know

The following is a summary of what we know as of July 2020. Further detail is provided in 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 Special Educational Needs and Disabilities - Joint Strategic Needs Assessment accessed here: https://www.cumbriaobservatory.org.uk/jsna/send/ .

2. Background

This Joint Strategic Needs Assessment (JSNA) chapter follows on from the first version of the SEND JSNA produced in October 2019 in response to the Joint Inspection of Children and Young People (CYP) with Special Educational Needs and Disabilities (SEND) in March 2019. Following on from the first JSNA, a workshop was held to consider the initial findings and to identify themes that need further more detailed work to enable a better understanding of need. The two themes this chapter will focus on are:

- Developing a better understanding of emotional well-being and mental health needs amongst our SEND population; and
- Improving our understanding of needs of children and young people with autistic spectrum conditions

National context

The world Health Organisation describes mental health as a ‘state of wellbeing in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community’.

Mental wellbeing impacts upon children and young people in a variety of ways including how they view themselves, their quality of life and the wider society. Emotional health and wellbeing has a significant impact on a child’s cognitive development, learning, physical health and their mental wellbeing in adulthood. Positive mental wellbeing is essential if children and young people are to flourish and lead rich and fulfilling lives. (Measuring Mental Wellbeing in Children and Young People, Public Health England, 2015).

As reported in NHS Digital’s survey of 9,117 children “Mental Health of Children and Young People in England, 2017” 1 in 8 children (12.8%) aged 5 to 19 years had at least one mental disorder; 1 in 20 (5.0%) met the criteria for two or more individual mental disorders. One in twelve (8.1%) of children and young people had an emotional disorder. Rates of mental disorder were higher in older age groups, 14.9% of young people aged 17 to 19 years reported an emotional disorder compared to 9% of children aged 11 to 16 years and 4.1% of children aged 5 to 10 years.

If we crudely apply the national survey prevalence of 12.8% to the Cumbrian population, there are an estimated 10,000 children and young people aged 5 to 19 years with a mental disorder in the county. If we do the same with the survey emotional disorder prevalence of

8.1%, there are an estimated 6,300 children and young people aged 5-19 years with an emotional disorder in the county.

Over one third (35.6%) of children and young people aged 5 to 19 years with a mental disorder were recognised as having special educational needs; 1 in 4 (26.8%) children with SEN had an emotional disorder, while two thirds (64.8%) had other disorders such as autism. Half of the children with special educational needs had an Education, Health and Care plan in place.

Two thirds (66.4%) of all children with a disorder had contact with a professional service in the past year because of worries about mental health; teachers were the most commonly cited source accounting for 48.5%, while 25.2% were mental health specialists.

SEN and psychological wellbeing – Department for Education

As reported in the Department for Education's "*The wellbeing of secondary school pupils with special educational needs; Research Report; July 2017*" children with SEN tend to have lower levels of subjective wellbeing ,when considering school, school work and friends, than children without SEN. Almost one in five children (19%) with SEN report being unhappy compared to 7% of children without SEN. There is little difference between children with/without SEN when considering their family and appearance. It is therefore clear that school is an issue for children with SEN which is not surprising as a child with SEN requires additional support at school.

The link between SEN and wellbeing appears much greater in relation to psychological wellbeing. There are higher proportions of children with SEN with a range of psychological difficulties - between 18-27% compared to 11-13% for children without SEN. However, it is important to note that aspects of psychological wellbeing may be a reason why a child is diagnosed with SEN. Children with SEN have higher average psychological difficulties including emotional difficulties, conduct problems, hyperactivity/inattention and peer relationship problems. There are a number of other significant factors which can impact on a child's wellbeing including their gender, family background, bullying and engagement with SEN. It is recognised that SEN is more prevalent in boys and that children with SEN are disproportionately from more disadvantaged families.

Although primary need measures children with 'social, emotional and mental health' needs, many more children will have these needs in addition to other difficulties. It is possible that having a psychological difficulty can lead to a SEN and low psychological wellbeing.

Special Educational Needs & Disabilities - Social Emotional and Mental Health needs

For children and young people with special educational needs and disabilities, there are specific categories of need collected through the statutory School Census. There are four broad areas of need including: communication and interaction; cognition and learning; social, emotional and mental health difficulties; sensory and/or physical needs. Further information about primary need can be found in the SEND JSNA Primary Need chapter.

Children and young people often have needs that cut across all areas including sensory requirements, assessments of need ensure that the range of needs are identified not just the primary need. Furthermore, children and young people with special educational needs and disabilities are likely to have emotional health and wellbeing needs.

Social, Emotional and Mental Health (SEMH) needs are a special educational need where a child communicates through behaviour in response to unmet social, emotional or mental health needs. Children and young people may experience a wide range of SEMH difficulties which present in different ways; these may include anger, frustration, becoming withdrawn or isolated, as well as displaying challenging behaviour such as verbal or physical aggression. There may be underlying mental health issues such as anxiety or depression, self-harming, substance misuse, eating disorders or other physical symptoms. They may also have other disorders such as attention deficit hyperactivity disorder (ADHD) or attachment disorder.

The National Clinical Practice Guidelines published by the British Psychological Society state that children with learning or physical disabilities have a greater risk of developing a mental health problem compared to the rest of the population.

Children and young people with special educational needs and disabilities are likely to have emotional wellbeing and mental health needs even though SEMH may not be their primary need. It is also important to note that not all children and young people with emotional wellbeing and mental health needs receive SEN support or have an EHCP.

Special Educational Needs & Disabilities - Autistic Spectrum Disorder

Autism is a spectrum condition and while individuals may share certain difficulties it will affect them in different ways. The term Autism is used to describe all diagnostic autism profiles including Asperger syndrome and Pathological Demand Avoidance (PDA). Asperger syndrome is associated with individuals who are on the autism spectrum but do not have learning disabilities, have good language skills but have social communication difficulties. PDA describes a person who may significantly avoid demands and expectations caused by high levels of anxiety relating to conforming to social demands; and of not being in control of a situation. Autism is often diagnosed alongside other conditions including mental health conditions, accounting for an estimated 70% (Source: National Autistic Society).

It is recognised nationally that the prevalence of ASD is underreported and is estimated to account for just 1% of the total population. It is worth noting that there may be children and young people with high functioning ASD, who are not known to the local authority because they do not have an EHCP or SEN support. Children and young people with ASD but without an EHCP or SEN support may still need support, in particular those with anxiety.

3. Mental Health and Wellbeing risk factors – general population

For the general population, around half of mental health problems start by the mid-teens, and three quarters by the mid-20s, however, treatment often does not start until a number of years later. Inequality and deprivation can have a significant impact on the mental health of children and young people; wider determinants such as employment and income, crime, safety and housing are often some of the risk factors. Levels of severe mental illness are closely linked to many forms of inequality; the prevalence of psychotic disorders among the lowest fifth of household income are 9 times higher than in the highest; and double the level of common mental health problems. Deprivation includes income, employment, health, education, crime, access to housing and services, and living environment. People who live in deprived areas are more likely to need mental health services but are often less likely to access these. Deprivation can have an impact on the overall health and wellbeing of the population. [Public Health England].

Using the Indices of Deprivation 2019, in Cumbria there are 26 (out of 321) areas known as Lower Super Output Areas (LSOAs) that fall within the 10% most deprived nationally in terms of overall deprivation; these areas are located in the districts of Allerdale, Barrow-in-Furness, Carlisle and Copeland. Across the districts, Barrow-in-Furness has the greatest levels of deprivation.

Map 3 in Appendix 1 presents Cumbria's LSOAs shaded according to their level of deprivation (deprivation Decile); Decile 1 (shaded red) represents the 10% most deprived nationally while Decile 10 (shaded green) represents the 10% least deprived. In Allerdale these areas include: Moss Bay, St. Michaels, Ewanrigg, Ellenborough and Moorclose. Barrow-in-Furness: Central, Hindpool, Barrow Island, Ormsgill, Risedale and Newbarns. Carlisle: Belle Vue, Upperby, Morton and Botcherby. Copeland: Sandwith and Harbour. There are no LSOAs in the districts of Eden and South Lakeland in the 10% most deprived.

It is important to note that emotional health and wellbeing of children and young people does not just relate to overall deprivation; often there are difficulties for those living in rural areas where access to services is limited. Barriers to services are significant in many rural areas across Cumbria. Using the Indices of Deprivation – Barriers to Housing & Services domain, there are 37 LSOAs across Cumbria that fall within the 10% most deprived nationally; these are located in all districts with the exception of Barrow-in-Furness.

Map 4 in Appendix 1 presents Cumbria's LSOAs shaded according to their level of deprivation in relation to Barriers to Housing and Services. Decile 1 (shaded red) represents the 10% most deprived nationally, Decile 10 (shaded green) represents the 10% least deprived. In Allerdale these areas include: Boltons, Broughton St. Bridgets, Crummock, Dalton, Marsh, Wampool, Warnell and Waver. Carlisle: Burgh, Dalston, Great Corby, Irthing, Lyne and Stanwix Rural. Copeland: Beckermet, Ennerdale, Millom and Seascale. Eden: Brough, Crosby Ravensworth, Greystoke, Hartside, Hesket, Kirkoswald, Morland, Skelton, Ullswater, Warcop. South Lakeland: Coniston, Crooklands, Hawkshead, Low Furness, Lyth Valley, Sedbergh, Staveley-in-Cartmel, and Whinfell.

4. Cumbrian picture

As reported in the SEND Primary Needs chapter, there are 10,154 pupils aged 2-18 years (in all state-funded schools) with SEN support, accounting for 14.6% of all pupils. Of those, there are 1,185 pupils with the primary need of Social, Emotional and Mental Health (SEMH), accounting for 11.7% of all pupils with SEN; this is lower than the national average of 17.1%. (Including Pupil Referral Units, this number increases to 1,275 pupils with a primary need of SEMH).

There are 1,010 pupils with the primary need of Autistic Spectrum Disorder, accounting for 9.9% of pupils with SEN, this compares to 11.0% nationally. (Including Pupil Referral Units, this increases to 1,021 pupils).

Across the districts, Allerdale has the greatest proportion of pupils with SEN with the primary need of SEMH accounting for 16.7%, followed by Carlisle at 15.8%. Copeland has the greatest proportion of pupils with the primary need of Autistic Spectrum Disorder accounting for 20.9% and Allerdale at 12.5%; this compares to just 5.4% in Eden.

Education, Health & Care Plans

As reported in the SEND Primary Needs chapter, there are 3,206 children and young people (aged 0-25 years) with an Education, Health & Care Plan (EHCP). The greatest primary need for those with an EHCP is Autistic Spectrum Disorder, accounting for 1,004 children and young people (31.3%). 449 children and young people have a primary need of Social, Emotional & Mental Health, accounting for 14.0%.

SEN are more prevalent in boys than girls; 72.6% of EHCPs account for males, compared to 27.3% for females. The greatest primary need for males with an EHCP is Social, Emotional & Mental Health, accounting for 369 males (82.0%); this compares to 80 females (17.8%). The second greatest primary need in males with an EHCP is Autistic Spectrum Disorder, accounting for 813 males (81.0%); this compares to 191 females (19.0%).

The greatest number of children and young people with an EHCP with the primary need of ASD are aged 11-15 years, accounting for 335 children (33.4%); and those aged 5-10 years, accounting for 325 children (32.4%). The greatest number of children and young people with the primary need of Social, Emotional & Mental Health are aged 11-15 years accounting for 201 children (44.8%), and those aged 16-19 years, accounting for 132 children (29.4%).

Map 1 in Appendix 1 presents the number of children and young people (aged 0-25 years) with SEN (SEN support and/or an EHCP) with a primary need of Social, Emotional and Mental Health; by Lower Super Output Area. [Based on postcode of the child/young person]. Darker shaded areas represent areas with the greatest numbers – these include Allerdale (Moorclose and Moss Bay wards); Barrow-in-Furness (Roosecote and Central wards); Carlisle (Belle Vue, Upperby, Botcherby wards); Copeland (Distington and Sandwith wards); Eden (Brough, Penrith and Appleby wards); and South Lakeland (Ulverston and Kendal wards).

Map 2 in Appendix 1 presents the number of children and young people (aged 0-25 years) with SEN (SEN support and/or an EHCP) with a primary need of Autistic Spectrum Disorder; by Lower Super Output Area. [Based on postcode of the child/young person]. Darker shaded areas represent areas with the greatest numbers – these include Allerdale (Moss Bay and Broughton St. Bridget's wards); Barrow-in-Furness (Central, Dalton and Walney wards); Carlisle (Harraby ward); Copeland (Egremont, Sandwith, Seascale, Mirehouse and Cleator Moor wards); Eden (Penrith); and South Lakeland (Kendal).

North Cumbria Integrated Care – community referrals for Autistic Spectrum Conditions: North and South Cumbria

In 2019, there were 542 accepted referrals for children and young people aged 0-25 years into for Autistic Spectrum Conditions. (This includes referrals into community paediatrics where the referral reason was Autistic Spectrum Conditions; or if they were on the autism assessment pathway. it also includes accepted referrals into the Adult Autism Assessment service). Of those, 345 referrals were for children and young people in North Cumbria, accounting for 64%, while 194 referrals were in South Cumbria, accounting for 36%. *(See Table 11).*

Table 11: Accepted referrals into community paediatrics for Autistic Spectrum Disorder; and accepted referrals into the adult Autism Assessment service; North and South Cumbria; 2018 and 2019

	2018		2019	
	Number	Proportion	Number	Proportion
North Cumbria	396	68%	345	64%
South Cumbria	166	29%	194	36%
Out of County	20	3%	*	1%
Total	582		542	

Source: North Cumbria Integrated Care NHS Foundation Trust. **Numbers below 5 are suppressed*.

The majority of referrals for Autistic Spectrum Conditions were for males, accounting for 356 (65.7%), compared to 186 referrals for females (34.3%). *(See Table 13).* While the greatest proportion of referrals were for children aged 11-15 years, accounting for 1 in 3 children (36.2%). *(See Table 13).*

[N.B due to changes in service provision (the transfer of the Adult Autism Team to CNTW in October 2019), some data for children aged 17+ years in 2019 is incomplete]

[N.B areas with greater numbers of referrals may be due to better recording of the Autism assessment process].

Table 12: Accepted referrals into community paediatrics for Autistic Spectrum Disorder; and accepted referrals into the adult Autism Assessment service by Gender & Age; Cumbria (North and South Cumbria combined); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	42	119	161	29	87	116
5 to 10	68	148	216	59	137	196
11 to 15	30	79	109	51	76	127
16 to 19	15	31	46	25	21	46
20 to 25	18	32	50	22	35	57
Total	173	409	582	186	356	542

Source: North Cumbria Integrated Care NHS Foundation Trust.

Table 13: Proportion of accepted referrals into community paediatrics for Autistic Spectrum Disorder; and accepted referrals into the adult Autism Assessment service by Gender & Age; Cumbria (North and South Cumbria combined); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	24.3%	29.1%	27.7%	15.6%	24.4%	21.4%
5 to 10	39.3%	36.2%	37.1%	31.7%	38.5%	36.2%
11 to 15	17.3%	19.3%	18.7%	27.4%	21.3%	23.4%
16 to 19	8.7%	7.6%	7.9%	13.4%	5.9%	8.5%
20 to 25	10.4%	7.8%	8.6%	11.8%	9.8%	10.5%
Total	29.7%	70.3%		34.3%	65.7%	

Source: North Cumbria Integrated Care NHS Foundation Trust. **Numbers below 5 are suppressed*.

Referrals into Children and Young Adults Mental Health services (CNTW): North Cumbria

In 2019, there were 6,715 referrals for children's and young adults (aged 0-25 years) mental health services including: Acute Urgent Care Crisis; Adults Community Mental Health Assessment & Recovery Teams; Children Urgent Care Crisis; Learning Disability and Autism services; and Child & Adolescent Mental Health Services. Of those referrals, 667 were for children and young people with a record of an Education, Health & Care Plan, accounting for 10% of all referrals. *(See Table 1).*

[N.B. The data contained within this section covers North Cumbria, however, there are some cases where some children and young people reside in South Cumbria].

Table 1: Referrals into ALL children's and young people's community Mental Health Services by service; North (and South) Cumbria; 2018 and 2019

	2018			2019		
	All referrals	EHCP	EHCP %	All referrals	EHCP	EHCP %
Acute Urgent Care Crisis	1,536	40	3%	2,078	61	3%
Adults CMHART	861	15	2%	824	16	2%
Children Urgent Care Crisis	407	52	13%	505	57	11%
LD, Autism & CAMHS	3,124	634	20%	3,306	533	16%
Total	5,929	741	12%	6,715	667	10%

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

Across the districts, the greatest number of referrals were in Carlisle followed by Allerdale. *(See Table 2).*

Table 2: Referrals into ALL children's and young people's community Mental Health Services; North (and South) Cumbria by District; 2018 and 2019

	Acute Urgent Care Crisis	Adults CMHART	Children Urgent Care Crisis	LD, Autism & CAMHS	Total
Allerdale	480	201	145	1,057	1,883

Barrow-in-Furness	186	*	*	30	222
Carlisle	719	345	175	1,155	2,395
Copeland	297	147	107	651	1,203
Eden	180	95	45	342	662
South Lakeland	61	*	*	24	88
Out of County/NAs	155	32	28	47	262
Total	2,078	824	505	3,306	6,715

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust. *[Numbers below 5 are suppressed].*

In 2019, the split between referrals into ALL mental health services were similar for both males and females accounting for 48.0% and 52.0% respectively. In terms of age, the greatest number of referrals were for young people aged 20-25 years, accounting for 30.0%; 1 in 4 referrals were for children aged 11-15 years (25.2%) and 16-19 years (25.4%).

Table 3: Referrals into ALL children's and young people's community Mental Health Services; North (and South) Cumbria; by Age and Gender (North and South Cumbria); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	48	159	207	52	146	198
5 to 10	346	711	1,057	340	766	1,106
11 to 15	852	684	1,536	964	728	1,692
16 to 19	847	556	1,404	1,037	668	1,705
20 to 25	967	758	1,725	1,102	912	2,014
Total	3,060	2,868	5,929	3,495	3,220	6,715

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

Table 4: Proportion of referrals into ALL children's and young people's community Mental Health Services; North (and South) Cumbria; by Age and Gender (North and South Cumbria); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	1.6%	5.5%	3.5%	1.5%	4.5%	2.9%
5 to 10	11.3%	24.8%	17.8%	9.7%	23.8%	16.5%
11 to 15	27.8%	23.8%	25.9%	27.6%	22.6%	25.2%
16 to 19	27.7%	19.4%	23.7%	29.7%	20.7%	25.4%
20 to 25	31.6%	26.4%	29.1%	31.5%	28.3%	30.0%
Total	51.6%	48.4%		52.0%	48.0%	

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

Acute Urgent Care Crisis: North Cumbria

In 2019, there were 2,078 referrals into children and young people's (aged 11-25 years) Acute Urgent Care Crisis services. Of those, only 61 referrals were for children and young people with an Education, Health & Care Plan, accounting for just 2.9% of all referrals. Across the districts, the greatest number of referrals were in Carlisle and Allerdale. (See Table 5).

Table 5: Referrals into Acute Urgent Care Crisis; by District (North and South Cumbria); 2018 and 2019

	2018			2019		
	All referrals	EHCP	EHCP %	All referrals	EHCP	EHCP %
Allerdale	351	3	0.9%	480	7	1.5%
Barrow-in-Furness	67	2	3.0%	186	8	4.3%
Carlisle	510	23	4.5%	719	23	3.2%
Copeland	257	5	1.9%	297	13	4.4%
Eden	128	3	2.3%	180	6	3.3%
South Lakeland	39	4	10.3%	61	4	6.6%
Out of County/NAs	184	0	0.0%	155	0	0.0%
Total	1,536	40	2.6%	2,078	61	2.9%

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust. *[Numbers below 5 are suppressed].*

In 2019, the greatest number of referrals into Acute Urgent Care Crisis services were for young people aged 20-25 years, accounting for 1,292 referrals, 62.2%. (See Table 6).

Table 6: Referrals into Acute Urgent Care Crisis; by Age and Gender (North and South Cumbria); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
11 to 15	33	21	54	61	33	94
16 to 19	298	164	462	425	267	692
20 to 25	592	428	1,020	710	582	1,292
Total	923	613	1,536	1,196	882	2,078

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

Table 7: Proportion of referrals into Acute Urgent Care Crisis; by Age and Gender (North and South Cumbria); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
11 to 15	3.6%	3.4%	3.5%	5.1%	3.7%	4.5%
16 to 19	32.3%	26.8%	30.1%	35.5%	30.3%	33.3%
20 to 25	64.1%	69.8%	66.4%	59.4%	66.0%	62.2%
Total	60.1%	39.9%		57.6%	42.4%	

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

Learning Disability, Autism and CAMHS: North Cumbria

In 2019, there were 3,306 referrals into children and young people's (aged 0-25 years) Learning Disability, Autism and Child & Adolescent Mental Health Services. Of those, 533 referrals were for children and young people with an Education, Health & Care Plan, accounting for 16% of all referrals. Across the districts, the greatest number of referrals were in Carlisle followed by Allerdale. The greatest proportion of referrals for children and young people with an EHCP was in Eden (19%) followed by Allerdale (17%). (See Table 8).

Table 8: Referrals into Learning Disabilities, Autism and Child & Adolescent Mental Health Service; by District (North and South Cumbria); 2018 and 2019

	2018			2019		
	All referrals	EHCP	EHCP %	All referrals	EHCP	EHCP %
Allerdale	879	188	21%	1,057	179	17%
Barrow-in-Furness	22	3	14%	30	4	13%
Carlisle	1,111	212	19%	1,155	174	15%
Copeland	630	149	24%	651	103	16%
Eden	345	70	20%	342	64	19%
South Lakeland	22	3	14%	24	3	13%
Out of County/NAs	115	9	8%	47	6	13%
Total	3,124	634	20%	3,306	533	16%

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

In 2019, the greatest proportion of referrals into Learning Disabilities, Autism and Child & Adolescent Mental Health services were for children and young people aged 11-15 years, accounting for 40.3%, followed by 5-10 years, accounting for 33.1%. *(See Table 10).*

Table 9: Referrals into Learning Disabilities, Autism and Child & Adolescent Mental Health Services; by Age and Gender (North and South Cumbria); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	48	159	207	52	145	197
5 to 10	341	707	1,048	340	755	1,095
11 to 15	642	589	1,231	714	619	1,333
16 to 19	289	228	518	295	227	522
20 to 25	54	66	120	65	94	159
Total	1,374	1,749	3,124	1,466	1,840	3,306

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

Table 10: Proportion of referrals into Learning Disabilities, Autism and Child & Adolescent Mental Health Services; by Age and Gender (North and South Cumbria); 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	3.5%	9.1%	6.6%	3.5%	7.9%	6.0%
5 to 10	24.8%	40.4%	33.5%	23.2%	41.0%	33.1%
11 to 15	46.7%	33.7%	39.4%	48.7%	33.6%	40.3%
16 to 19	21.0%	13.0%	16.6%	20.1%	12.3%	15.8%
20 to 25	3.9%	3.8%	3.8%	4.4%	5.1%	4.8%
Total	44.0%	56.0%		44.3%	55.7%	

Source: Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust.

Map 5 in Appendix 1 presents the number of referrals into children's Learning Disabilities, Autism and Child & Adolescent Mental Health Services by Lower Super Output Area [based on postcode of the child/young person]. Darker shaded areas represent areas with the greatest numbers of referrals. By district, the areas include Allerdale: Moss Bay, Moorclose, Wigton and Aspatria; Carlisle: Belle Vue, Upperby, Botcherby, Currock, Dalston, Harraby, Denton Holme, Belah, Morton, Brampton and Yewdale; Copeland: Egremont, Mirehouse, Sandwith and Distington; Eden: Penrith.

Referrals into Children and Young Adults Mental Health services (LSCFT): South Cumbria

The following data has been sourced from the previous provider of community mental health services – Cumbria Partnership Foundation Trust, covering South Cumbria. The data presented refers to all children and young people aged 0-25 years; there is no data available for children and young people with an Education, Health & Care Plan.

In 2019, there were 3,097 referrals for children's and young adults (aged 0-25 years) community mental health services. Of those referrals, 1,441 were for Child & Adolescent Mental Health Services (CAMHS) *(See Table 14).*

Table 14: Referrals into ALL children's and young people's community Mental Health Services by service; South (and North) Cumbria; 2018 and 2019

	2018 All referrals	2019 All referrals
Adult - CMHT	257	353
Adult A & E Liaison	224	293
CAMHS	1,027	1,441
Crisis Resolution and Home Treatment	400	627
Early Intervention Service	27	35
Eating Disorder	6	17
Learning Disability	231	331
Grand Total	2,172	3,097

Source: Lancashire & South Cumbria NHS Foundation Trust.

Across the districts, the greatest number of referrals were in Barrow-in-Furness. *(See Table 15).*

Table 15: Referrals into ALL children's and young people's community Mental Health Services; South (and North) Cumbria by District; 2018 and 2019

	Adult - CMHT	Adult A & E Liaison	CAMHS	Crisis Resolution and Home Treatment	Early Intervention Service	Eating Disorder	Learning Disability
Allerdale	*	*	*	7			
Barrow-in-Furness	269	320	1,120	491	28	*	307
Carlisle	*		*	*			
Copeland	31	*	63	36	*	*	40
Eden	*		*	*			
South Lakeland	230	49	1,024	282	25	19	241
Out of County/NAs	76	138	256	202	*	*	48

Total	610	517	2,468	1027	62	23	638

Source: Lancashire & South Cumbria NHS Foundation Trust. *[Numbers below 5 are suppressed].*

In 2019, there were more referrals for females than males into ALL mental health services accounting for 53.43% compared to 46.57% respectively. In terms of age, the greatest number of referrals were for young people aged 20-25 years, accounting for 28.96%. *(See Tables 16 & 17)).*

Table 16: Referrals into ALL children's and young people's community Mental Health Services; South (and North) Cumbria; by Age and Gender; 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	12	31	43	21	52	73
5 to 10	90	188	278	130	311	441
11 to 15	333	289	622	492	365	857
16 to 19	378	218	596	509	318	827
20 to 25	382	248	630	501	395	896
Total	1,195	974	2,169	1,653	1,441	3,094

Source: Lancashire & South Cumbria NHS Foundation Trust.

Table 17: Proportion of referrals into ALL children's and young people's community Mental Health Services; South (and North) Cumbria; by Age and Gender; 2018 and 2019

Age (years)	2018			2019		
	Female	Male	Total	Female	Male	Total
1 to 4	27.91%	72.09%	1.98%	28.77%	71.23%	2.36%
5 to 10	32.37%	67.63%	12.82%	29.48%	70.52%	14.25%
11 to 15	53.54%	46.46%	28.68%	57.41%	42.59%	27.70%
16 to 19	63.42%	36.58%	27.48%	61.55%	38.45%	26.73%
20 to 25	60.63%	39.37%	29.05%	55.92%	44.08%	28.96%
Total	55.09%	44.91%		53.43%	46.57%	

Source: Lancashire & South Cumbria NHS Foundation Trust.

5. Other mental health services and service use in Cumbria

MyTime is part of the CAMHS service provision for children and young people needing emotional health and wellbeing support. MyTime work with mild to moderate emotional health presentations such as anger, anxiety, low mood, self-harm and depression.

As reported in North Cumbria's Local Transformation Plan, 839 children and young people aged 5 to 18 years were referred to MyTime during October 2018 to October 2019 (North Cumbria only). Since October 2018, MyTime has experienced a 73% increase in referrals.

As reported in Barnardo's My Time Annual Report – South Cumbria & Barrow, 534 children and young people aged 5 to 18 years were referred to MyTime South during 2019/20, an increase of +208 from 326 in 2018/19.

The West Coast Resilience Project provided by Cumbria Youth Alliance is targeted at vulnerable children and young people aged 14 to 25 years in deprived west coastal areas. In its first year between May 2018 to June 2019, 2,152 children and young people engaged on the programme.

Kooth is a universal online emotional support service for children and young people aged 11 to 18. As reported in North Cumbria's Local Transformation Plan, throughout 2018/19, 2,183 young people used the service, around 182 new registrations per month. Across the districts, greatest numbers/demand were in Barrow, Carlisle and Whitehaven, likely reflecting the greater numbers of children and young people in those areas.

Information about further mental health services can be found in the "Primary Mental Health Worker Report 2019-20", Lancashire & South Cumbria NHS Foundation Trust/Barnado's.

6. Children and Young People's Mental Health and Wellbeing – general population

Figure 1 below presents how children and young people's mental health and wellbeing in Cumbria (*all* children) compares with the rest of England. Overall, when comparing to England, the health and wellbeing of children in Cumbria is mixed. Based on the results from the 2017 Mental Health of Children and Young People's Survey, 2017, there are an estimated 8,366 children and young people aged 5 to 17 with a mental disorder in Cumbria. Rates of 'hospital admissions as a result of self-harm' for children aged 10-14 years and children and young people aged 10-24 years are worse than the national average at 330.6 per 100,000 compared to 210.4 per 100,000; and 548.1 compared to 444.0 respectively. [Data is for all children and young people and is not available for children and young people with Special Educational Needs].

Figure 1: Cumbria Area Profile: Children and Young People's Mental Health and Wellbeing

Data quality: 🟥 Significant concerns 🟨 Some concerns 🟩 Robust

Compared with benchmark: 🟢 Better 🟡 Similar 🔴 Worse ○ Not compared

Quintiles: Best ● ● ● ● ● Worst ○ Not applicable

Recent trends: – Could not be calculated ➡ No significant change ⬆ Increasing / Getting worse ⬆ Increasing / Getting better ⬇ Decreasing / Getting worse ⬇ Decreasing / Getting better ⬆ Increasing ⬇ Decreasing

Benchmark Value
Worst/Lowest 25th Percentile 75th Percentile Best/Highest

Indicator	Period	Cumbria			Region	England	England		
		Recent Trend	Count	Value	Value	Value	Worst/ Lowest	Range	Best/ Highest
Estimated number of children and young people with mental disorders – aged 5 to 17 🟨	2017/18	–	-	8,366	-	-	-	-	-
Estimated prevalence of emotional disorders: % population aged 5-16 🟨	2015	–	2,256	3.6%*	3.7%*	3.6%*	2.8%		4.2%
Estimated prevalence of conduct disorders: % population aged 5-16 🟨	2015	–	3,551	5.7%*	5.8%*	5.6%*	4.0%		6.9%
Estimated prevalence of hyperkinetic disorders: % population aged 5-16 🟨	2015	–	938	1.5%*	1.6%*	1.5%*	1.1%		1.9%
Prevalence of potential eating disorders among young people: estimated number aged 16 - 24 🟥	2013	–	6,365	6,365*	110693*	*	-	-	-
Prevalence of ADHD among young people: estimated number aged 16 - 24 🟥	2013	–	6,805	6,805*	116681*	*	-	-	-
Percentage of looked after children whose emotional wellbeing is a cause for concern	2018/19	–	79	28.3%	34.3%	38.6%	70.4%		20.3%
Hospital admissions as a result of self-harm (10-24 years)	2018/19	–	410	548.1	517.4	444.0	1,072.7		91.1
Hospital admissions as a result of self-harm (10-14 yrs)	2017/18	➡	86	330.6	313.5	210.4	627.1		35.3
Hospital admissions as a result of self-harm (15-19 yrs)	2017/18	➡	172	673.8	706.7	648.6	1,540.3		170.1
Hospital admissions as a result of self-harm (20-24 yrs)	2017/18	⬇	86	346.5	449.8	406.0	1,149.1		75.8
School pupils with social, emotional and mental health needs: % of school pupils with social, emotional and mental health needs (Primary school age) 🟩	2018	–	628	1.60%	2.12%	2.19%	3.95%		1.17%
School pupils with social, emotional and mental health needs: % of school pupils with social, emotional and mental health needs (Secondary school age) 🟩	2018	–	467	1.59%	2.19%	2.31%	4.66%		1.17%
School pupils with social, emotional and mental health needs: % of school pupils with social, emotional and mental health needs (School age) 🟩	2018	–	1,098	1.59%	2.35%	2.39%	4.26%		1.24%

Source: Public Health England

7. User Views and Views from Practitioners

Cumbria SEND Parent/Carer Survey 2019 – Cumbria County Council

In the Written Statement of Action there is a commitment to carry out a large scale postal/online survey of parents and carers of children and young adults (up to age 25 years) with Special Educational Needs and Disabilities. A survey took place between 12th November to 31st December 2019 with the aim of exploring the experiences of SEND services and the SEND Improvement Programme. Surveys were sent to both parents and carers and children who have an Education Health & Care Plan. For the purpose of this JSNA chapter, responses and themes will mainly focus on emotional health and wellbeing.

539 (out of 3,426 surveys mailed) parents and carers completed the survey, a response rate of 16% [NB. due to a relatively low response rate, caution should be used when drawing conclusions]. Of those responses, the most common primary need was Autistic Spectrum Disorder accounting for almost half (45%), while Social, Emotional and Mental Health accounted for 9%. 40% of additional needs accounted for Autistic Spectrum Disorder, 36% accounted for Social, emotional and Mental Health.

96% of parents and carers reported that they had accessed education services in Cumbria; 75% had accessed health services; 47% had accessed social care; while 52% had accessed emotional health and wellbeing services.

Feedback from parents and carers on their experience of emo*tional health and wellbeing* services in Cumbria was generally poor:

- 42% agreed that their child has been able to access provision in the area;
- 42% agreed their child's needs were properly identified by the service at the earliest opportunity
- 55% agreed their views and child's views are taken into account by the service
- 57% are involved in setting targets/outcomes for their child
- 45% are satisfied with the monitoring and assessment of their child's provision
- 46% agree that different services and professionals work well together to support their child
- 48% agreed the provision is currently meeting their child's needs
- 48% agreed support with transport is appropriate

When parents and carers were asked what issues they would prioritise for improvement, the greatest responses related to early intervention/quicker access to services, accounting for 27%, followed by communication with parents, accounting for 21%; this compares to 5% for mental health services (access and provision).

Some comments received from parents and carers covering all aspects of SEND services include:

- *"being supported in education and having routine and structure helps my child"*
- *"there is a lack of communication of what services are available in the area"*
- *"lack of communication between different departments and professionals"*
- *"the time it takes to get reviewed EHCP after annual review is too long"*

- *“To be listened to, parents/carers are experts in their children’s needs but get overlooked”*
- *“Earlier identification of need – therefore more support/training in primary schools”*

A supplementary survey was carried out for children and young people that receive SEND services in Cumbria; 369 children completed the survey, a response rate of 11%. *[NB. due to a relatively low response rate, caution should be used when drawing conclusions].*

Results paint a positive picture on the support children and young people receive from those that help them learn and stay healthy. Most respondents felt that the people who help them learn and stay healthy know what they need and listen to what they want.

Some of the key findings are as follows:

- 75% agreed the people who help them learn know what they need
- 74% agreed the people who help them learn listen to what they want
- 48% agreed they help decide what they want to happen about school and learning
- 75% agreed that the people who help them to stay healthy know what they need
- 70% felt that the people who help them to stay healthy listen to what they want
- 56% agreed they help decide that they want to happen to help them stay healthy

When children and young people were asked about the help and support they get and to share feedback. The greatest responses related to lack of help/support, accounting for 17 responses; while 11 respondents agreed they were generally satisfied.

Some comments received from children and young people relating to the help and support they get include:

- *“Since receiving a place at a special school my life has changed positively”*
- *“I like getting all the help I get because it makes me happy*
- *“The help I get it is very poor sometimes I get it and I don’t, so I probably need more support”*
- *Don’t get any help or support apart from school, never been told about any help or support*

Feedback from parents and carers

Following discussion(s) with parents and carers for children and young people with Autistic Spectrum Disorder, some of the key points and areas of concern to consider are set out below: *(N.B. these views don't necessarily represent the views of all parents and carers and should therefore be used with caution when drawing conclusions).*

- It is Important to consider the emotional wellbeing and mental health of ALL children and young people with SEND.
- **Prevention** – it is important to focus on prevention before situations escalate and end at crisis point.
- **Broad spectrum and individual needs with differ dramatically** - need to consider how broad the spectrum of ASD is and how individual needs will differ.
- **Support for parents and carers and their emotional health and wellbeing** - it is important to consider what support and help they may need; there can be significant emotional distress, particularly when the child is young/baby.
- **Stress management life tools** – provide and raise awareness of the tools available for parents, carers and their children. Long-term support is important. Stress is a significant issue for people with SEND; it is important to teach stress management strategies (i.e. yoga, breathing, exercise). Some good work already in schools but funding/time is short.
- **Good mental health –** can be supported through breath and physical movement (as above). Exercise positive impact and helpful for supporting mental health.
- **Positive impact of exercise but can also cause stress** – Exercise can have a very positive impact and is helpful for supporting mental health, however, some exercise such as PE in school can be overwhelming and distressing.
- **Healthy, physical activity and exercise –** tailor physical activity and exercise to support needs - identify likes, dislikes and triggers. Much more is needed in terms of what is offered in mainstream schools. Good examples in James Rennie. Much more difficult in rural schools where there are only one or two pupils with SEN. Needs to be a supportive pathway created for those with SEND to encourage physical activity. (example Triple A – getting young people active).
- **Occupational Therapy and sensory sessions** - positive impact of Occupational Therapy and sensory sessions (example of case studies in South where this has helped significantly).
- **Criminal offending** – children and young people with ASD often offend. Work should be been done in relation to preventing criminal offending through Triple A and North Cumbria CCG.
- **Schools -** more training is needed for school staff;
- **Sex education/sexual health/information around puberty** – concerns that the current offer in schools is inadequate. More advice and guidance is needed for

parents, carers and school teachers. Worth noting that some children with ASD develop early and may sexually offend.

- **Support Groups for young children** – there are gaps in provision/support groups for younger children (i.e. primary age)
- **Being heard** – it is important to allow children and young people to be heard; somewhere where their needs, frustrations and anxieties can be heard and supported.
- **Adoption** - more support is needed for all - post adoption gaps in support. Often trauma presents as SEN in adoptive children.
- **ASD Pathway** – needs significantly improved
- **Interim support for those awaiting treatment** – support while children and parents/carers are waiting for mental health services would be helpful, including support groups
- **Local Offer** – ensure this is up-to-date. Raise awareness - not all parents and carers are aware this is available.

Feedback from practitioners

Following discussion(s) with practitioner(s) at Child and Adolescent Mental Health Services, some of the key points relating to why might children and young people with SEND may be more vulnerable to developing mental health problems. Also a note of current services offered to this client group:

Attachment/Infancy

Early support is needed – parents and carers need much more support and help with the relationship with the child at the very early stages.

- SEND is usually unexpected. There is often a need for parents to grieve for the child they expected to have, alongside the task of developing a relationship with the baby they have.
- Children with SEND are different from an ‘average’ child in at least one way (usually in several ways) and getting to know them takes a little more effort and allows the adult to make fewer assumptions.
- Communication (verbal and non-verbal) may be impaired. So the ‘dance’ of interaction between carer and baby is harder to learn and may never be fluid and comfortable.

A difficult or unsatisfying relationship between carer and baby increases the risk of mental health problems for either parent and/or infant.

Communication

Finding reliable means of communication is crucial throughout childhood. This is clearly seen in the research on the prevalence of mental health problems in people with hearing impairment.

- Without the muscular control of our facial expression, the brain misses out on useful signals to tell us what we are feeling.
- Without words, it is difficult to name the emotion and look for specific strategies to manage it.
- Without reliable communication it is much more difficult for children to express any specific emotion or elicit a helpful response from their adults or friends.

Stigma

Social standing becomes important once a child is at school. At first they need to belong and then they need to compete. These are key to a child's self-esteem and thus, mental health.

- A child needs group membership; they do not want to feel different. Any type of segregation risks making the minority group feel 'less' or inferior, but standard practice leaves the 'special' needs unmet.
- By the end of primary school there is a lot of competition. It's about being recognised and valued by your peers (and adults). It may be "Who is best at football?" or "Who is best at making their friends laugh?" but children with SEND may find this competitive aspect of being with peers extremely difficult.
- In secondary school all the values of our society are present including stigma around disability. Any adolescent may struggle with developing emotional regulation, a sense of identity, good peer relationships and independence from parents; accompanied by media images of an unobtainable ideal. Those with SEND may have to manage those tasks, while being short of positive role models or any adults with whom they can identify.

Services

- CAMHS - Tier 3 service (Core CAMHS; Eating Disorders; ADHD) and CAIS/Crisis
- MyTime (Barnados) – Tier 2
- PAC, Children's Centres – Tier 1
- Referrals are received into CAMHS and are triaged by CAMHS and MyTime within 24 hours. We decide what is needed and where the referral should go.
- If an initial assessment by CAMHS is needed an appointment letter is sent out the same day. So families know within a few days if it is CAMHS who will deal with the referral.

- Initial assessments are usually offered for a month after triage (although this changes with demands on the service).
- An interim service/offer of advice is available from CAMHS while families wait; useful resources available
- Waiting times have reduced significantly in the past 18 months (Jan 2019-June 2020).
- Prior to covid-19 approximately 15 referrals were received per day
- Most referrals for children with SEND presenting with unusual behaviour will probably go to the LD service. Moderate-severe mental health problems are rare in any group of children. We do get requests for ASD assessments every week and have to explain ASD assessments are done by our paediatric colleagues, not CAMHS. However a significant number of children with a significant mental health problem - who are also on the autistic spectrum- are treated within CAMHS.
- A small proportion of referrals have an EHCP, perhaps not reflecting the true need
- A significant number of children with an EHCP have Autism
- CAMHS service is much smaller in Cumbria compared to other areas.

8. Qualitative Deep Dive - The Lived Experience of Families

SEND and Mental Health Emotional Wellbeing (MHEWB) - Qualitative Deep Dive
What have families 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 X) 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 by2022/23.

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 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.

9. 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"

10. Further information

Special Educational Needs in England; January 2019:
https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2019

Cumbria County Council – Special Educational Needs and Disabilities JSNA:
https://www.cumbriaobservatory.org.uk/jsna/send/

Public Health, Cumbria County Council, 5-19 mental health and wellbeing:
https://www.cumbria.gov.uk/ph5to19/mentalhealth.asp

The wellbeing of secondary school pupils with SEN; Department for Education:
https://www.gov.uk/government/publications/the-wellbeing-of-secondary-school-pupils-with-sen

Measuring Mental Wellbeing in Children and Young People; Public Health England:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/768983/Measuring_mental_wellbeing_in_children_and_young_people.pdf

Mental Health of Children and Young People in England, NHS Digital, 2017:
www.digital.nhs.uk

Cumbria SEND Parent/Carer Survey 2019

North Cumbria Children & young People's Resilience, Emotional Wellbeing and Mental Health – Local Transformation Plan 2019-2020:
https://northcumbriaccg.nhs.uk/publications/strategies/navigate/18637/3463

Child & Adolescent Mental Health Service (East/West); Cumbria, Northumberland Tyne & Wear NHS Foundation Trust: https://www.cntw.nhs.uk/services/?filter_page=2

Child & Adolescent Mental Health Service (South Cumbria); Lancashire & South Cumbria NHS Foundation Trust: https://www.lscft.nhs.uk/CAMHS

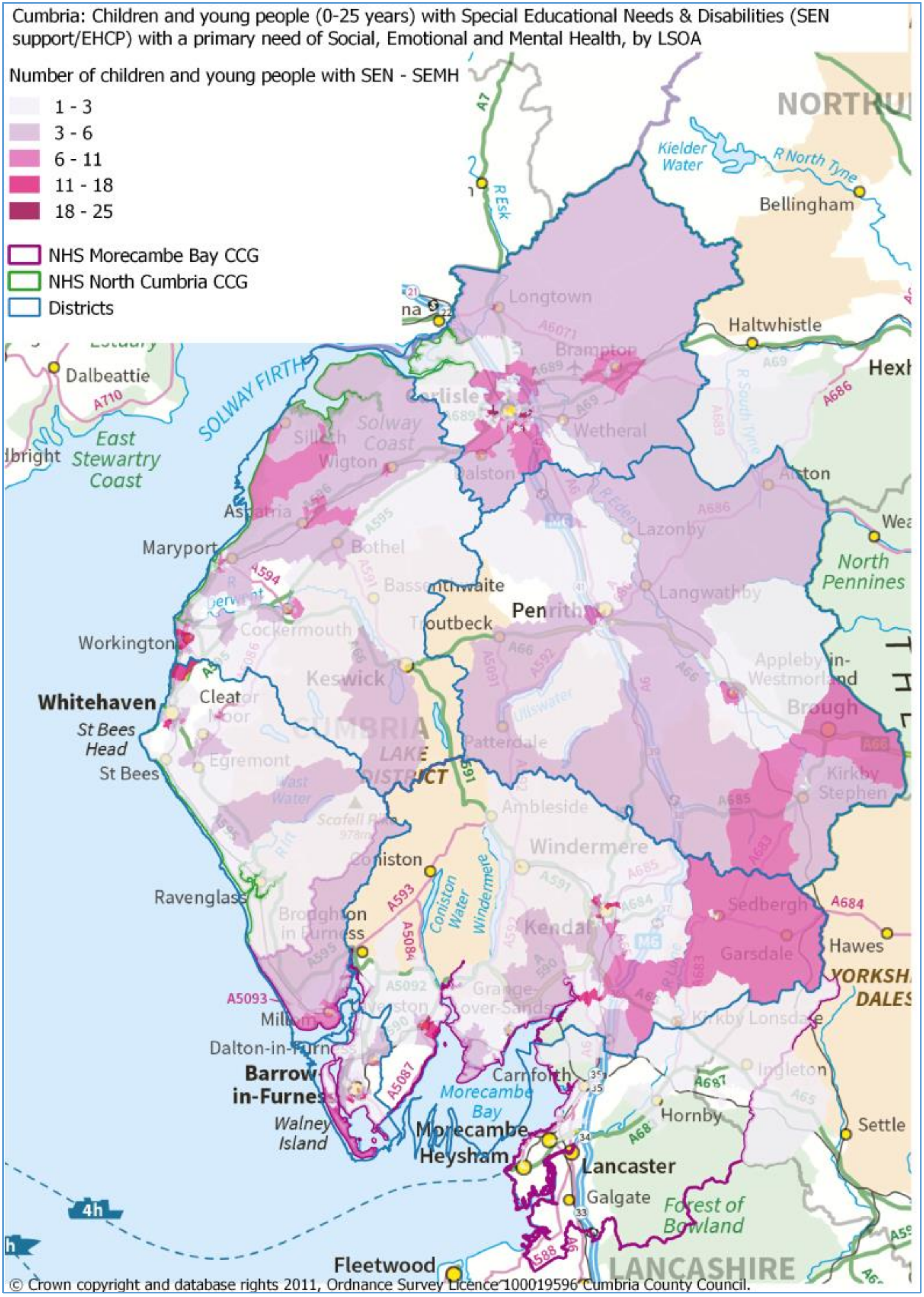
Barnardo's – MyTime: https://www.barnardos.org.uk/what-we-do/services/mytime-cumbria

Kooth: https://localoffer.cumbria.gov.uk/kb5/cumbria/fsd/service.page?id=zG5R-lRoVsA

English Indices of Deprivation 2019: https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019

11. Appendix 1

Map 1: Cumbria - Children and young people (0-25 years) with SEND (SEN support and/or an EHCP) with a primary need of Social, Emotional and Mental Health; by Lower Super Output Area.

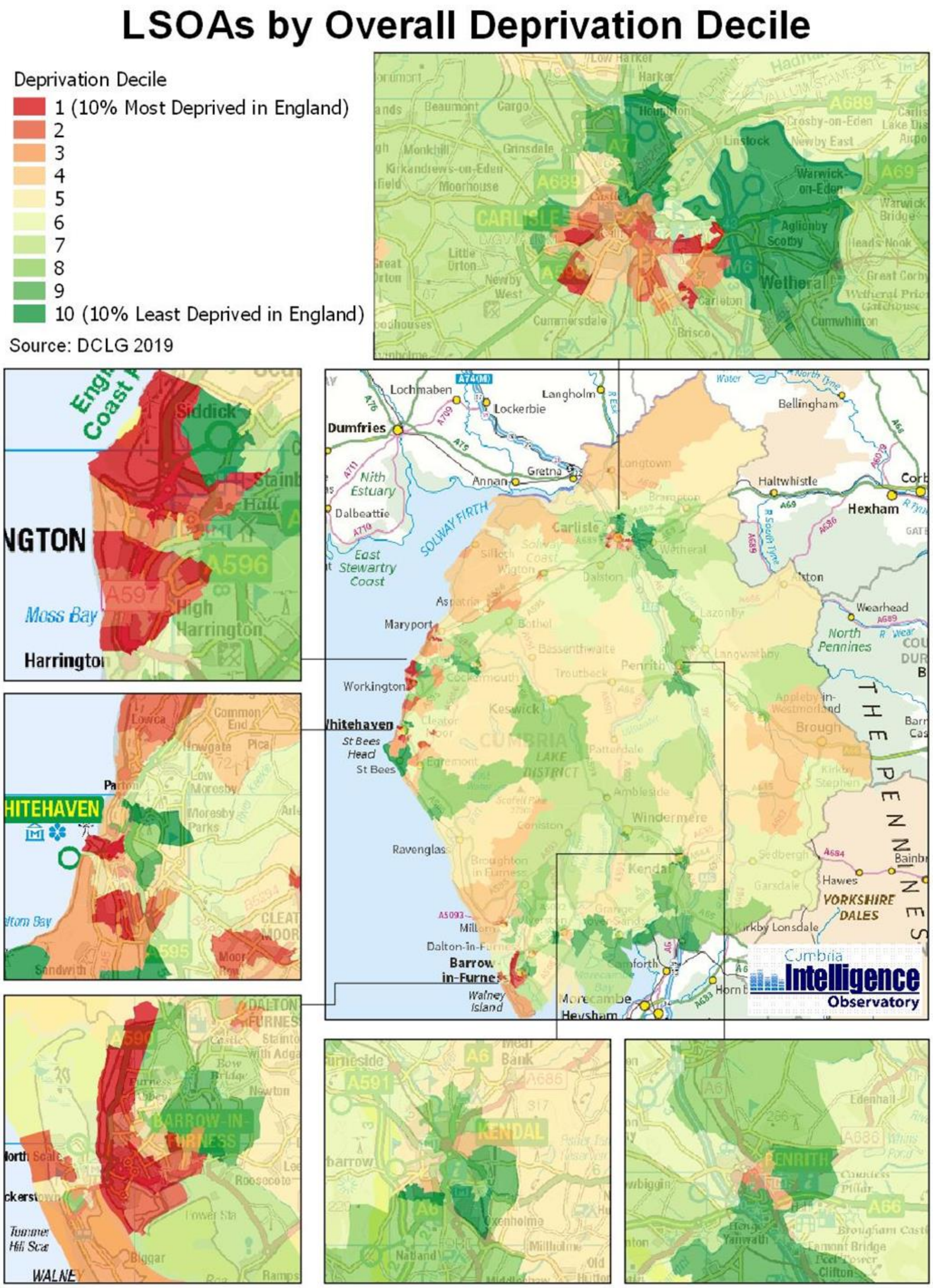


Source: Cumbria County Council, 2019. [Based on postcode of the child/young person].

Map 2: Cumbria - Children and young people (0-25 years) with SEND (SEN support and/or an EHCP) with a primary need of Autistic Spectrum Disorder; by Lower Super Output Area.

Source: Cumbria County Council, 2019. [Based on postcode of the child/young person].

Map 3: Cumbria – Overall Deprivation by Lower Super Output Area.



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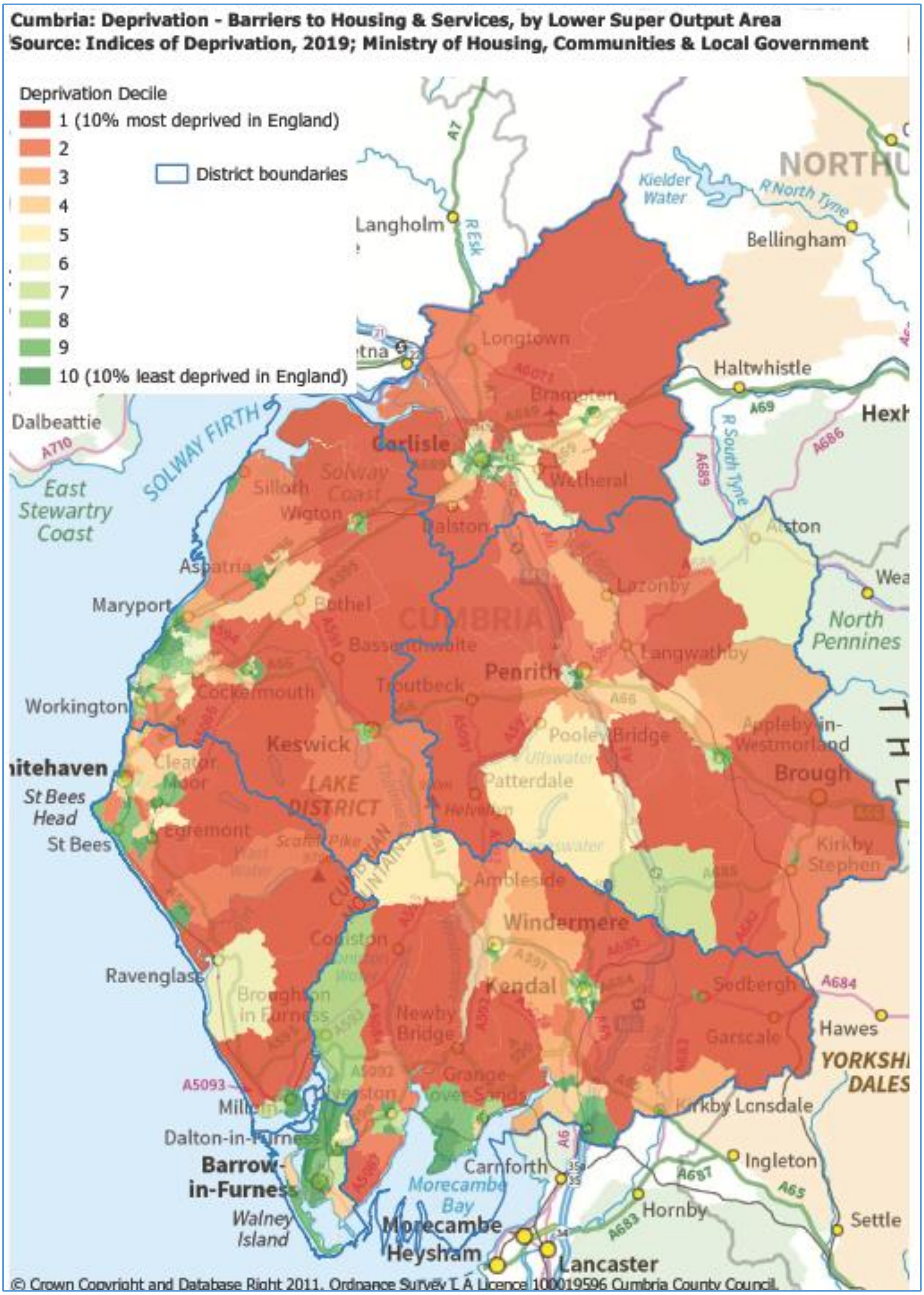
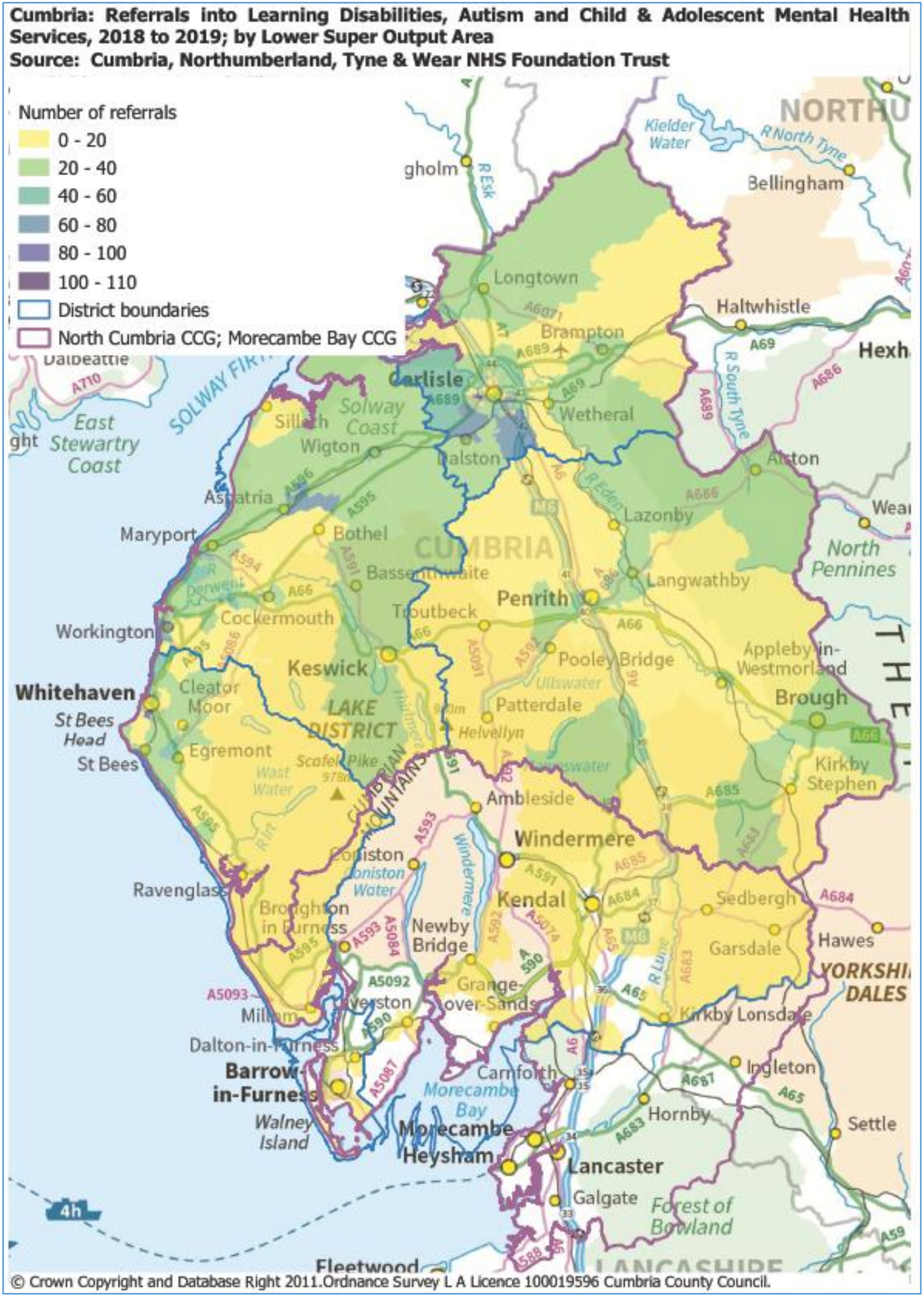
Source: Indices of Multiple Deprivation 2019

Map 4: Cumbria – Deprivation: Barriers to Housing and Services, by Lower Super Output Area.



Source: Indices of Multiple Deprivation 2019

Map 5: Cumbria: Referrals into Children's Learning Disabilities, Autism and CAMHs services; by Lower Super Output Area



Source: Cumbria County Council/Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust, 2018 to 2019

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