

## Children and Young People in Liverpool with Special Educational Needs and/or Disabilities: Health Needs Assessment

August 2017



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## Executive Summary

The purpose of this health needs assessment (HNA) is to inform partners of the health needs of children and young people with special educational needs and/or disabilities (SEN+/-D) living in Liverpool. It includes statistical data and information from focus groups, interviews and conversations with pupils, parents, carers, teachers, school nurses, and wider stakeholders. Interviews, focus groups, and other informal feedback from a range of stakeholders was cross-referenced and triangulated with other sources of information to draw conclusions on felt and expressed needs.

- The numbers and rates of SEN+/-D in children are difficult to accurately measure. Modelled estimates suggest that between 2,573 and 4,631 children have some form of disability. In November 2015, just over 4,000 children aged under 18 in Liverpool received disability living allowance which proportionately is greater than the national average (4% in Liverpool compared with 3.3% nationally).
- Since 2011, the number of pupils with special educational needs (SEN Support, Statements or EHCPs) in Liverpool maintained schools has been on the decline. However within that cohort the number of pupils with statements of special educational need or EHCPs has been rising primarily due to large increases in those with autistic-spectrum disorders (ASD), profound and multiple learning disabilities, and other disorders.
- In 2016, 1,610 (2.3%) of Liverpool pupils had an education health and care plan (EHCP) or statement of special educational needs, a slightly lower percentage of pupils than in England as a whole (2.8%), and similar to other comparator cities.
- In Liverpool, most children and young people with Statements or EHCPs (3 out of 4) attend special schools. This is much more common than in England as a whole, where less than 2 out of 4 attend special schools and most are integrated into mainstream schools.
- The most common primary needs of pupils with statements or EHCPs in January 2016 were autistic-spectrum disorders (27.1%), severe learning difficulties (25.4%) and social, emotional and mental health (SEMH) needs (13.6%), while 4.1% had physical disability as the primary need. Most notably since 2011, there have been significant increases in the numbers of pupils with autistic spectrum disorders (75% increase) and severe learning difficulties (77% increase) identified as a primary need.

The recommendations in this report respond to key emerging themes concerning:

- Improving support for parents and carers to help them navigate and cope with health care systems
- Improving the management of clinical care in and out of school, including routine and emergency procedures for children with SEN+/-D
- Improving oversight and clinical governance of clinical support offered in schools
- Improving support for families around school transition points
- Strengthening support to enable more children with SEN+/-D to integrate into mainstream schools

## 1. Recommendations

The tables below highlight recommendations arising from this report. A number of priority recommendations have been identified as needing priority action. These are highlighted in bold text. These recommendations are also listed in the relevant areas of the report, numbered in order of appearance in the text

### 1.1 Key Principles

No.	Recommendation
3	Commissioners of services for children and young people with SEN+/-D should: a) Strengthen their commitment to working together for achieving high quality child and family -centred outcomes for children and young people with SEN+/-D b) Work with all providers to develop clear outcome focussed delivery plans and effective communication systems that are centred on the need(s) of individual children/young people and their family.
11	A Behavioural Insight study should be undertaken to examine further the attitudes and behaviours to achieving an inclusive “mainstream first” system and culture in Liverpool which will, as far as possible, integrate children with SEN+/-D into mainstream society.
13	<b>Healthcare providers in partnership with their commissioners should develop and strengthen further the clinical governance arrangements for both Public Health school nurses and clinical paediatric nurses based in special schools as a priority.</b>
17	Commissioners should determine and agree the distinct but complementary relationship between: a) Those nurses providing a public health service, i.e. public health school nurses (SCPHN-SN) and their teams, to all children and young people of school age in Liverpool and b) Clinical paediatric nurses (and their teams), who provide a year-round clinical service, who have current clinical knowledge and skills.

### 1.2 Vaccination

No.	Recommendation
1	Review current arrangements for vaccinating children in special schools for seasonal influenza. Re-establish a whole-school approach to seasonal influenza vaccination in special schools, including offer of influenza vaccination to all pupils in the school.

### 1.3 Improving Early Recognition and Diagnosis

Early recognition of new and/or developing medical and behavioural problems is vital to improving early referral, diagnosis and support for children and young people with SEN+/-D. Early recognition and intervention can have lifelong benefits for physical and emotional health outcomes, and may help to overcome barriers and so reduce health inequalities.

	Recommendation
2	Partners should continue to work together to develop and implement a local planned system of early-recognition and support for children including access to training with suspected new-onset ASD in all educational settings. This system should integrate with the local ASD pathway.

10	A specific health needs assessment of young people who offend be undertaken to identify the extent of health needs and opportunity for services to be able to respond to improve health outcomes for this group and contribute to reducing health inequalities
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## 1.4 Strengthening Support for Parents and Carers

	Recommendation
4	All new specifications for public health nursing, will clearly include the role of health visitor/school nurse/family nurse as partners and advocates for parents and carers, supporting them to recognise their strengths and capabilities and ensuring parents/carers have the knowledge and skills to access appropriate services in a timely manner.
5	<b>Front line workers offering services to children/young people and their families in this cohort have a responsibility to recognise when families are beginning to struggle to cope. Front line staff working with families in this cohort must engage with early help policies and processes in a timely way to ensure that families gain extra support appropriately.</b>
6	<b>Health, Public health, Education and Social Care commissioners of services must work together to ensure providers of care work within frameworks and policies that safeguard children and encompass the breadth of universal, targeted and specialist roles and services to be effective in identifying, engaging and supporting families when they struggle to cope. This includes the provision of training, supervision, support and governance arrangements</b>
7	Relevant health and social care information which is designed to support parents/carers of children and young people with SEN+/-D should be up to date and always be made accessible in both written and alternative formats to ensure equity of access for all families regardless of digital knowledge, online access, social status, culture, language, literacy or ability.

## 1.5 Transition

No.	Recommendation
8	Both healthcare and education providers should develop opportunities to work closer together to improve the transition processes for children and young people with SEN+/-D and their parents / carers, with a particular emphasis on assessment of needs just prior to transition points.
9	Systems should be established to anticipate future support needs for the parents/carers of children with SEN+/-D to minimise the impact of increasing care needs in adulthood and later life.

## 1.6 Emotional Health and Wellbeing

No.	Recommendation
12	Partners should adopt the recommendations of the Whole School Approaches Review and where necessary, strengthen the pathways to supporting children and young people's emotional health and wellbeing during the school years, working together to provide interventions that are tailored to the specific needs of the child.

## 1.7 Workforce Considerations

An array of children's physical and emotional health needs in special schools are currently met by a combination of school staff, nurses in special schools, and one-to-one support carers. The workforce recommendations below are key to maximising available resources to meet the needs of children and young people with SEN+/-D.

No.	Recommendation
14	<b>Healthcare providers, schools and carer organisations should work in partnership to ensure clarity of the role of one-to-one carers for meeting health needs both at school and at home.</b>
15	Public Health School Nursing services should work in partnership with school staff, parent representatives, commissioners and other health partners to develop tailored 'whole school' approaches to sustainable public health and healthcare policies, including the formulation of a school health profile and subsequent action plan. Each setting should have an identified named school nurse and school staff member to oversee the approach to implementation of the plan.
16	<b>Commissioners and providers of clinical paediatric nursing support for children and young people with SEN+/-D need to address ongoing clinical skills training needs, including early recognition, referral and support and dealing with emergency situations for anyone working to support children's clinical health needs in special and mainstream schools.</b>

## 2. Introduction

This Health Needs Assessment (HNA) provides insight into the health needs of children and young people with special educational needs and/or disabilities living in Liverpool. It specifically focuses on health (including mental health) provision in schools for children and young people with the most complex needs. This report brings together insight from routinely-collated data, from interviews, surveys, and focus group(s) with pupils, parents, carers, school nurses, and wider stakeholders.

Children and young people with Special Educational Needs and/or disabilities (SEN+/-D) are a subgroup of the whole childhood population and were the focus for this health needs assessment. The aims, policy context, and scope of the assessment are laid out first, then data from routine sources, followed by findings from interviews and focus groups, and closing with recommendations.

## 3. Aims

- To determine the health and well-being needs of children and young people aged 4-19 years in Liverpool (in line with the school years of the 0-19 Healthy Child Programme(HCP)), who also have SEN+/-D, under the following broad categories (as in the SEND code of practice<sup>i</sup>):
  - Communication and interaction
  - Cognition and learning
  - Social, emotional, and mental health difficulties
  - Sensory and/or physical needs
- To seek the views of children and young people, parents and carers, school/college staff, and provider staff on the felt and expressed health needs of Liverpool children and young people with SEN+/-D
- To determine current health and social care provision in relation to health needs in educational settings
- To develop a set of evidence-based recommendations that will contribute to the redesign of 0-19 healthy child programme delivery

## 4. Policy Context

A list of policies relevant to the needs of children and young people with SEN+/-D is included in Appendix 1. This includes items such as the recent Children and Families Act, the Rights of the Child, Human Rights Act, and Disability & Discrimination and Equality acts.

## 5. Scope

This HNA included children and young people aged 4-19 years with special educational needs and / or disabilities (SEN+/-D) attending maintained, non-independent schools in Liverpool local authority area. Pupils in maintained schools in Liverpool currently have access to a school nursing service provided by Liverpool Community Health NHS Trust (LCH).

School nursing is commissioned by Liverpool City Council Public Health as a public health nursing service for school-aged children. The LCH provision in special schools from school nursing is, however, made

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<sup>i</sup> Department of Health 2015. <https://www.gov.uk/government/publications/SEN+/-D-code-of-practice-0-to-25>



up of clinical nurse and health care assistant roles, often staffed by nurses from paediatric critical care backgrounds.

This Health Needs Assessment (HNA) combined quantitative data from Children's Services, Local Authority Public Health, Liverpool CCG, and Liverpool Community Health Trust with qualitative data from engagement with children and young people, parents, carers, school staff, provider staff, and commissioners. The HNA was focussed in scope, because of limited time and resources. The main concern of the assessment was to inform the future, effective provision of an integrated 0-19 HCP that delivers needs-centred care by school nurses and partner services for pupils with SEN+/-D.

This assessment has:

- Considered the health and care needs of some of the most vulnerable school-aged children and young people.
- Listened to the voices of those most affected by SEN+/-D
- Analysed key themes coming through qualitative data
- Made recommendations within the scope of its aims and objectives

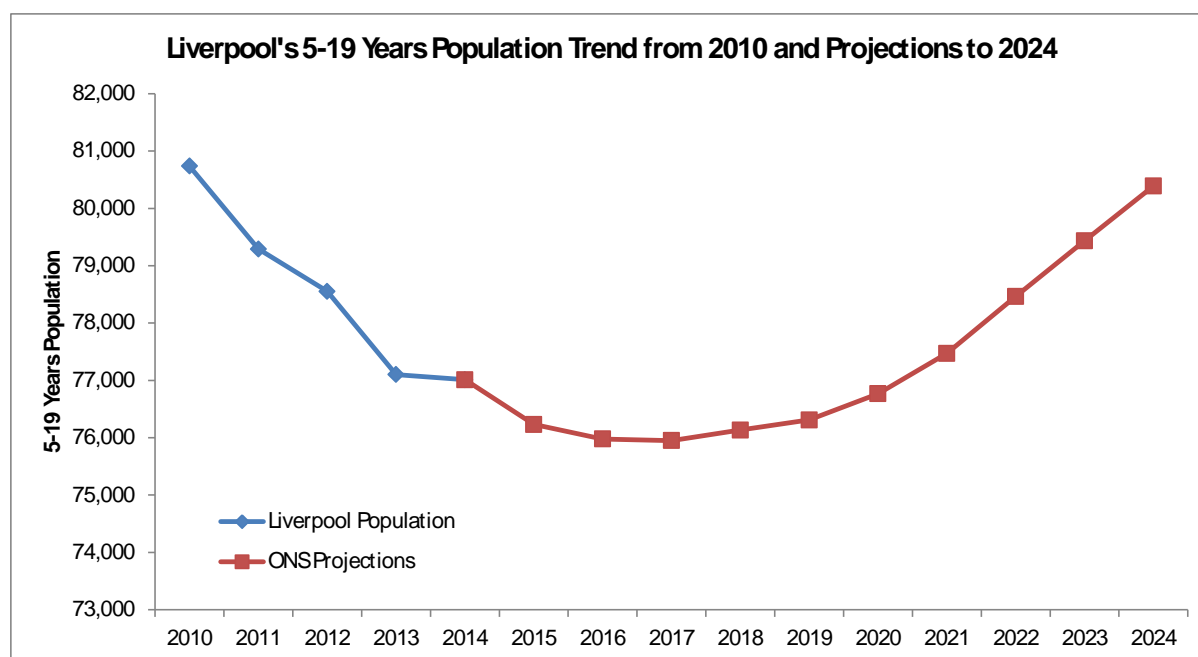
It was not possible to assess and outline all of the provision available for children with SEN+/-D across Liverpool, provision for those younger than 4 or older than 19, provision for those attending school outside Liverpool local authority area, those attending non-mainstream schools, or those educated at home. Some quantitative data relevant to children and young people with SEN+/-D is included. More detailed children's health data are available in other products, such as the Children's Joint Strategic Needs Assessment. Children and Young People in Liverpool with Special Educational Needs and/or Disabilities

## 5.1 Demographics

### Current population of children and young people in Liverpool

According to the most recent ONS estimates, there were 79,317 children and young people aged 5-19 years living in Liverpool in 2016. Over the previous five years, this number fell by 3,726 (a 4.6% decrease). The Office for National Statistics (ONS) has projected a decline until 2017, followed by a reversal (Figure 1).

Figure 1



(Source: Office for National Statistics Mid-Year Population Estimates and 2012-based Population Projections)

Speke-Garston ward has the highest number of 5-19 year olds residents (4,038) followed by Central (3,594) then Yew Tree (3,156). St Michael's (1,356), Woolton (1,693), and Church (1,996) have the fewest 5-19 year old residents.

In January 2017, there were 70,910 pupils enrolled in schools/academies in Liverpool, including maintained nursery schools and pupil referral units, free schools Studio and University Technical College (UTC) (Liverpool Spring School Census 2017). This is a 4% increase compared with 2015, with pupil numbers at their highest in the last five years. Reception numbers rose by 512 pupils (10%) over the period, while secondary pupil numbers fell by 1%.

Within Liverpool schools, 14.3% of pupils speak a first language known or believed to be other than English. This is up from 12.5% in January 2016. The proportion of minority ethnic pupils in Liverpool establishments has increased from 22.6% in January 2016 to 23.7% in January 2017. Concerning deprivation, 44% of pupils in Liverpool schools live in IDACI decile 1, the most deprived 10% of areas in the country, compared with 2.5% who live in IDACI decile 10, the least deprived. Also, 24.3% of pupils are known to be eligible for and claiming free school meals (a reduction from 26.0% in January 2016).

### Current population of children and young people with SEN+/-D

Many different and overlapping definitions of special educational need (SEN) and disability make it difficult to accurately collate information on how many children in Liverpool are affected by one or the other. The Thomas Coram Research Unit (TCRU) has estimated that between 3.0 percent and 5.4 percent of children in England have some form of disability. If applied to the population of Liverpool this would equate to between 2,573 and 4,631 children in Liverpool experiencing some form of disability.

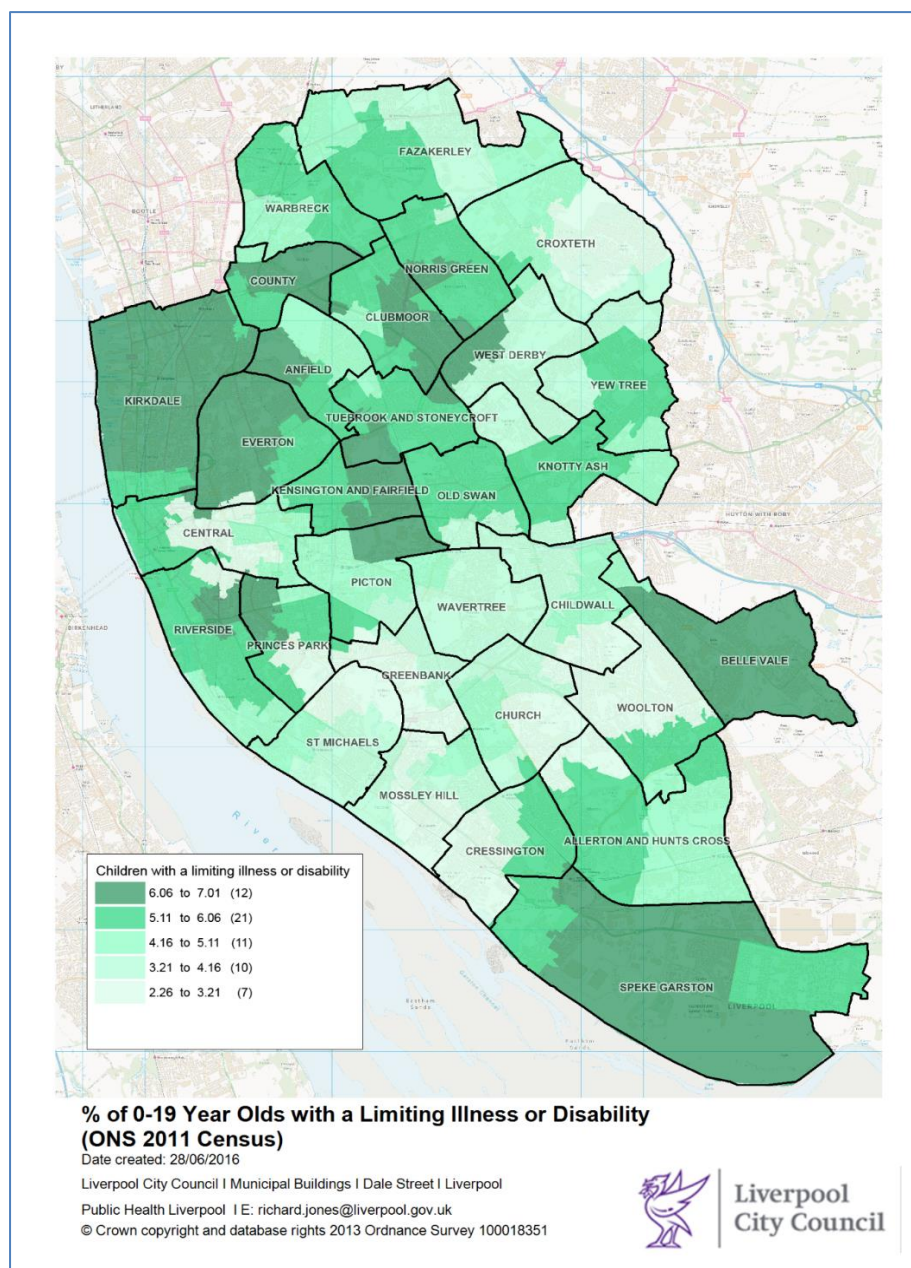
The Equality Act 2010 defines a disability as:

*“...a physical or mental impairment [that] has a substantial and long-term adverse effect on [a person’s] ability to carry out normal day-to-day activities.”*

Data from the Office for National Statistics, various research estimates, and benefit claims can be used to estimate the number of children and young people affected in Liverpool.

Data from the 2011 census revealed 15,926 0-19 year olds in Liverpool with a (long-standing/limiting) illness or disability. These data were calculated by the Office for National Statistics using the General Household Survey and the Family Fund Trust register of applicants. These children and young people are not evenly spread across the local authority area. Instead, there are higher concentrations in more Northern coastal regions of the local authority area and in Belle Vale and Speke (Figure 2).

Figure 2



Older estimates from the National Child and Maternal Health Network (Chimat) provide a break-down of long-standing illness estimates by age (Table 1), and age-specific estimates of the severely-disabled population in Liverpool (Table 2). These two tables demonstrate a fairly even spread of long-standing illness of disability, but that severe disability is more common in younger age-bands.

**Table 1 - Age-specific estimates (population aged 0 to 19 years) with long-standing illness or disability in Liverpool local authority (ONS 2011).**

Age	Boys	Girls	Total
0-4	1,890	1,664	3,554
5-9	2,825	1,980	4,805
10-14	2,420	2,261	4,681
15-19	2,898	2,688	5,586
<b>0-19</b>	<b>10,033</b>	<b>8,593</b>	<b>18,626</b>

**Table 2 - Age-specific estimates (population aged 0 to 19 years) of severely disabled population in Liverpool (ONS 2011).**

Age	Boys	Girls	Total
0-4	20	10	30
5-9	14	6	20
10-14	10	5	15
15-19	5	3	8
<b>0-19</b>	<b>49</b>	<b>24</b>	<b>73</b>

## Disability Living Allowance

Disability Living Allowance (DLA) for children is available to help with the extra costs of looking after a child who has difficulty walking, cannot walk, or who has care needs over and above those of a child of the same age with no disability. DLA figures can give an indication of the number of children with disability in the city.

Liverpool has a higher percentage of children who receive DLA than the national average. For example in November 2015, almost 6% of 5-11 year olds in Liverpool received DLA compared with 4% nationally. This included 3,510 children aged 5 to 17 (Table 3). The number and percentage has increased during the five years available in children aged 0-16, but decreased in the 16-24 age-group.

**Table 3 – Number and Percentage of Liverpool Children & Young Adults Receiving Disability Living Allowance 2010-15**

	Nov-10	Nov-15		Nov-10	Nov-15		Nov-10	Nov-15
	Liverpool (No.)	Liverpool (No.)		Liverpool %	Liverpool %		England %	England %
Aged Under 5	380	500		1.47	1.78		1.2	1.35
Aged 5-11	1,050	1,720		3.9	5.93		3.3	3.93
Aged 11-16	1,310	1,500		4.26	5.45		4.09	4.92
Aged 16-17	470	290		4.24	2.91		3.38	2.79
Aged 18-24	1,580	1,390		2.36	2.04		2.58	2.46

## 5.2 Types of Special Educational Need

### Introduction

According to the UK Department for Education:

*“A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.*

*A child of compulsory school age or a young person has a learning difficulty or disability if he or she:*

- has a significantly greater difficulty in learning than the majority of others of the same age, or*
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions”*

Children and young people with SEN+/-D will usually be receiving additional support in school for SEN. The nature of that support will vary depending on the extent and nature of the pupil's needs. Schools have significant resources and expertise to meet the needs of most pupils. In accordance with the SEN Code of Practice, schools adopt an 'Assess, Plan, Do, Review' approach to identifying and meeting need, known as SEN Support. For some cases, external specialist advice is sought (e.g. from educational psychologist, specialist teachers, etc). When a child's needs are above and beyond those which can be met through SEN Support, the Local Authority may carry out a statutory assessment, which may lead to an Educational Health and Care Plan (EHCP) being drawn up. Data on the primary types of need for pupils with EHCPs or statements of SEN are collated locally and nationally for analysis. This section contains information on the number of pupils receiving support for SEN, including those with and without EHCPs or statements, comparisons with other areas, and details of the primary types of need recorded. Some will have a single need, while others will have multiple needs. Unless otherwise stated, all Local Authority SEN data within this report is from the January 2017 School Census returns and is based on pupils attending Liverpool schools only. Pupils whose statement or EHCP is maintained by Liverpool but do not attend Liverpool schools are not included. All Academies and Free Schools are included.

The number of pupils with special educational needs (SEN Support, Statements or EHCPs) in Liverpool maintained schools decreased from 17,069 pupils in 2011 to 12,507 in 2017 (27% decrease) notwithstanding a 1% increase in numbers compared with 2016. However, the number of pupils with statements of special educational need or EHCPs continues to rise – from 1300 (1.9% of the total pupil population) in 2011 to 1656 (2.3%) in 2017 (a 27% increase).

In 2015, 1,610 (2.3%) of Liverpool pupils had an education health and care plan (EHCP) or statement of special educational needs, a slightly lower percentage of pupils than in England as a whole (2.8%), and similar to other comparator cities (Table 4Error! Reference source not found.).

Table 4 – Percentage of School Pupils with EHCPs or Statements, Liverpool and Comparator Cities

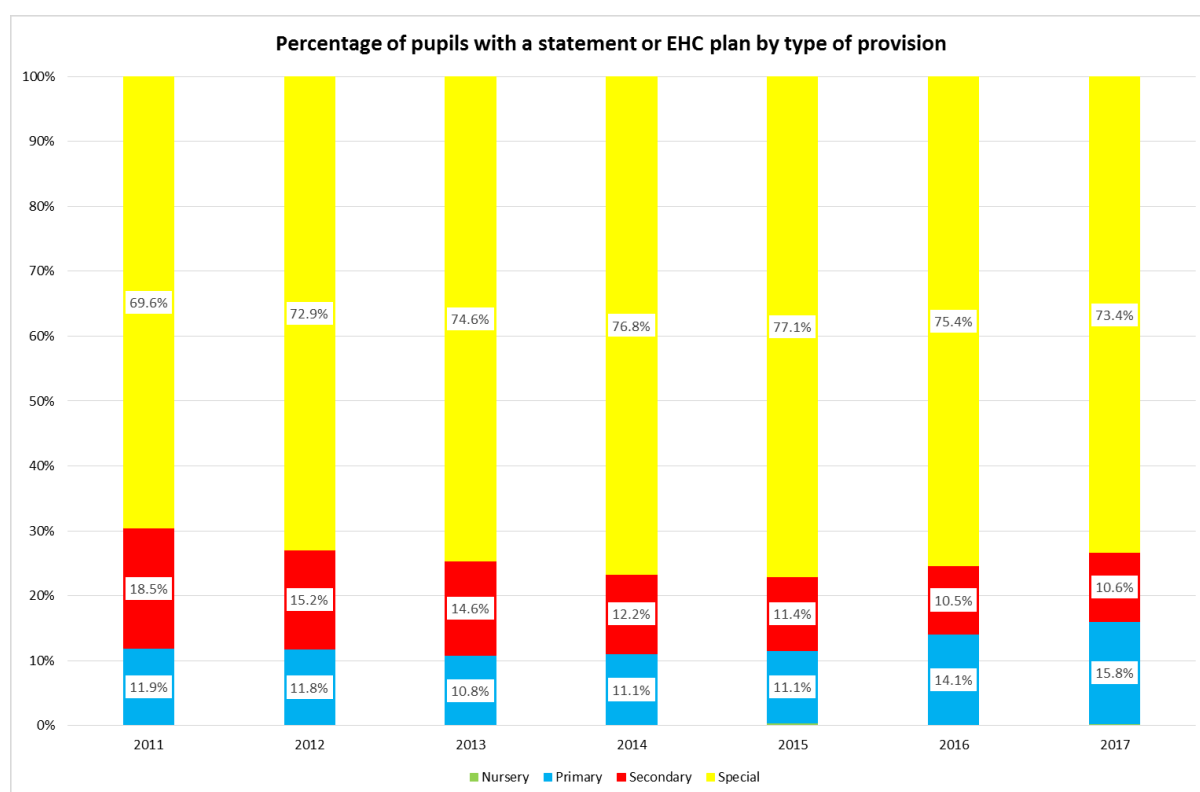
City	2013	2014	2015
Birmingham	3.1	3.3	3.2
Manchester	2.7	2.7	2.7
Bristol, City of	2.8	2.7	2.7
Sheffield	2.5	2.5	2.7
<b>Liverpool</b>	<b>2.2</b>	<b>2.2</b>	<b>2.3</b>
Newcastle upon Tyne	2.1	2.0	2.3
Leeds	1.7	1.7	2.1
Nottingham	1.5	1.5	1.6
<b>England</b>	<b>2.8</b>	<b>2.8</b>	<b>2.8</b>

### Type of Need

For pupils with statements or an EHCP, the most common type of primary need is autistic spectrum disorder (ASD) (28.2% of the statement/EHCP cohort). The number of pupils with ASD as a primary need has increased by 75% since 2011. For pupils on SEN Support, the most common is Speech, Language and Communication needs (20% of the SEN Support cohort). The number of pupils on SEN Support with ASD as a primary need has increased by 39% since 2015. Notably however, there are more pupils in National Curriculum Years N1 to 6 with statements or an EHCP with Severe Learning Difficulties (SLD) (199 pupils) than with ASD (167 pupils). Further, the number of pupils with SLD as a primary need has increased by 77% since 2011. Thirty-nine percent of all pupils with special educational needs were eligible for free school meals compared with 24% of pupils without SEN.

While the percentage of pupils with EHCPs or statements attending special schools has fallen, it is important to note that the actual number of pupils attending special schools has increased. In 2013, 74.6% of pupils with statements attended maintained special schools. This increased to 77% in 2015 but fell to 73.4% in 2017 (Figure 3). These percentage figures are much higher than for England as a whole where the figure is more in the region of 43% (2016). In England, more children and young people are supported in mainstream schools rather than in special schools.

Figure 3



## Ethnicity

Special educational needs remain most prevalent in Travellers of Irish Heritage with 57% having SEN, this having reduced from 65% in 2016. There has been a small increase in the percentage of Black Caribbean pupils with SEN from 21% to 22%. This group is now has the second highest prevalence of special educational needs.

## Gender

There are nearly three times more boys with a statement or EHCP in special schools than girls – 892 boys compared to 323 girls. Boys are twice as likely to have a statement or EHCP at primary school and two and a half times more likely at secondary. Overall, boys account for 73% of all statements and EHCPs. The numbers of both girls and boys with statements or plans have increased at similar rates since 2011. Boys are more than one and a half times more likely to be on SEN Support than girls, with 20% of boys in Liverpool schools on SEN support compared with 11% of girls. Sixty-four percent of all pupils on SEN support are boys.

The most prevalent need amongst girls on SEN Support in January 2017 (Table 5) was Specific Learning Difficulties. For boys it was Speech, Language and Communication needs. Boys on SEN Support are more than twice as likely to have ASD as a primary need than girls. The numbers of girls and boys on SEN Support with ASD as a primary need have increased by 20% and 21% respectively compared to 2016. Whilst moderate learning difficulty (MLD) is the second most prevalent need amongst girls on

SEN Support and the fourth most prevalent need amongst boys, the number of pupils with MLD is falling.

The most prevalent need amongst girls with Statements or EHCPs (Table 6) was Severe Learning Difficulties (28.7% of the cohort), while for boys this was ASD (32.2%). Again, boys were more likely than girls to have ASD as a primary need, with more than four times more boys than girls with ASD, though girls were more likely to have Severe Learning Difficulty.

**Table 5 – Primary type of need for pupils receiving SEN support, disaggregated by sex**

	Girls	Boys	% of Girls at SEN Support	% of Boys at SEN Support
ASD	219	802	5.6%	11.5%
HI	78	76	2.0%	1.1%
MLD	723	997	18.5%	14.3%
MSI	8	8	0.2%	0.1%
NSA	243	228	6.2%	3.3%
OTH	462	592	11.8%	8.5%
PD	139	185	3.6%	2.7%
PMLD	1	9	0.0%	0.1%
SEMH	535	1379	13.7%	19.8%
SLCN	654	1524	16.8%	21.9%
SLD	14	24	0.4%	0.3%
SPLD	788	1088	20.2%	15.7%
VI	35	40	0.9%	0.6%
<b>Total</b>	<b>3899</b>	<b>6952</b>		

ASD: Autistic-spectrum disorder, HI: Hearing impairment, MLD: Moderate learning difficulty, MSI: Multi-sensory impairment, NSA: no specialist assessment, OTH: Other, PD: Physical disability, PMLD: Profound and multiple learning difficulties, SEMH: Social, emotional, and mental health, SLCN: Speech, language, and communication needs, SLD: Severe learning difficulty, SPLD: Specific learning difficulty, VI: Visual impairment



Table 6 – Primary type of need for pupils with statements or EHCPs, disaggregated by sex

	Girls	Boys	% of Girls statements or EHCPs	% of statements or EHCPs Boys or
ASD	80	387	17.7%	32.2%
HI	14	12	3.1%	1.0%
MLD	62	96	13.7%	8.0%
MSI	0	4	0.0%	0.3%
NSA	1	0	0.2%	0.0%
OTH	19	55	4.2%	4.6%
PD	35	35	7.7%	2.9%
PMLD	54	54	11.9%	4.5%
SEMH	22	192	4.9%	16.0%
SLCN	23	39	5.1%	3.2%
SLD	130	294	28.7%	24.4%
SPLD	11	33	2.4%	2.7%
VI	2	2	0.4%	0.2%
<b>Total</b>	<b>453</b>	<b>1203</b>		

ASD: Autistic-spectrum disorder, HI: Hearing impairment, MLD: Moderate learning difficulty, MSI: Multi-sensory impairment, NSA: no specialist assessment, OTH: Other, PD: Physical disability, PMLD: Profound and multiple learning difficulties, SEMH: Social, emotional, and mental health, SLCN: Speech, language, and communication needs, SLD: Severe learning difficulty, SPLD: Specific learning difficulty, VI: Visual impairment

### Special Educational Needs by Year Group

The overall number of secondary aged pupils on SEN Support has dropped by 48 since 2016 – from 4294 to 4246. Despite this decline, the greatest increase in SEN support numbers across all national curriculum year groups is in Year 9. Numbers in Year 9 have risen by 14% since 2016. The decline in secondary numbers is greatest across key stage 4 – there are now 148 fewer pupils in years 10 and 11 than in 2016.

There has been an increase in the number of pupils on SEN Support across all of the key stage one year groups – there are 125 more pupils in reception and years 1 and 2 on SEN Support than in 2016. Year 3 has the highest number of pupils on SEN Support across all year groups. The number of pupils with a statement or EHCP has increased by 24% across key stage one. This is the largest increase across all of the key stages. Years 9 and 11 have the highest number of pupils with a statement or an EHCP.

## Visual Impairment

There is a spectrum of visual impairment from mild to complete sight loss, and a range of support is offered to children and young people in the city who have visual impairments, from universal to targeted services. Data from local authority services usually show prevalence of visual impairment at approximately 20 children per 10,000 nationally. The prevalence rate reported by the Department for Education finds, however, 10.5 per 10,000 whose primary special educational need is a visual or multi-sensory impairment. The discrepancy between local authority and Department for Education data occurs because Department for Education data only includes children whose primary disability is sight problems, which likely under-represents the number of children and young people with a visual impairment. Local data demonstrates 75 pupils in Liverpool receiving SEN support with visual impairment as their primary need, and 4 pupils with statements or Education Health and Care Plans (EHCPs) whose primary need is visual impairment (total 84, approximately 15.8 per 10,000).

## Deaf and hard of hearing.

The most recent data available is somewhat outdated now. In 2010 there were 6.2 per 10,000 population aged 0-17 in Liverpool who were registered as hard of hearing and 3.4 per 10,000 population aged 0-17 who were registered as deaf compared to 2% nationally for both categories. This data was collected every 3 years but was discontinued in 2010. The table below shows how this compared to national data.

## 5.3 Special Educational Needs in Looked After Children

This section of the report contains information on the special educational needs of looked after children. As at 31<sup>st</sup> March 2016. There were 706 children looked after continuously for at least 12 months (711 in 2015). Of the children looked after continuously for 12 months, 501 were of compulsory school age. In 2015, there were 500 children in the cohort. Around 50% of compulsory school-aged looked after children (249) had some form of special educational need compare with 19.5% of those in the general population, including 32.5% (163) receiving SEN support (17% for all Liverpool pupils) and 17.2% (86) having a Statement or EHCP (2.4% for all Liverpool pupils).

## 5.4 Children's Continuing Care

Liverpool CCG commission bespoke packages of care for children (up to 18 years old) with one or more physical, emotional, behavioural, or mental health needs that could not realistically be met by existing services. Such needs can emerge at any age, prompting a referral (usually from a teacher, social-worker, or health-worker) to the continuing care commissioning team. Examples of these packages of care can range from one-to-one support for children with complex physical health needs (e.g. needing regular monitoring, or oral suction), to respite care needs for families whose children have complex behavioural needs linked to autistic-spectrum disorders.

As part of the process of commissioning packages of care, the team is able to identify emerging areas of need, and to develop new responses to meet these. Recent data (May 2016) show that 64 children and young people in Liverpool have packages of care (Table 7). Eight of these had learning disability needs, 4 have mental health needs, and 58 had physical needs (some have a combination), (see Table 8).

**Table 7 – Number of children and young people with a care package May 2016**

Age Groups	Number receiving care packages
0-4 Years	7
4-11 Years	19
11-16 Years	25
16-18 Years	9
>18 Years	4
<b>Grand Total</b>	<b>64</b>

**Table 8 – Patients by Client Group**

Client Group	0-4 Years	4-11 Years	11-16 Years	16-18 Years	>18 Years	Total
Learning Disability	0	3	3	0	2	8
Mental Health	0	2	2	0	0	4
Physical Disability	7	16	23	9	3	58
<b>Grand Total</b>	<b>7</b>	<b>21</b>	<b>28</b>	<b>9</b>	<b>5</b>	<b>70</b>

## 5.5 Vaccination

It is especially important to offer vaccination to children and young people with SEN+/-D, because many are in clinical risk groups. The presence of a large proportion of this cohort in special school settings in Liverpool currently facilitates understanding about immunisation history, but collated data are not routinely available for children and young people with SEN+/-D at either mainstream or special school levels. Data on immunisation status is currently checked and recorded on paper, but not centrally collated.

Current arrangements in school nursing require that all pupils with SEN+/-D are checked on admission to both primary and secondary special school settings to see if their childhood immunisation status is up to date according to the routine schedule. This is usually carried out by the clinical nurses working in these schools. Action is taken where pupils are not up to date, either to provide catch-up immunisation in the school or to refer the pupil to general practice for catch-up vaccination as appropriate to individual needs.

Children who are eligible for the national childhood influenza programme are offered seasonal influenza vaccination (school years 1, 2, and 3 for 2016/17). Those who are not in these year-groups are provided with information and advised to attend their GP practice. Coverage and uptake of vaccinations in this group of children needs to be understood. The current fragmented delivery and collation of data for this group presents some risk in ensuring adequate levels of uptake.

For eligible cohorts, the uptake of the seasonal influenza vaccine offered in special schools for 2016/17 included four out of six schools having greater than 50% uptake (**Error! Reference source not found.**).

#### Special school seasonal influenza uptake for eligible age-groups 2015/16-2016/17

School	2015/16 uptake (Y1 & Y2)	2016/17 uptake (Y1, 2 & 3)
School A	No primary school age cohort	61.5%
School B	44%	60%
School C	41%	34.7%
School D	35%	51.4%
School E	No primary school age cohort	0%
School F	Not provider	100%
School G	No primary school age cohort	No primary school age cohort
School H	No primary school age cohort	No primary school age cohort
School I	No primary school age cohort	No primary school age cohort

Many special schools have classes containing mixed age-groups, including those eligible and not eligible for the childhood programme. This has led, in some cases, to nurses being able only to vaccinate only some pupils in a class group and not others. Further, only a proportion of pupils in the school will have been offered vaccination, with close mixing of pupils in break periods, assemblies, and other school activities.

Many pupils in special schools have ASD, and administering influenza vaccine in GP practices can prove a lot more difficult for these children and young people than in the school environment. An unfamiliar environment for these pupils may affect vaccination uptake, reducing the likelihood of so-called 'herd immunity' in special schools.

**Recommendation 1:** Review current arrangements for delivery and reporting of vaccinations for children in special schools for seasonal influenza. Establish a whole-school approach to seasonal influenza vaccination in special schools, including offer of influenza vaccination to all pupils in the school.

## 6. Stakeholder Views

This section presents information collected as part of this health needs assessment. For this assessment, views were sought from:

- Children and young people with Special Educational Needs +/- Disabilities (SEN+/-D),
- Parents and carers,
- School nurses,
- Special school head teachers,
- Wider stakeholders.

Views were sought through a combination of informal conversations, routine meetings, face-to-face semi-structured interviews, focus-groups, and surveys. Whilst this approach can give a rich understanding of felt and expressed needs, views may not adequately represent the full range of stakeholders' views across the city alongside the range of health needs that exist in school settings.

This places a limit on the generalisability of findings. Nevertheless, the findings presented here were triangulated to enhance their validity and to guide future thinking, enquiry and delivery of services.

There were key emerging themes across all groups in relation to both health needs and the role of school nurses and allied professionals. Key themes from pupil focus groups are presented first, followed by grouped themes emerging from our conversations with stakeholders, parents, carers, professionals, school nurses, and commissioners.

## **6.1 Methods**

### **Children and Young People**

Because of limited time, two focus groups with pupils from two large special schools and one resourced mainstream primary school who had a range of additional needs were carried out, including a group who were actively experienced in sharing their views and speaking on behalf of other pupils in the school who could not communicate.

Focus group sessions focussed on finding out what “health”, “wellbeing”, and “being happy” meant to the children and young people, the role(s) of those who support their health in school, and the ‘school nurse’. They were able to express this through speech or by drawing. School staff attended to support pupils to express themselves and to communicate.

### **Parents & Carers**

Parents of children and young people with special educational needs and/or disabilities (SEN+/-D) who were already actively involved in representing parent and carer views in the city were interviewed. Two focus groups were carried out with parents and carers of children with SEN+/-D, including those with complex physical disabilities and those with autistic-spectrum disorders, severe learning difficulties, and social, emotional and mental health needs.

Responses were recorded on paper by two facilitators attending each focus group. These were then analysed by two investigators to extract key-themes, including frequently-occurring themes and new and potentially useful information.

### **Nursing Staff in Special Schools**

A survey and three focus groups with nurses working in special schools in Liverpool was carried out. Some nursing staff in special schools have a long history of working with children with complex physical needs, including the care of children with significant airway, physiotherapy, ventilation, feeding, and other physical needs.

### **Stakeholders**

Managers and key leaders in Child and Adolescent Mental Health Services, Liverpool Local Authority Looked-After Children’s Education Service (LACES) and Targeted Services for Young People, and Liverpool CCG were also interviewed.

### **School Staff**

Information from Public Health’s regular discussions and meetings with special school head teachers, and opportunistic meetings and discussions with special school staff were also taken into consideration.

## 6.2 Views of Children and Young People

Discussions were held with children and young people with SEN+/-D in primary and secondary special schools. Children and young people spoke about what “health”, “wellbeing”, and “being happy” meant to them, who helps them to stay healthy in school, and the role of the school nurse, including how to improve the service.

### Key Themes

Children and young people said that health means:

- Being happy
- Being safe
- Feeling good and having energy
- Exercise – jogging, dancing, cycling, walking, athletics, jumping, and many more examples
- Healthy food - fruit and vegetables
- Having a voice
- Being able to do things
- Growing
- Sharing ideas
- Feeling positive
- How you feel inside
- Getting enough sleep

For those children and young people spoken to, health was about feeling able to talk, being able to enjoy life, to move around and be happy. They considered a wide range of people as helping them to stay healthy. These included medical professionals, school teachers, parents and carers, but also social workers, the police, drivers, escorts, all other staff in the school, brothers, sisters, and grandparents.

Pupils consistently said that they enjoyed seeing the school nurse, that they were treated well by the school nursing team and that they felt the school nurse helped them to stay healthy and to get better when they were unwell. School nurses were seen to help with physical ailments, but also helped by chatting to you, being friendly, and talking to parents.

The question pupils found most difficult to answer, was how to make the service better, including some commenting that it couldn't be any better. Pupils felt nursing in school could be improved by:

- Telling children and young people about what medicines they are taking
- Getting to know the nurses, “...it's better when you know them...”
- Putting music in the nurse's room
- Making the school nurses' room bigger – to see more people at once
- Some felt that it would be good to keep nurses consistent, while others liked the idea of having more nurses, including students

One pupil commented that he would like to help to look after other pupils, especially those who have physical problems. It was considered worth highlighting this individual comment for future opportunities for peer support and learning.

### 6.3 Respondents' views on most pressing needs

Parents, carers, and stakeholders were asked what they thought were the most important or pressing health needs affecting children and young people with SEN+/-D in Liverpool. Through the analysis, we categorised these responses into four key themes:

- Autistic-spectrum disorders,
- Children and young people with complex and multiple physical health needs (especially those attending special schools),
- In relation to mental wellbeing and maintaining quality of care:
  - Access to support for parents and carers, and
  - Difficulties with transition from primary to secondary and to adult services.

#### Autistic-spectrum disorders (ASD)

Many stakeholders suggested that the prevalence of ASD is increasing in the city, but that it is unclear why. There is some research evidence that a large proportion of this is due to widened diagnostic criteria and improved recognition of ASD<sup>ii</sup>. Initial data demonstrated a backlog of children and young people awaiting assessment and diagnosis for possible ASD in the city. This has now improved through a waiting list initiative from Liverpool CCG. Achieving a more timely diagnosis will enable more appropriate support to be put in place towards improvement in long-term health outcomes.

**Recommendation 2:** Partners should continue to work together to develop and implement a local planned system of early-recognition and support for children including access to training with suspected new-onset ASD in all educational settings. This system should integrate with the local ASD pathway.

#### Children and young people with complex and multiple physical health needs.

As noted earlier, 64 children with EHCPs or Statements and 323 with SEN support have physical disability as their primary need. Parents, carers and other stakeholders identified the needs of young people with the most complex physical conditions as very important. The needs of this group are usually met by existing support capacity at the school, parents, carers, school staff, 1 to 1 carers, bespoke packages of care, or a combination of these.

Parents and carers of children with some of the most complex physical health needs took part in interviews and one focus group. Children and young people in this group often have multiple and complex health and social needs that need individually-tailored approaches. Parents/carers who responded made reference to the difficulties they faced; challenges of supply meeting demand, their needs at home and navigating the healthcare system, which all contribute to strain on families.

Special school staff and nurses supporting special schools said that the complexity of need of pupils in these schools had increased over a number of years.

*"When I first started... to have a child with a tracheostomy in school was a big deal... now we have five" (Special School Nurse)*

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<sup>ii</sup> Hansen, S.N. *et al.* Explaining the increase in the prevalence of autistic spectrum disorders. JAMA Paediatrics 2015; 169 (1); 56-62

Staff felt this to be a triumph; more children are thought to be surviving with complex physical needs and being able to attend school, but also recognised the challenges for services, particularly for nursing and school staff. The system needs flexibility to adapt to changing and emerging needs as children with life-threatening conditions live longer.

### **Access to support for parents and carers**

Parents and carers saw themselves as the main drivers of their children's care. While care is accessible and children and young people with complex needs were said to receive support, respondents highlighted the difficulties they found in navigating their way through the healthcare system. It is important to note however, the retrospective nature of these responses and the more recent development of Liverpool's Local Offer/Early Help Directory, bringing together information for children and young people with SEN+/-D and their parents or carers in one place<sup>iii</sup>.

Various stakeholders expressed a view that unless parents' actively sought support, they might not receive everything they are entitled to or needed. Some parents (and carers) of children with SEN+/-D have no or limited access to the internet, while others may be unwilling or unable in other ways to actively seek additional support. Further, some parents and carers also have learning or other difficulties that might be limiting their access to support. School nurses and other front line workers often support families to navigate these difficulties, including conducting home-visits to support more vulnerable families, but it is not clear from these responses whether or not all who need this support are accessing it, which could worsen health outcomes and widen health inequalities.

*"...if you don't push... you don't get what you need." (Parent of a child with complex needs)*

For children with more complex needs, there are often multiple professionals involved in their care. Some parents need help and support to navigate this depending on their own needs or abilities and how well they are coping. Respondents consistently highlighted their recognition of the difficulty for services like school nursing in supporting this need but that it was a very necessary part of care.

Respondents expressed a continuing need for easier access to written materials, better signposting, suggestions and follow-up for families. This especially relates to families who do not have internet access.

### **Recommendation 3: Commissioners of services for children and young people with SEN+/-D should:**

- a) Strengthen their commitment to working together for achieving high quality child and family - centred outcomes for children and young people with SEN+/-D.
- b) Work with all providers to develop clear outcome focussed delivery plans and effective communication systems that are centred on the need(s) of individual children/young people and their family.

**Recommendation 4:** All new specifications for public health nursing, will clearly include the role of health visitor/school nurse/family nurse as partners and advocates for parents and carers, supporting them to recognise their strengths and capabilities and ensuring parents/carers have the knowledge and skills to access appropriate services in a timely manner.

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<sup>iii</sup> <https://liverpool.gov.uk/schools-and-learning/special-educational-needs/send-local-offer/>



**Recommendation 5:** Front line workers offering services to children/young people and their families in this cohort have a responsibility to recognise when families are beginning to struggle to cope. Front line staff working with families in this cohort must engage with early help policies and processes in a timely way to ensure that families gain extra support appropriately.

**Recommendation 6:** Health, Public health, Education and Social Care commissioners of services must work together to ensure providers of care work within frameworks and policies that safeguard children and encompass the breadth of universal, targeted and specialist roles and services to be effective in identifying, engaging and supporting families when they struggle to cope. This includes the provision of training, supervision, support and governance arrangements.

**Recommendation 7:** Relevant health and social care information which is designed to support parents/carers of children and young people with SEN+/-D should be up to date and always be made accessible in both written and alternative formats to ensure equity of access for all families regardless of digital knowledge, online access, social status, culture, language, literacy or ability.

### Difficulties with transition

Many more children with complex needs are surviving to adulthood and transitioning to adult services. Parents, carers, and stakeholders spoke of the difficulties facing families as they reach this stage, expressing their views about the preparedness of adult services to accommodate their children. They highlighted the difficulties they face as families during this period and the importance of continued co-ordinated healthcare for young people with complex or multiple conditions beyond the age of eighteen. Again, parents and carers highlighted the importance of knowing how to access additional support to help guide them and their children through this period.

Parents, carers, and other stakeholders also spoke about approaches to transition into and from primary to secondary school. In primary school, children are usually placed in a single class with a consistent teacher. In secondary school pupils transition to a system of subject-teachers and rotating around classes. This highlights the importance of co-ordinated care between health and education services during these transition phases.

**Recommendation 8:** Both healthcare and education providers should develop opportunities to work closer together to improve the transition processes for children and young people with SEN+/-D and their parents / carers, with a particular emphasis on assessment of needs just prior to transition points.

**Recommendation 9:** Systems should be established to anticipate future support needs for the parents/carers of children with SEN+/-D to minimise the impact of increasing care needs in adulthood and later life.

### Children and young people who offend

The actual levels of health needs among youth offenders are beyond the scope of the HNA. This particular group are known to be far less likely to engage with health and social care services and education services and paradoxically be far more likely to have some of the highest level of emotional, behavioural and mental health needs and physical health needs among children and young people within the city.

Meeting the health needs of this hard to reach group presents significant challenges for services to improve health outcomes and reduce health inequalities. Provision of offender health services is an important part of responding to these health needs. However, the complex issues for this group and the very specific aspects for engagement would require further work with an appropriate methodology as a specific health needs assessment to determine the extent of need and guidance for service responses.

**Recommendation 10: A specific health needs assessment of young people who offend be undertaken to identify the extent of health needs and opportunity for services to be able to respond to improve health outcomes for this group and contribute to reducing health inequalities**

## 6.4 Mainstream or Special School

The choice of mainstream or special school placement bears further discussion because of the potential implications of this on the wider integration of children and young people into society, their ability to secure employment, strengthen their life chances and the impacts of these on long-term health outcomes. Liverpool stands out in comparison with other cities, in that children and young people with SEN+/-D are more likely to go to a special than mainstream school. In England as a whole, this is reversed. Furthermore, the extent of clinical nursing input within special schools in Liverpool is uncommonly greater when compared nationally and within other districts in Merseyside.

Arguments exist about the directional causal pathway between the extent of clinically resourced special schools and demand for places in those schools, if they are seen as the best available resource by stakeholders. Multiple stakeholders including school nurses, other providers, and commissioners suggested that Liverpool might be importing children and young people with particularly complex levels of physical need from other areas of the North West, leading to an increase in demand for special schools. For Liverpool however, rates of physical disability as primary need for children with SEN are lower than other areas (1.9%), the North West (2.7%) and England (3.5%). In addition, the percentage of all school pupils with SEN+/-D is lower in Liverpool (2.4%) than both the North West (2.8%) and England (2.8%). However, caution needs to be applied in the interpretation of these data as they do not consider the complexity of medical needs for these children and young people in the city.

Parents, carers, and school nurses all expressed a willingness to support children and young people in mainstream settings, although it was acknowledged that this would not always be possible. In contrast to the suggestion of mainstream integration as a form of social inclusion, many respondents in this sample, including professionals, parents and carers, took a negative view on placing children in mainstream settings when referring to the children and young people they knew.

It was clear that everyone who contributed to this assessment wanted the best possible outcomes for children and young people, whether that meant mainstream-integration or if a special school was thought best for the person concerned. There are of course many possible factors for determining and responding to attitudes and behaviours towards mainstream-integration however it has not been possible to look into these in more detail as part of this HNA. Furthermore, the methodology underpinning this HNA suggests considerable caution in seeking to generalise these views across Liverpool as a whole. A deeper level of insight with a larger sample would be necessary to understand a greater extent the views in the city on the normalisation of a “mainstream first” system and culture

to support the integration of children and young people with SEN+/-D with their optimal ability to secure employment, and support their long-term health and social outcomes.

**Recommendation 11:** A Behavioural Insight study should be undertaken to examine further the attitudes and behaviours to achieving an inclusive “mainstream first” system and culture in Liverpool which will, as far as possible, integrate children with SEN+/-D into mainstream society.

## 6.5 How Needs are met in Special Schools

### Further types of health need seen in children and young people with SEN+/-D

Multiple respondents highlighted emotional health and wellbeing needs as pressing needs for children with SEN+/-D in Liverpool. Unmet needs were expressed around anxiety, emotional wellbeing, sexual health, and relationships education in this group.

#### General Principles

Particularly in relation to children with emotional and behavioural needs and ASD, parents and carers expressed the view that better communication and a more understanding approach was needed from services. For example, some respondents reported difficulties whenever they tried to visit potential new schools, especially around transition from primary to secondary school. A number of further examples were cited that highlighted the need for better awareness of autistic-spectrum disorders (ASD) and how to support children with ASD including tailored approaches to working with their families.

Sexual health and relationships education were particularly topical for parents and carers who felt their children had particularly complex physical and behavioural needs. There were differing opinions on how best to meet these needs. These are currently taught in special schools by school education staff, but some parents felt that particular young people would need a tailored approach, probably delivered by someone who already has a good rapport with the pupil, and in some cases on a 1 to 1 basis. In general, it was felt that discussions around sexual health and relationships needed to happen in a way which is tailored to the specific needs of the young person.

The recent Whole School Approaches Review<sup>iv</sup> of Mental Health and Emotional Wellbeing in the city called for more resources to be available around mental health to support young people with special needs.

**Recommendation 12** Partners should adopt the recommendations of the Whole School Approaches Review and where necessary, strengthen the pathways to supporting children and young people’s emotional health and wellbeing during the school years, working together to provide interventions that are tailored to the specific needs of the child.

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<sup>iv</sup> Whole School Approaches to Mental Health & Emotional Wellbeing in Liverpool: Citywide review March 2017  
<http://www.liverpoollearningpartnership.com/blogs/mental-health-emotional-wellbeing/>

## Roles and Responsibilities

Whilst schools hold the overall responsibility for ensuring that arrangements are in place for supporting pupils with medical conditions (DfE 2015), it is best served to exercising that responsibility with good partnership arrangements with local healthcare services. For example, school nurses are an external resource that are able to support pupils and staff in the school to fulfil that responsibility.

There are a number of key professionals involved in the medical care of children and young people with SEN+/-D in special schools. These include (but are not limited to) nurses in special schools, 1 to 1 support staff, continuing care agency carers, community paediatric matrons, Liverpool Child and Adolescent Mental Health Services (CAMHS), in-school physiotherapy services, and continuing care commissioning nurses.

There are a number of children in schools who have 1 to 1 carers who are funded through continuing care criteria. These are children whose health needs cannot be met by existing services alone. Those who fall into this category because of physical health needs are case-managed by the community paediatric matrons, while those with behavioural and other needs are case-managed by CAMHS. The pupils have a bespoke package of care that may include a 1 to 1 carer. The nature of working-relationships between nurses and 1 to 1 carers in the special schools is said to vary largely based on child health need but also on how the schools operate on an individual basis.

The quality of healthcare, wellbeing and safety of pupils is paramount and to that end, meeting the challenges of good understanding of the range of different roles, training, communication, lines of accountability and governance are essential. Feedback from respondents suggested that whilst most of these features appeared to be in place, that these aspects could be built on further to strengthen the quality of care. For example, the arrangements for provision of routine procedures or clinical care at home or in school need to be agreed between partners and families and consistently applied in a way that maintains continuity and safety of care and optimal attendance at school.

**Recommendation 13** Healthcare providers in partnership with their commissioners should develop and strengthen further the clinical governance arrangements for both Public Health school nurses and clinical paediatric nurses based in special schools as a priority.

**Recommendation 14:** Healthcare providers, schools and carer organisations should work in partnership to ensure clarity of the role of one-to-one carers for meeting health needs both at school and at home.

**Recommendation 15:** Public Health School Nursing services should work in partnership with school staff, parent representatives, commissioners and other health partners to develop tailored ‘whole school’ approaches to sustainable public health and healthcare policies, including the formulation of a school health profile and subsequent action plan. Each setting should have an identified named school nurse and school staff member to oversee the approach to implementation of the plan.

## Addressing Health Needs in Special Schools – knowledge and skills

As noted above, it became clear from many respondents that better access to clinical skills training is needed by teachers, parents, carers, and nursing staff in order to support children and young people effectively and safely.

All professionals responding emphasised their willingness to receive training in this area so that they could better support children and young people in school, but that there were difficulties in being able to access clinical skills training which ideally for school staff, was said to be more accessible when delivered on school sites as it was generally impractical for staff to attend training off-site.

Nurses in special schools expressed their keenness to develop their role and provide a better quality service for pupils. However, many nurses reported longstanding difficulties in accessing training to be able to support pupils with clinical needs. Indeed, up to date clinical skills are important for improving the care of children and young people with SEN+/-D. This is particularly important in being able to respond to acute situations or emergencies in school where children and young people in this environment are much more likely to need emergency medical care. All staff in contact with pupils with additional emergency care needs need to be adequately trained to deal with these needs. Overall, clear, accessible arrangements need to be in place to enable school staff, parents, carers, health and other professionals to access regular good quality training and refresher updates to safely support children in meeting their health and care needs.

**Recommendation 16:** Commissioner and provider of clinical paediatric nursing support for children and young people with SEN+/-D need to address ongoing clinical skills training needs, including early recognition, referral and support and dealing with emergency situations for anyone working to support children's clinical health needs in special and mainstream schools.

## 6.6 The Roles of Nurses and Allied Professionals in Special Schools

Parents and carers differed in their opinions of what they felt the role of the school nurse was. This depended on the types of need their children had. Some parents and carers of children with ASD and behavioural needs had not met the school nurse and were unsure of their role. Others answered that the school nurse is involved with:

- Physical development
- Height and weight
- Checking hearing and sight
- Head lice
- Signposting to other services
- Talking to girls about starting periods
- Attending medicals with the paediatrician (special schools)
- Mental health checks
- Emotional support
- Eye tests
- Integrating with other professionals
- Identifying early disease
- Being able to access specialist help – e.g. with continence issues.

It was clear from those spoken to that the role of nurses supporting special school pupils was considerably more clinical in nature than that of mainstream public health school nurses. Nurses in special schools also offer outreach-support to some pupils in mainstream who needed support with routine clinical procedures. Parents, carers, school staff, and school nurses all said that without their presence, many of the children would not otherwise be able to attend school, and rates of unplanned hospital admission would likely be much higher.

The clinical role includes a range of activities:

- Supporting routine procedures (e.g. blood pressure, insulin pumps, gastrostomy/jejunostomy feeds, nebulisers, oxygen delivery, oral suction, and more),
- Responding to emergencies,
- Identifying early deterioration and arranging early-intervention,
- Supporting parents to navigate the complex health and social care system (including some parents with additional needs), including accessing clinic appointments and changes to medications,
- Signposting parents to additional sources of support,
- Offering assurance and support to school staff,
- Arranging urgent appointments with hospital consultants,
- Contributing to safeguarding, care plans, and routine medical assessments,
- Carrying out sight and hearing tests,
- Supporting regular medical assessments alongside a paediatrician

Children in Liverpool special schools often have a complex array of additional needs that include such things as ambulatory ventilators, artificial feeding methods, respiratory suction, physiotherapy needs, insulin pumps, care for frequent fits and administration of various medications. In some Liverpool special schools, these needs are met by a combination of school staff, nurses, and support workers working in partnership to meet the needs of the child. In other special schools, most routine medical procedures are provided by a nursing team. Such needs would usually be met by the child's parent(s) or carer(s) while at home once they had received adequate training in how to do so, and in partnership with additional support services according to need.

In general, it was found that the nurses in special schools have good working relationships with a wide range of professionals and with families. These nurses are uniquely positioned to be able to have oversight of the clinical needs of children and young people, to carry out early diagnosis and early referral, to prevent unplanned hospital admissions, to contribute to early help and safeguarding and to have a strategic coordinating role for working with partners to improve the health of children and young people. Nurses in special schools appear to have, and report, good working relationships with families and a wide range of professionals.

Public Health school nurses and special school clinical nurses both have a role to play in the delivery of a healthy child programme. However, each has a different focus for care: The Public Health aspect of the school nursing service delivers an inclusive universal public health offer for children in schools based on the requirements of the 5-19 healthy child programme. Clinical nursing teams however, carry out a role providing clinical interventions of care using their paediatric nursing skills. However, these roles

are complementary, heavily interwoven and provide opportunities for joint working to improve the health of children and young people and optimise their ability to attend school.

Many stakeholders highlighted the need for clarity around the role of public health and clinical school nurses for children with SEN +/-D, and expressed confusion around the scope of roles, the crossover between public health and clinical school nursing and the interface between these and other services. Respondents felt that nurses in schools should be able to work more flexibly around the needs of children and young people, but that boundaries should also be explicit and roles clear to enable these nursing services to deploy their resources to best effectiveness. It should be noted that this area is already being addressed through ongoing partnership working between commissioners and providers to strengthen clinical leadership and governance for the service and agree roles and responsibilities.

**Recommendation 17: Commissioners should determine and agree the distinct but complementary relationship between:**

- a) Those nurses providing a public health service, i.e. public health school nurses (SCPHN-SN) and their teams, to all children and young people of school age in Liverpool and,
- b) Clinical paediatric nurses (and their teams), who provide a year-round clinical service, who have current clinical knowledge and skills.

Various other professionals also operate in special schools to support children and young people with SEN+/-D. These include, for example, in-school physiotherapy teams who apply regular planned programs of physiotherapy including chest physiotherapy. They also work together with public health school nurses and other professionals to identify and apply early interventions to reduce unplanned admissions.

The Community Children's Nursing Team (CCNT) is provided by Alder Hey Children's Hospital. The CCNT is a specialist nursing service that offers specialist nursing support and training in homes, children's centres and other community settings. It supports children with a range of conditions from general to complex health needs.

Individually-tailored packages of care for children and young people whose needs cannot be met by existing services (i.e. under continuing care funding) usually results in a bespoke package of care for a child, often in the form of a 1 to 1 carer. Approximately two thirds of those in receipt of continuing care funding receive this for physical needs, the remainder for behavioural needs.

The Community Paediatric Complex Care Matron's Service supports the most medically complex children and young people. These matrons are the lead professionals for all children with who receive continuing care for medical reasons.

## **7. Conclusions**

This health needs assessment (HNA) has highlighted new information about the needs of and provision for children and young people in Liverpool with special educational needs and/or disability (SEN+/-D). Existing system capacity could be maximised through better access to training for all providing care, better partnership-working, and by enhancing and improving the roles of school nurses for children with SEN +/-D. In addition, important themes have emerged around:

- Improving support for parents and carers to help them navigate and cope with health systems
- Improving the management of clinical care in and out of school, including routine and emergency procedures for children with SEN+/-D
- Improving oversight and clinical governance of medical support in schools
- Improving support for families around school transition points
- Strengthening support to enable more children with SEN+/-D to integrate into mainstream schools

## Appendix 1 –Policy Context

The following policies, strategies, and other documents are relevant to the needs of children and young people with SEN+/-D:

The United Nations Convention on the Rights of the Child<sup>v</sup>

The Children and Families Act (2014)<sup>vi</sup>

Human Rights Act (1998)<sup>vii</sup>

Children and Families Act (2014)<sup>viii</sup>

Equality Act (2010)<sup>ix</sup>

Disability-Discrimination Act (1995)<sup>x</sup>

Care Act (2014)<sup>xi</sup>

Getting it right for children, young people and families, Department of Health (2012)<sup>xii</sup>

Supporting pupils at school with medical conditions, Department for Education (2015)<sup>xiii</sup>

Quality criteria for young people friendly health services, Department of Health (2011)<sup>xiv</sup>

Maximising the school nursing team contribution to the public health of school-aged children, Department of Health (2014)<sup>xv</sup>

Healthy Child Programme 0 to 19: health visitor and school nurse commissioning, Public Health England (2016)<sup>xvi</sup>

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<sup>v</sup> <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

<sup>vi</sup> <http://www.legislation.gov.uk/ukpga/2014/6/contents>

<sup>vii</sup> <http://www.legislation.gov.uk/ukpga/1998/42/contents>

<sup>viii</sup> <http://www.legislation.gov.uk/ukpga/2014/6/contents>

<sup>ix</sup> <http://www.legislation.gov.uk/ukpga/2010/15/contents>

<sup>x</sup> <http://www.legislation.gov.uk/ukpga/1995/50/contents>

<sup>xi</sup> <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<sup>xii</sup> <https://www.gov.uk/government/publications/getting-it-right-for-children-young-people-and-families>

<sup>xiii</sup> <https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>

<sup>xiv</sup> <https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>

<sup>xv</sup> <https://www.gov.uk/government/publications/school-nursing-public-health-services>

<sup>xvi</sup> <https://www.gov.uk/government/publications/healthy-child-programme-0-to-19-health-visitor-and-school-nurse-commissioning>