

Knowsley Joint Strategic Needs Assessment

Children with Disabilities and Complex Health Needs

This report

This report has been prepared by Knowsley Council in consultation with the Knowsley Clinical Commissioning Group (CCG) and partner organisations of the Health and Wellbeing Board (HWB). Its purpose is to set out current understanding of issues relating to Children with Disabilities and Complex Health Needs in Knowsley, based on analysis of the latest available data.

It is one of a series of reports that inform Knowsley's understanding of local health and wellbeing priorities, based on analysis of needs, and set out in its Joint Strategic Needs Assessment (JSNA). Other JSNA reports cover topics that relate closely to children and young people's mental health, and these are available on the Knowsley Knowledge JSNA website. They include:

- [Looked After Children](#)
- [Children In Need or at risk of harm](#)
- [Child & Family Poverty](#)
- [Children with Disabilities & Complex Needs](#)
- [Schools Capacity & Admissions](#)
- [Educational Attainment and Attendance](#)
- [Employment and Unemployment](#)

This report is based on the most recently published formal statistics. Where later data is available but still classed as 'provisional' it will only be referenced if it signals significant change. New data releases will be monitored to ensure that the report can be updated as necessary.

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Further information

For a PDF copy of this report, and other research intelligence products, visit **Knowsley Knowledge** – the website of Knowsley's JSNA

This review deals specifically with those children in Knowsley who suffer from disabilities and complex needs. Whilst housing and homelessness, child and family poverty, and Children Looked After are referred to throughout the analysis, specific intelligence on these populations is covered in separate reports.

Children with disabilities and complex health needs can be defined as having one or more of the following conditions:

- Physical or mental impairment
- Sensory impairment
- Learning disability
- Long term medical condition
- Social disorder

A number of acronyms are used throughout this document:

DfE – Department for Education

DH – Department of Health

EHC – Education, Health and Care plans

ASC – Autistic Spectrum Condition

CCG – Clinical Commissioning Group

CIN – Children in Need

CLA – Children Looked After

CIN SB – Children in Need Short Break

CLA SB – Children Looked After Short Break

SEN – Special Educational Needs

SEND – Special Educational Needs and Disabilities

DDA – Disability Discrimination Act

DLA – Disability Living Allowance

CHCN – Complex Health Care Needs

NICE – National Institute for Health and Care Excellence

Although not included in the Children with Disabilities and Complex Health Needs cohort, there can be significant overlap between services supporting children involved in anti-social behaviour, gangs and other Youth Offending issues, intelligence on this is included in the Crime JSNA.

Contributors

The majority of this report is based on evidence and analysis from the following organisations:

- KMBC Commissioning Services
- KMBC DCFS Inclusion Services
- KMBC Short Breaks
- Department for Education

EXECUTIVE SUMMARY

This summary is intended to provide a stand-alone briefing on current intelligence about Children with Disabilities and Complex Health Needs in Knowsley.

What are the most critical Children with Disabilities and Complex Health Needs challenges facing Knowsley?

- Formal disability registers are not held at local authority level and numbers of children are only known where services support particular needs. There are national estimates that 7.3%¹ of children are disabled. At this level of prevalence there would be approximately 2,708 children with a disability with approximately 1,041 of these aged between 5 and 11 years old.

However, local authorities have provided estimates ranging from 3% 5.4%. (Tony Norman 2010) If these rates are applied to Knowsley then there would be between 1,113 and 2,003 disabled children in the borough.

- The number of disabled people is forecast to rise nationally by between 23% and 40% by 2022. Applying this rise to Knowsley equates to anywhere between an extra 256 and 1083 children with disabilities in Knowsley by 2022.
- Increased permanent demand and reduced budgets – investment in Early Help is key.
- Increased diagnosis of autism and increased number of children with complex needs surviving birth leading to an absolute increase in the population and greater demands on services.
- Early intervention – services that can meet needs earlier need to be well resourced as it is known that these services will be needed at some point e.g. speech and language, behaviour support, parental support and short breaks.

Short Breaks providers have reported an increase in the numbers of younger children i.e. 2 – 6 year olds accessing activities and an increase in the level of challenging behaviour associated with these children.

For children aged 0-statutory school age, services to meet the needs as early as possible are accessed through the Child Development Team. The team meets the first Tuesday of the month and they look at all the requests for services and allocate appropriately. Examples of services to be accessed are Speech and Language, Community Paediatrician, Occupational Health, Portage Service and Physiotherapy.

- Access to universal services is a regularly raised issue as universal services are not necessarily well set up for children with disabilities to access provision

¹ Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey, School of Health and Social Studies, University of Warwick 2010

and to make their provision accessible requests for additional financial support from services are not uncommon.

- Local data and intelligence needs to be smarter e.g. numbers of children coming through, referencing type of disability, type of needs, demographic data etc. is available at service level e.g. Knowsley's Child Development Team (CDT), but a more integrated approach and better access to health intelligence is required to enable us to plan services more effectively for the future.

What is the scale of the problem, and who is most affected in Knowsley?

- Nationally, 13.2% of Children in Need have a disability, in Knowsley the proportion is 15.8%.
- In Knowsley, there are more children with SEN as a proportion of all school children than for its comparators. Knowsley is higher for all categories, those with a statement, without a statement, on school action plus and school action.
- The number of children receiving disability living allowance is an indicator that can be used to measure the number of children with disabilities. In Knowsley, 1,710 children and young people aged 24 years and under receive disability living allowance.
- Research suggests that there has been an increase in the number of children with a disability or complex health needs, due to more children being diagnosed at an early age and advancements in medical technology and therapies.

Have things been improving or getting worse?

There have been notable improvements following short break investment, through grant funding, in activities and family networks. There are 5 family support groups in Knowsley providing parental support, weekly activities and special events. The family forum meet every month and provide families with information and support on a range of local and national agenda's. The family networks enable parents to peer support each other and have resulted in volunteer and paid job opportunities for parents and siblings. Parental support networks have also been able to coordinate the parent voice and have created the opportunity for co-production arrangements both in the development of the short break offer and in implementing the SEND Reforms. The relationship between the council and the parent groups is very positive and allows for transparent decision making and greater empowerment and resilience.

The Short Breaks Activity programme provides 16 activity sessions a week with approximately 220 children who regularly attend. There are also 8 summer clubs plus the parent groups offer. Families do not need a formal assessment or referral to attend.

The function of the Short Breaks provision is to prevent families with a disabled child reaching crisis point and therefore needing high cost interventions. The cost saving in preventing just a few children entering the Looked After system far exceeds the total short breaks budget. A costing exercise of Knowsley's Short Breaks programme was undertaken in 2009/10, finding that the prevention of 4 children entering the Looked After System represented a cost saving of £208,000 and a maximum cost saving of £800,000. It is expected that future analysis will show the savings made from early and successful intervention would be at least equal to these amounts for a similar number of children.

Through a regular cycle of evaluation parents describe the Short Breaks offer as a 'lifeline' and that without it they would not be able to cope. Additionally they report reductions in stress and improvements in children's behaviour, communication and mobility and relationships within the family.

How are things expected to change over the next few years?

Government reforms both from the DfE and the DOH will bring the advent of more person centred approaches which are outcome focussed, personal budgets, more choice and control and creative ways of meeting needs (as opposed to traditional forms), EHC plans replacing statements – which will lead to more joined up plans and an expectation of more integrated service delivery.

How do we compare with national and regional averages, and statistical neighbours?

Lack of local intelligence and National data sets makes both comparison and projection problematic. The record of statemented children and numbers requiring support at school for special educational needs is higher than national and regional averages, however this can only serve as a proxy indicator and may simply reflect higher levels of deprivation.

At 26%, Knowsley has a higher proportion of pupils with SEN than England averages (17.9%) and higher percentages of statemented pupils at 3.7% (2.8% nationally). The number of maintained statements is lower now than in 2009; however a significant increase occurred between 2012 and 2013, three times greater than national increases.

How good is the available intelligence, and where are the gaps in our knowledge?

There is currently no local register of disabled children. Individual services hold records of those children with physical disabilities or complex needs, whilst many of the children will be recorded across a number of services, the information is not held centrally.

Local data and intelligence needs to be smarter e.g. numbers of children coming through, type of disability, type of needs, demographic data etc. to enable us to plan services more effectively for the future.

The Ofsted inspection of Knowsley services found that the voice of children is not heard and their experiences are not fully understood, whilst social workers place too

much focus on the needs of adults. Whilst the views of Children Looked After on the services and support they receive are well documented nationally and locally, there is no framework to gather the views of children who receive services under section 17: this would include young people accessing residential short breaks as CiN .

Each of the Children's JSNA reports reference some of the currently available insight from vulnerable children whilst highlighting recording the experience of children as a key intelligence gap.

We have a commitment to broaden consultation with young people and their families and will be developing an insight plan to mainstream consultation processes in order to support service development and better hear the views of young people accessing our services.

Consultation should be designed with particular regard to the Office of the Children's Commissioners recommendations on hearing the voice of the child published in their report of December 2014 "Children and young people giving feedback on services for children in need: ideas from a participation programme".

CHILDREN WITH DISABILITIES AND COMPLEX NEEDS

Introduction

1. WHY ARE CHILDREN WITH DISABILITIES AND COMPLEX HEALTH NEEDS IMPORTANT?

Children with disabilities and complex health needs often suffer from significant inequalities in health, employment, education and the wider society. They have poorer health, wellbeing and social outcomes compared to their peers, with accessibility and the specialised nature of their needs being detrimental.

Children with disabilities and complex health needs often face a range of issues that can be unique to the individual and may require tailored specialist services. The objective for Knowsley is to understand these needs and then develop and implement the required services for the individual child to reach his or her potential. To reach their potential to make a positive contribution to society, children and young people with disabilities and their families need effective support from statutory health, education, social care and voluntary services at the appropriate stages of their lives. Current and future financial pressures and new national policies require more integrated, joint approaches to ensure the best use of resources to support the needs of children with disabilities and complex needs.

Children with disabilities and complex health needs can be defined as having one or more of the following conditions:

- Physical or mental impairment
- Sensory impairment
- Learning disability
- Long term medical condition
- Social disorder

Without appropriate and effective support, children with disabilities and complex needs are likely to face challenges and disadvantages in life proportionate to those faced by other vulnerable groups. These children are more likely to live in poverty and to suffer mental health conditions, they will miss more school and are more likely to underachieve educationally and not reach their full potential.

Complex Health Needs

There is no single definition of children with complex needs. This assessment will consider a range of conditions, including:

- a serious on-going i.e. chronic illness

- an illness, condition or disability that results in the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to social or physical barriers
- significant developmental or acquired impairments or delays in one or more areas of cognitive development, sensory or physical development, communication development, social, behavioural or emotional development
- a condition which has a high probability of resulting in developmental delay or deteriorating functional ability and whose ability to achieve their potential is impaired due to a wide range of barriers facing them
- vulnerability and risk that is likely to require support at key transitions and during transition into adulthood

Other medical conditions such as obesity could possibly be an issue for children with disabilities and complex health needs. This may be due to genetic, metabolic or mobility factors and support should be provided to the children and their families to help the child maintain a healthy weight.

Autistic Spectrum Condition (ASC)

Autistic spectrum condition (ASC) is a lifelong condition characterised by impairments in three main areas: social interaction, communication and the presence of repetitive behaviours (known as the triad of impairments). The term “spectrum” is used due to the significant variations between individual cases, including severity and presentation of the triad of impairments; differing IQ levels; and general functional abilities. Autistic Disorder, Asperger Syndrome and High Functioning Autism are all types of Autistic Spectrum Condition¹⁰.

From a local authority, Clinical Commissioning Group (CCG) and wider NHS perspective providing specialist, often intensive health and social care support has a significant impact on public resources. This can include the cost associated with the treatment, social care support; the cost of home adaptations and respite and other support for their carers / families. Beyond this, children with disabilities and complex conditions often need specialist educational support.

Impact on Knowsley residents

2. WHAT IS THE SCALE OF THE CHALLENGE FOR KNOWSLEY?

Estimating the number of children with disabilities and complex health needs in Knowsley is difficult because different definitions are used and not all are known to services. However, various measures can be used to pull together an overview of the prevalence and level of need. Identifying the scale of the challenge for Knowsley is difficult because each child potentially faces a range of issues that can be unique to the individual and that may require tailored specialist services.

Applying an estimated prevalence rate of 5% (a mid point between estimates provided above), and 1.2% for the most severely disabled, there are around 1,975 children with a disability living in Knowsley, with 474 children having the most severe disabilities.

Many families with children with disabilities require support from social care services, nationally, 13.2% of Children in Need have a disability, in Knowsley the proportion is 15.8%, a total of 181 children at March 2014.

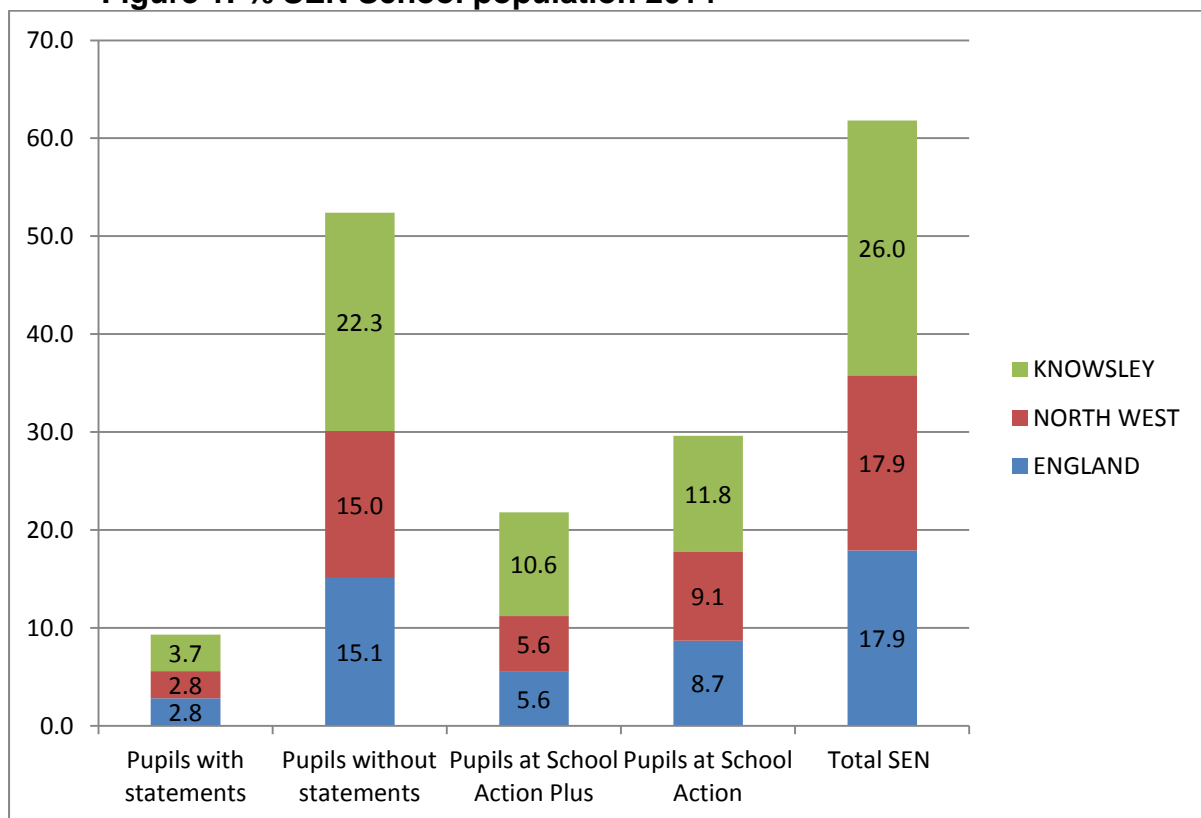
The scale of health and other inequalities

Children with Special Educational Needs (SEN)

SEN Statements and Learning Difficulty Assessments have been replaced by the 0 – 25 integrated Education, Health and Care Plan (EHC Plan) for individual children and young people with special educational needs and disabilities. However, existing SEN assessment provide a good overview of current levels of need.

A young person may have either a SEN or a disability but there is considerable overlap. Some children with SEN have statements. SEN statements are for those with more extreme educational needs and will describe the special help the child should receive. The local authority will usually make a statement if it decides that all of the special help the child needs cannot be provided from within the school's existing resources. The local authority may decide that the child's school can provide special help for the child's SEN without the need for a statement.

In Knowsley, there are more children with SEN as a proportion of all school children than for its comparators. Knowsley is higher for all categories, those with a statement, without a statement, on school action plus and school action. Figure 1 below shows the percentage of pupils identified within each of the SEN categories compared to North West and England. At 26%, Knowsley has a higher proportion of pupils with SEN than England averages (17.9%) and higher percentages of statemented pupils at 3.7% (2.8% nationally). The number of maintained statements is lower now than in 2009; however a significant increase occurred between 2012 and 2013, three times greater than national increases. 14% of current statements were new in the calendar year 2012, compared to 12% nationally.

Figure 1: % SEN School population 2014

The proportion of children in local schools with special educational needs is considerably higher than average, with particularly high levels of mild learning difficulties and emotional and behavioural referrals.

Overall in January 2014, there were 5,340 children in Knowsley schools with Special or Additional Educational Needs who need extra help from schools or a formal statement defining the additional support the child requires. Of these, 2,918 were School Action Plus or Statemented children. Table 1, shows the breakdown of pupils with a statement or school action plus by primary need. It shows that overall the highest percentage of pupils (irrespective of school type) were classified as having moderate learning difficulties (36.6%), followed by pupils having behavioural, emotional or social disorders (17.5%). The table shows comparisons in the levels between school types and against comparators (England and North West).

Some particular discrepancies to be aware of:

Primary Schools – Knowsley has over double the percentage of children, with moderate learning difficulties identified as the primary need who have a SEN statement or at school action plus than NW and England levels. 45.1%. Less have physical disabilities; speech, language and communication needs; and behaviour, emotional and social difficulties as a primary need.

Secondary Schools – Knowsley has higher percentages of children identified with moderate and specific learning disabilities as primary need than NW and England comparators.

Special Schools – Knowsley has slightly higher percentages of children identified with profound and multiple learning difficulties; speech, language and communication needs; physical disabilities; autistic spectrum disorder and behaviour, emotional and social difficulties as primary needs.

Table 1: Pupils with an SEN statement or at school action plus, by primary need type – February 2014

Condition	Primary school			Secondary school			Special schools		
	England	NW	Knowsley	England	NW	Knowsley	England	NW	Knowsley
Specific Learning Difficulty	8.7	10.9	8.2	16	15.9	21.8	1.2	1.5	0.0
Moderate Learning Difficulty	19.1	20.5	45.1	20.3	21.9	33.3	17.2	12.9	8.3
Severe Learning Difficulty	1.3	1.2	0.5	0.9	1.0	x	24.8	26.7	22.4
Profound & Multiple Learning Difficulty	0.4	0.5	0.2	0.1	0.1	x	8.8	10.1	12.1
Behaviour, Emotional & Social Difficulties	18.4	18.5	13.3	26.7	25.1	26.3	13.4	14.8	16.3
Speech, Language and Communications Needs	31.6	27.5	19.2	11.0	9.1	5.1	5.3	4.4	7.0
Hearing Impairment	2.3	2.3	1.0	3.0	3.3	2.4	1.4	0.7	x
Visual Impairment	1.3	1.5	0.5	1.7	1.7	1.0	0.8	0.8	0.8
Physical Disability	4.1	4.2	1.7	4.0	4.3	2.6	3.5	3.3	5.5
Autistic Spectrum Disorder	8.3	7.3	6.1	10.7	9.6	3.0	22.5	23.8	25.6
Other Difficulty/ Disability	4.3	5.4	4.1	5.8	7.9	4.0	0.9	0.9	1.5

Source: School Census, Department of Education 2014

Pupils with a SEN statement or at school action plus, by primary need type 2014

	Specific Learning Difficulty	Moderate Learning Difficulty	Severe Learning Difficulty	Profound & Multiple Learning Difficulty	Behaviour, Emotional & Social Difficulties	Speech, Language and Communications Needs	Hearing Impairment	Visual Impairment	Physical Disability	Autistic Spectrum Disorder	Other Difficulty/ Disability	Total
Primary	134	734	8	4	216	312	17	8	28	99	67	1,625
Secondary	179	274	x	x	216	42	20	8	21	25	33	820
Special	0	33	89	48	65	28	x	3	22	102	6	400

Source: School Census, Department of Education 2014

Pre school aged children known to Portage Service and Private, Voluntary and Independent Settings accessing Area SENCo support who need SEN Support

	Specific Learning Difficulty	Moderate Learning Difficulty	Severe Learning Difficulty	Profound & Multiple Learning Difficulty	Behaviour, Emotional & Social Difficulties	Speech, Language and Communications Needs	Hearing Impairment	Visual Impairment	Physical Disability	Autistic Spectrum Disorder	Other Difficulty/ Disability	ASC Pathway
1 year olds		3										
2 Year olds			2	3		8		2	3		6	13
3 -4 year olds		1				14		2	1	10		19

Children with Statements of special educational needs:

Knowsley supports 926 children with statements living in the Borough. The highest proportion of children statemented have an Autistic Spectrum Condition (311), the next highest have Behavioural, Emotional or Social disorders (169).

129 children have a physical disability, including hearing and visual impairment, 67 of whom have Profound and Multiple Learning Difficulties.

PMLD	Profound and multiple learning difficulty
HI/VI	Hearing impaired/visually impaired
ASC	Autistic spectrum condition
SLD	Severe learning difficulty
SALD	Speech and language difficulty
BESD	Behaviour, emotional and social difficulty
CL	Complex learning
PD	Physical difficulty
MLD/SpLD/Other	Moderate learning difficulty/specific learning difficulty

Figure 2:

Stated children by Need 2015

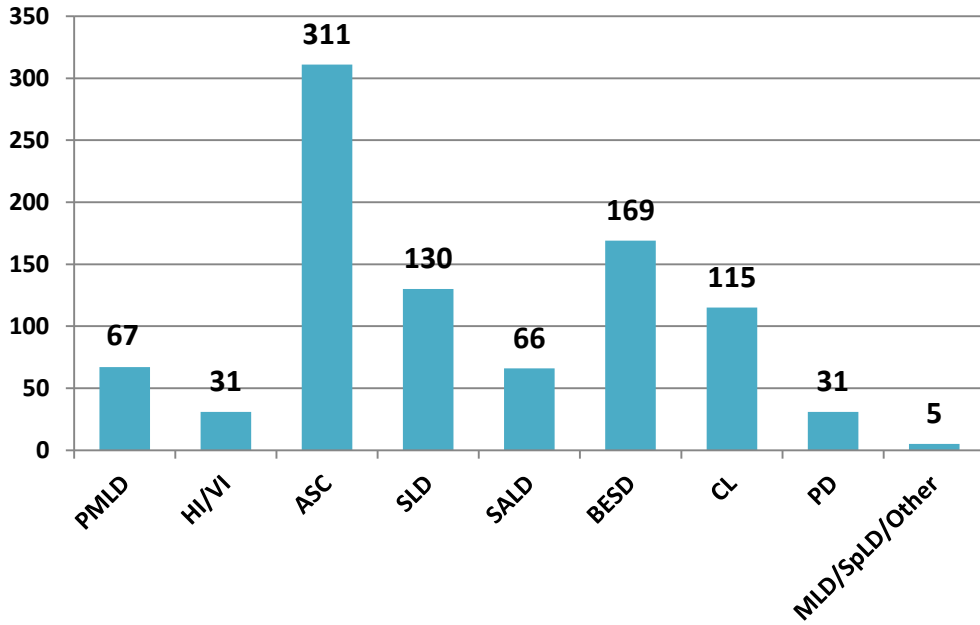


Figure 3:

Stated children by Need 2015

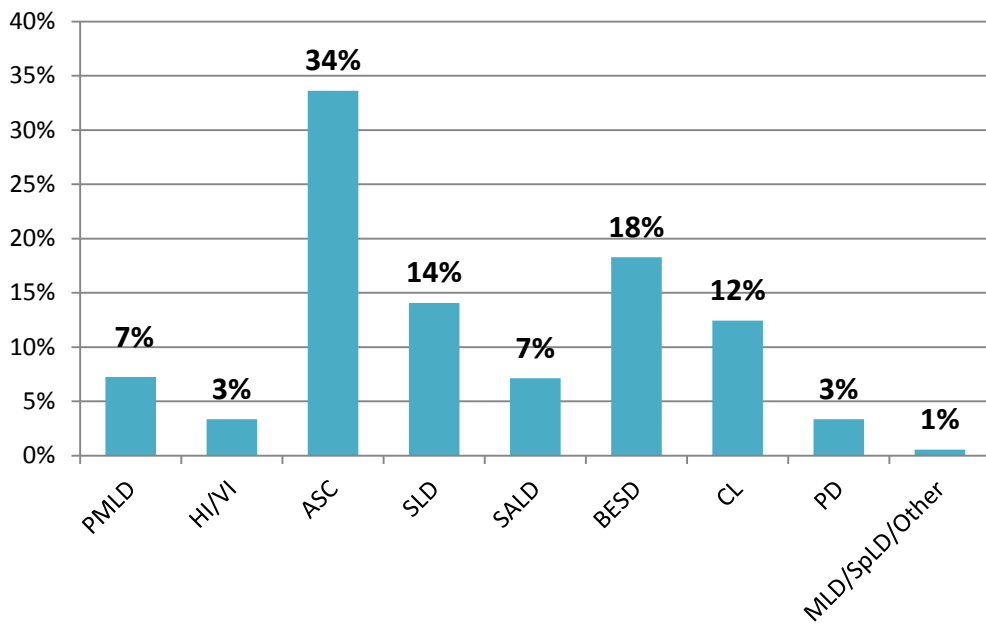
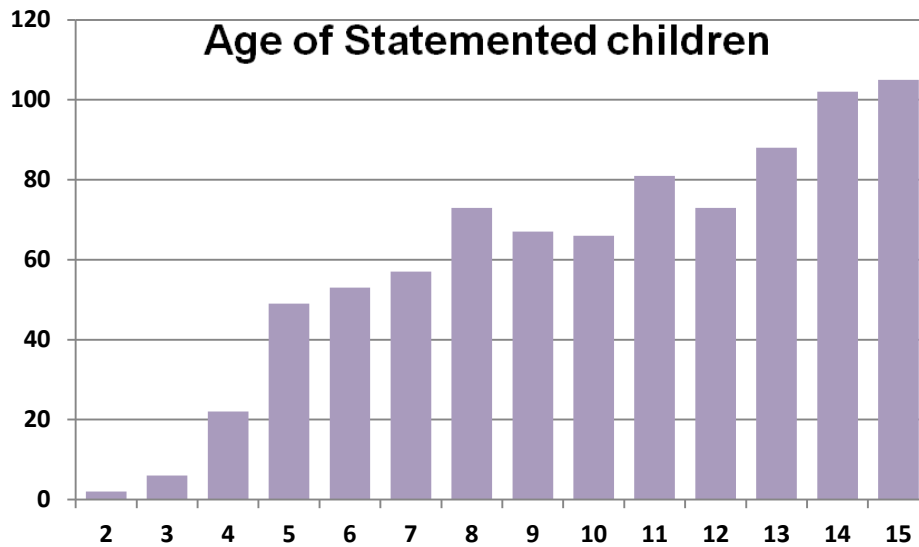


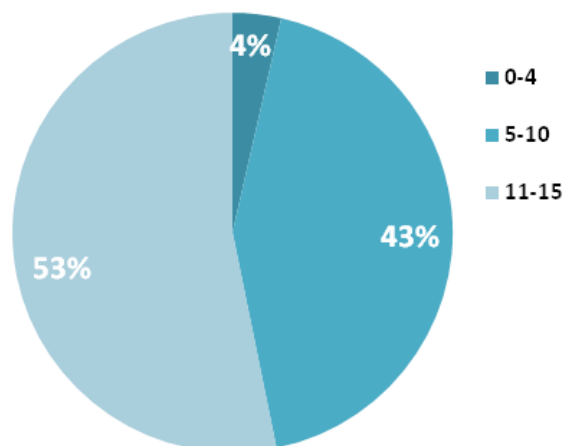
Figure 4:



A higher proportion of children with statements are over the age of eleven, however this is due in part to the age at which needs are first identified, the length of the diagnostic process, and the high prevalence of BESD which typically develops at a later age.

Figure 5:

Age of Statemented children



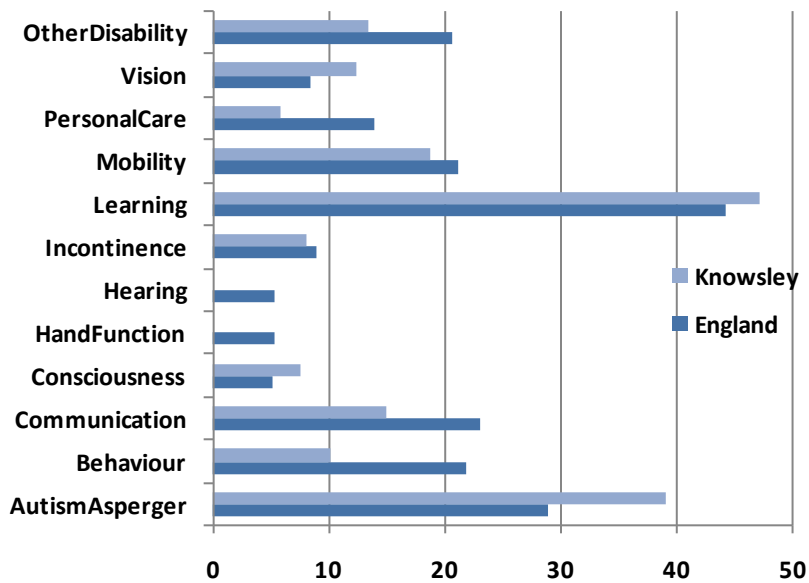
40% of statemented children are supported in Mainstream education, mostly within Knowsley schools. The highest level of inclusion is for those children with a physical disability (94%), the lowest level for those with complex learning needs.

DfE School Category Description	ASC	BESD	CL	HI/VI	MLD/SpLD/Other	PD	PMLD	SALD	SLD
Total	311	169	115	31	5	31	67	66	130
Mainstream educational provision	120	53	78	18	3	29	6	39	26
	39%	31%	68%	58%	60%	94%	9%	59%	20%

- ASC/Autism accounts for 34% of all statemented needs in the borough.
- 311 children have a statement for ASC in Knowsley, of whom 120 or 39% are supported in mainstream educational provision.
- Amongst local Children in Need in Knowsley Learning Difficulties are the highest noted form of disability, followed by Autism, or Asperger's Syndrome (73 children), this mirrors the national levels of disability in the CIN cohort.

Although rates have not changed across England since 2013, levels of Autism/Aspergers within the CIN cohort have increased significantly in Knowsley, it is not clear if this is an increase in identification or incidence.

Figure 6:

% CIN At 31/03/14 by disability

Identified challenges:

- Autism in Huyton is increasing and is higher than any other area of Knowsley. Despite being historically low in Whiston, diagnoses have risen recently.
- Timely ASC diagnosis remains a significant challenge, although in the last few years children are being diagnosed younger, this has also contributed to the rise in ASC numbers across the borough.

The Knowsley ASC Strategic Group was formed in October 2012 in order to address the emerging gaps in our Knowsley ASC Pathway highlighted by NICE Guidelines Baseline Assessment exercise. Work is progressing to combine the different neuro-development pathways for ASC diagnoses alongside ADHD and Motor Co-ordination Difficulties. The wider Neuro-developmental pathway process is informed by a broad range of partners:

- CCG commissioners
- Knowsley Authority commissioners
- Community Paediatrician
- GP
- Principle Education Psychologist
- Head of Outreach
- Early Years SEN Co-ordinators
- Speech and Language Therapist
- Occupational Therapist
- Parent Representative
- College Representative

Knowsley commissions the services of the Positive Behaviour Support Service (PBSS) to support individuals with challenging behaviours and their families to decrease behaviour and increase quality of life. Referrals are reserved for severe learning disability and/or autism.

The service uses Applied Behavioural Analysis principles to determine function of behaviour and designs person centred intervention. In the long term the service aims to reduce challenging behaviour, but also to provide the people around the child with strategies and knowledge to support the individual long term. With a focus on children who are highly likely to require full time residential provision without appropriate input, early intervention, and preventative support work from the service reduces the chances that a child may need to live away from the family.

Long-term limiting illness, disability or infirmity

2011 Census

The 2011 Census includes a question that enables people to indicate if they have a disability or limiting lifelong condition. This is a self-reported judgement, based on the person's own perception of their state of health and the extent to which any health conditions they have limit their daily activity. Whilst it may therefore under- or over- estimate levels of disability, it nevertheless provides a useful approximation of levels of limitations people feel their health places on their ability to lead full and active lives. Also, this is a broader definition than the DDA definition of disability, so this indicator is likely to be an overestimate of the number of disabled children, if we want to restrict estimates to those that would come under the DDA definition.

Number of Knowsley children and young people with long-term health problem or disability by general health by age, 2011 Census

	Number of residents	Day-to-day activities limited a lot	Day-to-day activities limited a little	Day-to-day activities not limited
0 to 15	28,666	613	725	27,328
16 to 24	17,931	562	583	16,786
All Ages	144,990	20,157	14,747	110,086

Source: Census 2011, Office for National Statistics 2013.

It shows that over 1,100 children and young people under the age of 24 were identified as having long term health problems or a disability that affected day

to day activities a lot. A further 1,300 plus were identified as having conditions that limited day to day activities a little.

Disability living allowance for Children

The number of children receiving disability living allowance is an indicator that can be used to measure the number of children with disabilities. 1,710 children and young people aged 24 years and under receive disability living allowance. This is a useful indicator, but only includes those that are eligible and claiming benefits.

Number of children in receipt of Disability Living Allowance (DLA) in Knowsley – February 2014

Age	Male	Female	Total
aged under 5	110	50	160
aged 5 to under 11	310	130	430
aged 11 to under 16	310	150	450
aged 16-17	110	60	170
aged 18-24	320	210	540
Total (all ages)	7,580	8,360	15,940

Source: Nomis 2014, figures are rounded to the nearest 10 and may not total..

Projections

Research suggests that there has been an increase in the number of children with a disability or complex health needs, due to more children being diagnosed at an early age and advancements in medical technology and therapies. Projections suggest the volume and prevalence of children and young people with disabilities may rise over the next 10 years. This is partly due to the above, plus an expected increase in the number of children and young people, meaning a higher demand for services for children with disabilities. Therefore it is important to ensure that the correct services are in place to prevent childhood disability and support those who are disabled.

Local knowledge indicates that the number of children with disabilities in the Borough is higher than the national average. The lack of available information locally about children with disabilities makes projections of future need difficult. Without exact percentages or detailed case information it is difficult to predict whether falling population numbers in the Borough will result in reductions in the level of need.

3. WHO IS MOST AT RISK OF DEVELOPING COMPLEX NEEDS?

Disabilities may be developmental or acquired. Sometimes, several factors may combine to cause a disability and often the exact cause is unknown. Any child is at risk of being born with a disability or developing a complex health condition irrespective of their family circumstances. However, there is evidence that particular factors increase the risk of children being born with a disability or having complex health needs, such as:

- Chromosomal and genetic abnormalities.
- Physical injury or infectious disease occurring during pregnancy.
- Poor nutrition, smoking and/or the use of drugs and alcohol during pregnancy - Smoking during pregnancy increases the risk of birth defects, infant mortality, low birth weight and infections during childhood. Available data for Knowsley shows that in Quarter 4 2012/13 a total of 22.63% of pregnant women smoked at the time of their delivery. Whilst this figure has fallen since the previous two quarters and overall since 2010/11, it is still much higher than both the North West (16.3%) and national (12.8%) averages which have both continuously fallen since 2009-10.
- Maternal age – there can be a higher risk of complications for mothers aged under 20 and over 40. Teenage mothers and their children are more likely to face poor physical health and emotional health outcomes. In Knowsley, more babies per 1,000 (36.4) are born to teenage mothers (aged 15-17) when compared to national (30.7) and regional (35.3) averages. However, Knowsley does perform better in this area when compared to statistical neighbour averages (40.1).
- Premature and multiple births – there can be a risk of low birth weight with premature or multiple births.
- Low birth weight – babies with a low birth weight have a higher risk of disability and long term health conditions. Those babies born weighing less than 2,500g (5lb 8oz) are considered to be underweight. Low birth weight is linked to age, smoking in pregnancy, prematurity, multiple births and ethnicity. Children born with low birth weight are more likely to have respiratory diseases, sleep apnea, heart problems, jaundice and chronic lung disease. In Knowsley, the proportion of low birth weight babies born between 2009 and 2011 was 7.5%. This was the second successive decrease, bringing the level of babies born with a low birth weight slightly lower than Knowsley's statistical neighbours (7.6%). It is also the lowest proportion since 1995-97. In 2011 alone, the proportion of births under 2,500g was even lower at 6.9%. However, despite these decreases there are still a higher proportion of babies born with a low birth weight in Knowsley than in the North West region (7.0%) and England (7.1%).
- Physical injury during childhood.
- Economic disadvantage – Children from low income and poverty stricken households are more likely to become disabled due to the association of poverty and poor health. Research published by the Children's Society estimates that 4 in 10 disabled children live in relative income poverty compared with around 3 in 10 of all children. Children with disabilities or disabled parents are more likely to be in

poverty due to a combination of factors such as high levels of worklessness and lower hours of work and pay. Likewise, disabled children are more susceptible to economic disadvantage as they are more likely to experience high living costs and barriers to employment in the future.

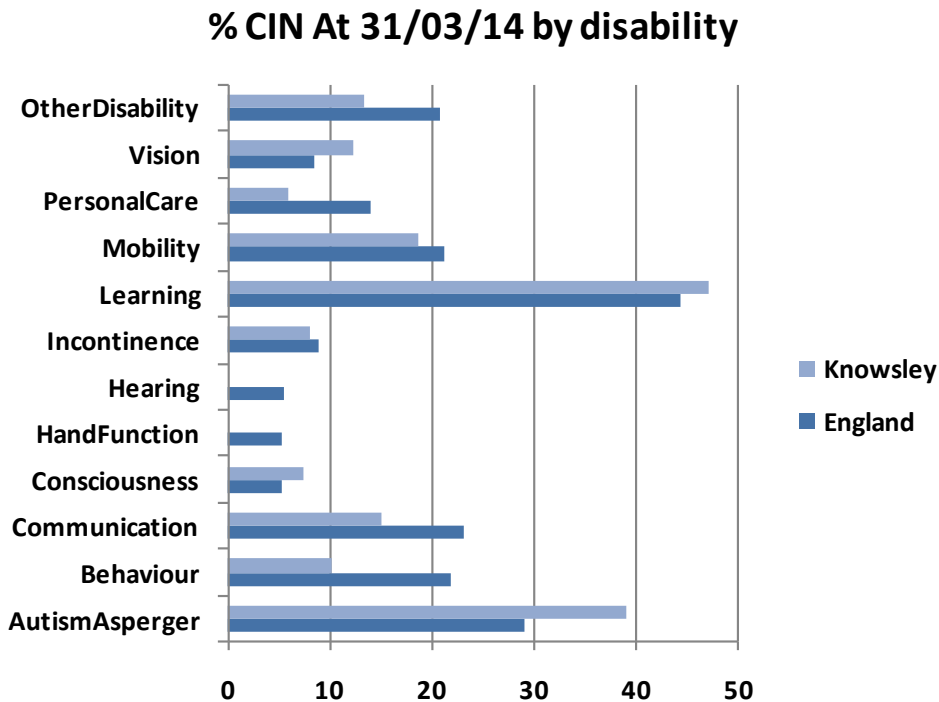
- Children with disabilities and complex health needs face a range of issues that can be unique to the individual which may require tailored specialist services. Family, social and economic conditions in which a child lives can also create additional needs. For example lone parents – can reduce accessibility to respite and have a negative impact on carer’s wellbeing. Children in lone parent families are at greater risk of living in poverty than children in couple families. There are 8,345 children in poverty in Knowsley that are living in a lone parent family; which represents 79% of all children in poverty in the borough. This compares with a national rate of 70%.
- Families who lack wider family/familial support and have a limited social network often have less access to respite and support as primary carers.
- Poor quality housing – can exacerbate issues, restricting mobility. The impact of poor quality housing on the life chances of children and young people is significant as their health, education and future opportunities suffer. Children living in poor housing are twice as likely to suffer from poor health as other children, particularly respiratory problems such as breathing difficulties, asthma and bronchitis. They are also more likely to suffer from behavioural issues, depression and mental health problems. What’s more, housing related hazards such as damp, mould, and structural defects increase the risk of an accident in the home and can exacerbate issues (poor lighting or lack of stair handrails).
- Poverty can have an impact on accessibility of respite support for carers and access to activities/specialist equipment to support child. Disabled children are more likely than their non-disabled peers to live in poverty as a result of lower incomes (because parents need to look after disabled children and so cannot work) and the impact of disability-related additional costs (an impact which is not captured by official figures). The highest concentrations of child poverty are centred around the Stockbridge (47.8%), Page Moss (46.7%) and Longview (40.4%) wards in Huyton, and the Northwood (48.9%) and Whitefield (40.5%) wards in Kirkby. There are also pockets of high child poverty in Halewood, Prescott and Cherryfield.
- The Children's Outreach and Residential Disability Service (CORDS) provide short breaks for Disabled Children at Fullerton Grove. At end of August 2015 37 children were accessing overnight short breaks. Three of these children receive short breaks under section 20, and a further

two are permanently Looked after by other carers and accessing short breaks with ourselves.

The remaining 32 children access stays under section 17 of the Children Act. This figure will be subject to change due to children accessing and leaving the service.

- Of the current children looked after population 6% have a disability. In addition there is provision required for short breaks for an additional 7 children looked after, and 30 children who require accommodation for short breaks. Children looked after are often identified as having multiple disabilities, in addition to any emotional or mental problems they may experience, which can make the child harder to place. In terms of current placements in Knowsley, there are three specialist places for children or young people with disabilities.
- As at March 2014, 187 or 15.8% of Children in Need supported by Children's Social Care in Knowsley were recorded as having a disability. This is slightly higher than National rates of 13.2%
- The greater proportion of children have a learning disability, whilst numbers with Autism/Aspergers related condition are the next highest. This is in line with the National averages for CIN.

Figure 7:



The primary issue is the overrepresentation of families from more disadvantaged socio-economic groups amongst those affected by disabilities. Disabilities can also be a major contributor to material disadvantage and poverty. Families with disabled children are likely to have low incomes because caring for disabled children limits parents' earning capacity. In addition, the costs of caring for a disabled child are greater and estimated to be £7,355 per annum compared with £2,100 for a non-disabled child.

4. WHICH AREAS OF THE BOROUGH ARE MOST AFFECTED?

Due to children with disabilities and complex health needs occurring across a wide selection of the population and with Knowsley having higher than average deprivation most areas of the borough could potentially be affected.

The Huyton areas of Knowsley have the highest number of statemented children (333), Kirkby the second highest (287). Lower numbers are prevalent in Halewood (110) and the PWCKV area (140) although this reflects the larger population of Kirkby and Huyton, prevalence is also highest in the poorer areas of North Huyton and South Kirkby.

Type	nk	Halewood	Huyton	Kirkby	PWCKV
ASC	9	36	135	92	39
BESD	23	17	58	48	23
CL	4	12	27	49	23
HI/VI	2	3	15	6	5
MLD/SpLD/Other			3	1	1
PD		5	10	12	4
PMLD	5	7	27	20	8
SALD	3	16	13	14	20
SLD	9	14	45	45	17

5. HOW DO RESIDENTS, COMMUNITIES AND STAKEHOLDERS VIEW THIS ISSUE?

National evidence

National insight from disabled children and their families tells us the following;

- Disabled children are more likely to live in poverty.
- Only 16% of mothers with disabled children work, compared to 61% of other mothers. Child care costs are often higher for children with disabilities or specialised care requirements.
- Families with disabled children spend £27.61 on loan repayments a week, compared to the UK average of £3.10.
- With lower than average incomes and higher than average expenditure, many families with disabled children are in debt. 22.6% have debts up to £5,000, 15% have debts of up to £10,000 and only 15.7% have no debts. In the general population 53% have debts.
- Caring for a disabled child can cause relationship problems. According to one study, 31% of couples report some problems, 13% cite major problems and 9% separate. Stress, depression and lack of sleep are commonly experienced problems.
- Disabled children are 13 times more likely to be excluded from school.

Local officers working with children with disabilities highlighted a series of issues of concern:

- With the SEND reforms transitional financing finishing and as there is a poor record of 'mainstreaming' good practice; there are concerns about the uncertainty of the post reform landscape in provision.
- Increasing size of younger/KS1 classes in Special school provision, more children are diagnosed at an earlier age due, in part, to the extension of the local childcare offer – this is a positive in terms of early intervention and meeting unmet need, but is increasing pressure on special schools locally but puts further pressure on limited resources.

- Support for transition, particularly into adulthood, but also between educational key stages is also an issue – too many LDD children in mainstream Primary transfer to secondary special school provision.
- More independence on admissions policy for Academy schools can make it difficult to find the right place for a child – there is anecdotal evidence of children refused places locally, three of Knowsley's six secondary education providers are scheduled to become Academies by 2016.
- With increasing applications and anecdotal evidence of families moving to access provision, the popularity of Bluebell Park is promising for better support for those who need it, but this impacts upon the opportunity for children to remain in mainstream provision where it may benefit the child.
- A lack of training in universal services, coupled with current low capacity to meet needs in mainstream provision will make meeting future needs of an increasing SEN and disabled population more difficult.
- Community integration and social awareness – where a child is sent out of the community and separated from local children for provision or care, they are unlikely to be accepted back into it – the resulting social isolation can increase the risk of exploitation CSE.
- Physical access to Health Services and distance from home is highlighted by families as a major issue - more than any issue of quality of service.
- Speech Language and Communication Needs are poorly identified in schools.
- High functioning ASC can go undiagnosed, often presenting in later adolescence picked up by other services such as Youth Offending who are finding increasing levels of undiagnosed Learning difficulties and other unmet needs.
- There is a strong correlation with neglect and early life trauma – ADHD - neglect in more affluent families often manifests as self-harm.

Engagement with parents, carers and older children with disabilities has provided insight through the local SPEAK voluntary organisation a Parent Carer Forum Knowsley. In January 2015 the management team of SPEAK announced that they were unable to continue with the level of demand and expansion of the forum and after 5 years of dedicated voluntary service they would be stepping down in April. The Council are now working with In Control to support the development of a new Family Forum that will have a specific strategic remit to support co-production of services for disabled children and their families in Knowsley. It is expected the new forum will be operational in September 2015.

Current service provision and actions

6. HOW DOES THIS ISSUE IMPACT ON SERVICE PROVISION AND USE?

A range of support is available for children with disabilities and their families. This includes short breaks and respite care, as well as family centres and activities for children.

Services are available to families who have children up to the age of 25 under the new SEND reforms (previously up to 18 years old) for individuals with;

- A substantial degree of sensory impairment or physical disability
- Severe learning disability as defined in their education statement
- A chronic and life threatening or life limiting illness
- Multiple disabilities which impact on family life

The services available include:

Short Breaks

A short break allows children to take part in fun activities away from their normal routine and can provide parents with a break from caring responsibilities. Children and young people who have a physical or mental impairment, which has a substantial and long term effect on their ability to carry out day to day activities, can benefit from a short break. Short breaks are a positive experience for children and families. They provide children with an opportunity to make friends, join activities, and take a break from their family. They also support parents in their caring role so that the whole family can enjoy activities together.

Different types and levels of short breaks are available that may last a few hours or days and can happen at home, in an approved foster carer's home, or a residential setting.

Targeted short breaks are for families with disabled children and are provided after a referral to the Short Breaks team. These include holiday play schemes, after school activities, and family fun sessions. The Short Breaks Activity programme provides 16 sessions a week across the borough which have high staff ratios and where staff have high level of experience of working with disabled children. The provision was reviewed monthly at the SPEAK Family Forum (prior to the discontinuation of this group in April 2015) and through an annual evaluation. A process of co-production with parents is used for any decision to develop or reduce the service.

Specialist short breaks are for families with disabled children who have the most complex needs. Referrals for specialist breaks go to the Children's

Complex Needs Resource Panel and families would need a core or specialist assessment and support from a disability social worker or health professional.

These include overnight stays in residential provision, health and care packages in the home.

This is a demand led service where the workload can rise or fall rapidly for many reasons. However, nationally the number of children with profound and multiple learning disabilities is rising each year as more children born with complex conditions are surviving early childhood, and more children are being diagnosed at a younger age. Due to variations in type and severity of disability it is difficult to specify the exact number of children with a disability. Locally, there has been an observed increase in the numbers and increased demand on services.

The provision of universal services is unable to meet the needs of children with disabilities and their families.

7. DO WE HAVE EVIDENCE OF WHAT WORKS?

There have been numerous reports and guidance on how to support children with disabilities and complex health needs and their families. Many of the reports are related to specific conditions and disabilities, therefore rather than listing all of the evidence please refer to the list of guides and reports on the CHIMAT website at: <http://www.chimat.org.uk/default.aspx?RID=81422>

The SCIE report 'Necessary stuff' (2007): The social care needs of children with complex health care needs and their families set out to identify what is known about the social care needs of children with complex health care needs (CHCN) and their families, and about the services designed to meet those needs.

The review was made up of three distinct parts:

1. a consultation with children with CHCN and their families;
2. a review of relevant research; and,
3. a survey to identify examples of good practice in service provision.

Many examples of 'good practice' on the part of professionals and paid support workers were identified, which illustrate ways of meeting CHCN with minimal disruption to the 'ordinary' lives/needs of the children and their families.

According to children with CHCN and their families, good practice in service provision:

- demonstrates flexibility and responsiveness to families' individual needs
- actively safeguards their 'ordinary' lives and needs
- works in partnership with families, valuing their knowledge and expertise

- works with wider networks, including family, friends, other services and settings.

Eight services that fulfilled these good practice criteria were selected. Common features included:

- families were perceived as competent experts
- the child and family were acknowledged as partners in defining need
- a high value was placed on individual relationships
- different aspects of a child and family's identity were actively recognised and accommodated
- autonomy was delegated to front line staff
- high levels of flexibility and responsiveness were provided
- tasks such as 'navigating', 'signposting', 'way-finding', 'advocating' or 'key working' were included within the function of the service
- volunteers were creatively used within programmes

The full report is available at:

<http://www.scie.org.uk/publications/knowledgereviews/kr18.pdf>

Research conducted by Barnardos identifies the following issues which should be considered if service provision is to be effective:

- Meet the child and family's need for information about the child's disability
- Recognise that disability can be expensive and help families access sources of financial support
- The need for breaks from care
- The potential need for extra domestic help for the child's family
- Helping parents and carers develop skills and strategies for supporting their child
- Providing appropriate social support for the family
- Coordinating services
- Consider whether there are any special or extra needs for Black & Minority Ethnic children

NICE guidance and quality standards

The National Institute for Health and Care Excellence (NICE) has produced guidance and quality standards on the following areas;

Attention deficit hyperactivity disorder (QS39)

The summary of the published quality standard on Attention deficit hyperactivity disorder. Published Date: 30/07/2013

The epilepsies in children and young people (QS27)

This quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals. Published Date: 28/02/2013

Spasticity in children and young people (CG145)

This clinical guideline offers evidence-based advice on the management of spasticity and co-existing motor disorders and their early musculoskeletal complications in children and young people with non-progressive brain disease. Published Date: 25/07/2012

Autism in children and young people (CG128)

The summary of the published clinical guideline on Autism in children and young people. It links to the published guidance and key documents. Published Date: 28/09/2011

8. WHAT IS THE CURRENT POLICY DIRECTION?**National**

A number of national guidance and policy documents have been published that set out the needs and approaches to commissioning and service standards required to support disabled children and young people and their families.

The National Service Framework for Children and Maternity Services (2004) sets national standards that commissioners and providers of children's and families' services must meet. Standard Eight sets out the requirement for children with complex needs:

"Children and young people who are disabled or who have complex health needs (should) receive coordinated, high quality and family centred services which are based on assessed needs, which promote social inclusion and where possible enable them and their families to live ordinary lives."

In 2007, *Aiming high for disabled children: better support for families* stated the Government's commitment to improving services and thereby outcomes for disabled children by calling for a core offer of services with standards based on good information sharing, transparency, participation of children and their families, assessment and feedback.

Better Care, Better Lives (2008) set out the Government's strategy for improving children's palliative care.

Statutory guidance on safeguarding and promoting the wellbeing of disabled children was published in 2010. This identified all the existing and new statutory guidance relevant to the provision of short breaks for disabled children and their families. The main elements covered being:

- short breaks and the provision of accommodation;
- assessment, planning, implementation and review cycle for children using short breaks; and,
- the different settings in which short breaks may take place.

The new duty for local authorities to provide a short breaks service came into force in April 2011. The Short Break Regulations Duty says that Local Authorities must:

- Provide a range of short breaks services.
- Give families the choice to access short breaks services using a direct payment.
- Publish a statement of their short break services on their website.
- Keep their short breaks statement under review.
- State in their short breaks service statement the range of short break services available, the criteria by which eligibility for services will be assessed, and how the range of services is designed to meet the needs of families with disabled children in their area.
- Consult parents as part of the review of the statement.
- Consider the legal implications of the eligibility criteria they apply to short break services.
- Not apply any eligibility criteria mechanistically without consideration of a particular family's needs.

The Children and Families Act 2014 (March 2014) introduced a number of changes in how children and young people with [special educational needs](#) (SEN) in England are supported. This included a move from special educational needs statements to education, health and care plans.

These changes came into effect on 1 September 2014.

What are the changes?

- Replacing Statements of SEN with Education Health and Care Plans (EHCPs)
- Personal budgets
- Knowsley's Transition Plan
- Personal budgets
- Services working together
- Birth to 25 years
- Local Offer
- Engaging parents, children and young people
- Resolving dispute

Replacing Statements of SEN with Education Health and Care Plans (EHCPs)

Special Educational Needs and Learning Disability Assessments (s139a) will be replaced by Education, Health and Care Plans (EHCPs). The EHCP will also be extended to young people aged 0-25 years, in order to support young people into adulthood.

Guidance states that EHCPs should be issued when the local authority considers the special educational needs of the child cannot reasonably be provided for with resources normally available to mainstream early years provision, school and post 16 institutions.

As the Bill and Code of Practice currently stands children and young people with primary health or care needs will not be issued with a plan, unless these needs impact their education.

The EHCP can also include wider information about a child's social care needs. If a child or young person has received a social care assessment under the Chronically Sick and Disabled Persons Act, any support identified must be included in the EHCP.

All existing Statement and Learning Disability Assessments will remain unchanged, but will transfer to an EHCP in two to three years.

Strategy for Knowsley

The Strategy for Knowsley: the Borough of Choice is the overarching strategy for the Borough. Its primary objective is to outline the Knowsley Partnership’s long term vision to make Knowsley a place where people want to live and work. The strategy addresses children’s disabilities and complex health needs by focusing on the overall health and wellbeing of people in Knowsley.

All council and partnership strategies, plans, policies and programmes should ultimately support the achievement of this vision. Ten strategic outcomes have been agreed to help the partnership to achieve its vision for Knowsley. Five of these relate directly to this plan and are highlighted below:

Empowered, resilient, cohesive communities	Safe, attractive, sustainable neighbourhoods	Children get the best possible start in life and have opportunities to reach their potential	Everybody has the opportunity to have the best health and wellbeing throughout their life	More people look after themselves and support others to do the same
People are protected from risks that can affect their health and wellbeing	Quality infrastructure and environment	Improved outcomes for our most vulnerable young people	Knowsley has the conditions in place to support sustainable business growth	Knowsley residents are empowered to realise their economic potential

9. CHALLENGES AND STRENGTHS

Challenges

- Increased permanent demand and reduced budgets – investment in Early Help is key.
- Increased diagnosis of autism and increased number of children with complex needs surviving birth.
- Effective early intervention – services that can meet needs earlier as it is known that these services will be needed at some point e.g. speech and language, behaviour support, parental support and short breaks

- Access to universal services is a huge issue as universal services are not geared up for children with disabilities to access provision and to make their provision accessible they request more money for additional support.
- Local data and intelligence needs to be smarter e.g. numbers of children coming through, type of disability, type of needs, demographic data etc. to enable us to plan services more effectively for the future.

Strengths

- A range of support is available within the borough for children with disabilities and their families. This includes short breaks and respite care, as well as activities for children.
- Massive improvements after short break investment in activities and family networks. The family networks enable parents to peer support each other and have resulted in job opportunities.
- Parental support networks have also been able to coordinate the parent voice and have created the opportunity for co-production arrangements both in the development of the short break offer and in implementing the SEND Reforms.

10. SOURCES OF EVIDENCE AND FURTHER INTELLIGENCE

Short Breaks providers' evaluations for weekly and summer provision.
Short Breaks Family group evaluations.
SPEAK Family Forum minutes and newsletters.
Short Breaks attendance monitoring form.