6. CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES

6.11 Special Educational Needs and Disability including Autism and Transition

6.11.1 Special Educational Needs and Disability

Special Educational Needs and Disability (SEND) for the purpose of this document is defined as those children and young people with a statement of special educational need (SEN), an Education Health and Care Plan (EHC Plan). It should be noted that some children and young people with SEND do not have a statutory plan through education, but may receive additional statutory services, for example health and social care.

Children's Social Care - Disabled Children assessed as 'Children in Need' under the Children's Act 1989 are defined as: a child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.

SEND Reforms

The enactment of the Children & Families Bill on 13th March 2014 required radical changes to the Special Educational Needs and Disability (SEND) provisions, known as the SEND Reforms:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

The Bill follows on from the SEN Green Paper, Support and aspiration: a new approach to special educational needs and disability published in March 2011. The SEND Code of Practice: 0 – 25 was published in July 2014 with an implementation date of September 1st, 2014.

The main elements of the SEND Reforms are:

- Replacing statements of SEN and learning difficulty assessments (LDAs) (for older young people) with a single, simpler birth to 25 years assessment process; an education, health and care (EHC) plan from 2014. Parents/carers who have children with an EHC plan would have the right to a personal budget to fund their support.
- Providing statutory protections comparable to those currently associated with a statement of SEN to up to 25-years-old in further education.

- Requiring local authorities (LAs) and health services to link up services for disabled children and young people - so they are jointly planned and commissioned.
- Requiring LAs to publish a Local Offer showing the support available to disabled children and young people and those with SEN, and their families.
- Introducing mediation for disputes and trialling giving children the right to appeal if they are unhappy with their support.
- School Action/School Action Plus (and Early Years Action/Early Years Action Plus) categories of support for pupils and students without Statements/EHC Plans were renamed 'SEN Support' from September 2014. The change of name does not affect which children/young people need/receive support for their Special Educational Needs.

For more details see Appendix 1.

6.11.1.1 The impact of SEND

Children who are disabled or who have special educational needs (SEN) have disproportionately poor outcomes[i]:

- At the moment, life chances for the approximately two million children in England identified with SEN or who are disabled are disproportionately poor. Young people with SEN are twice as likely not to be in education, employment or training, and many young people with complex support needs find it hard to make a successful transition from school to an adult life with work, friendships, good health and independence.
- Disabled children and children with SEN are more likely to be bullied or excluded than their peers.
- Many disabled children and children with SEN face significant barriers (such as physical and sensory impairments, learning difficulties, or a variety of other needs) to their progress and achieve less well than their peers at school and in further education.
- 1 in 5 children are currently identified as having some form of SEND, with 2.8% having a more complex need.
- In 2012 at Key Stage 2, pupils with SEND achieved roughly half as well as those with no identified SEND at English and Maths (43% achieved level 4 in comparison with 91%). The percentage of pupils with SEND achieving 5 or more GCSEs at grade A* to C was 22% in comparison with 69% with no identified SEND at Key Stage 4/5.
- Around 30% of all young people with statements of SEND at 16 are not in education, employment or training at 18 compared to 13% of their peers Employment rates for those with learning difficulties are much lower still: some data indicates less than 10% (NHS Information Centre for Health and Social Care (2008).
- In 2012, 46% of disabled people were in employment, compared to 76% of non-disabled people.

6.11.1.2 Information on SEND

The Institute of Education[ii] has highlighted that there is no nationally consistent definition of disability and therefore no single data source by local area. They have however, used surveys and data to produce estimates of the numbers of disabled children. Within each local authority area they have estimated that between 3.0-5.4% of Children and Young People have some form of disability, this would equate to between 3,241 and 5,834 children and young people in Buckinghamshire (up to age 18) based on our understanding of the overall children and young people population from the tables below):

Table 1 Number of CYP (as proportion of total county population)

Number of CYP (as proportion of total county population)	
2001	26%
2011	25%
2026	25%20

Table 2 Total Population and population of Children and Young People changes for Buckinghamshire; actual between 2001 and 2011 and projected to 2026

	2001 - 2011	**2011 – 2026**
Total Population	+5.5%	+4.9%
0 to 19 years	+2.8%	+4.9%

Table 3 Projected increase in population of Children and Young People between 2011 and 2026

0 – 4 years	-7.2%
5 – 9 years	+10.3%
10 – 14 years	+14.4%
15 – 19 years	+2.0%

6.11.1.3 Trends

- Within Buckinghamshire **c.3.1% of children and young people** have an additional need or disability. National research has estimated 3.0-5.4% so potentially another 2.3%.
- **Numbers are increasing**; many have eligible needs for services across health, social care and education, c.200 children by 2026, the highest numbers are in Aylesbury Vale and Wycombe.

- **Increasing complexity of need** e.g. profound and multiple disabilities up by 63% between 2009 and 2013, increased prevalence of Autistic Spectrum Disorder.[iii]

6.11.1.4 Inequalities

There is a distinct correlation between those children and young people living in wards with the lowest index of multiple deprivation and having a disability in Buckinghamshire.

- CYP with SEN are 15% more likely to be eligible and claiming for Free School Meals (FSM) -

Table 4 SEND in England

State-funded primary, state-funded secondary and special schools: Number and percentage of pupils known to be eligible for and claiming for FSM	England
Pupils without SEN	13.5%
Pupils with SEN	28.6%

Source: Taken from the National Tables SFR 25/2015 Special Educational Needs in England

6.11.1.5 Comparisons

DfE published data based on where a child of school age attends school (includes CYP attending Buckinghamshire schools funded by other LA) shows that in January 2015 the percentage of children with statements of SEN or EHC Plan based on where the pupil attends school is 3.2% for Buckinghamshire while the figure for England is 2.8% and the average for Buckinghamshire's statistical neighbours is 2.8%.

Local data collected is based on all CYP funded by Buckinghamshire regardless of where they attend school (non-published) also confirms Buckinghamshire has the higher rate of Statement/EHC Plan maintained across our statistical neighbours:

Table 5 Children and Young People with a Statement of Special Educational Needs (SEN), or EHC Plan maintained by each Local Authority - January 2016

	Number of Children and Young People with a Statement of Special Educational Needs (SEN), or EHC Plan maintained by each Local Authority - January 2016			Population Estimates for local authorities in the UK, mid-2015 - 0-25 year olds	Statements / EHC Plans maintained as a % of 0-25 population
	Statements	EHCP	Total	% Difference from Bucks	
Buckinghamshire	**2820**	**535**	**3355**		**2.0%**
Surrey	4725	1025	5750	119%	1.6%
Hampshire	4000	1560	5560	141%	1.4%
Hertfordshire	2055	2310	4365	124%	1.2%
Cambridgeshire	2000	1205	3205	23%	1.6%
Oxfordshire	1480	940	2420	34%	1.1%
Central Bedfordshire	890	290	1180	-50%	1.4%
West Berkshire	495	330	825	-71%	1.7%
Windsor and Maidenhead	650	100	750	-73%	1.7%
Wokingham	560	195	755	-70%	1.5%
Bracknell Forest	450	195	645	-77%	1.7%
Average for SN	1730	815	2545	10%	1.4%

6.11.1.6 Demand

The numbers of Buckinghamshire County Council (BCC) statements of SEN and Education Health and Care Plans recorded on ONE as at 31st March 16 are shown below.

Table 6 Buckinghamshire County Council (BCC) statements of SEN and Education Health and Care Plans recorded on ONE as at 31st March 16

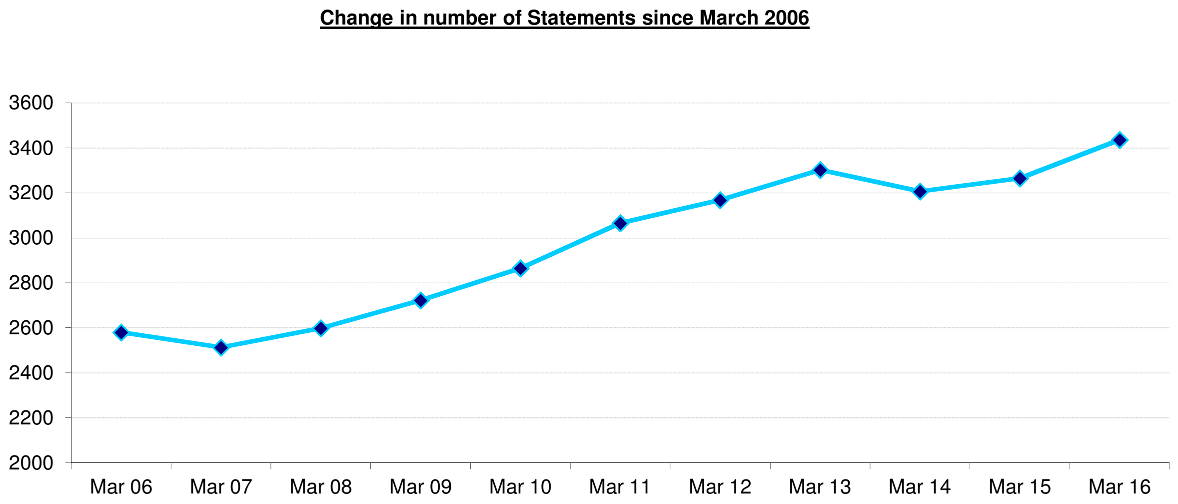
	Statements / Plans Financed	Statements / Plans Maintained	Exceptional High Needs Block Funding (HNBF)
2016	**3436**	**3382**	**281**
2015	3266	3202	185

Additionally there were 98 pupils with statements maintained and financed by other local authorities attending BCC state funded schools**.**

Count of statements/plans in this update will refer to the numbers financed by BCC unless otherwise stated.

3436 is an increase of 170 (5.2%) over the last year, from 3266 in March 2015 and is 229 more than in March 2014 (3207).

Figure 1 Number of Statements



Over the last 5 years ***the total number of statements/plans has increased by 12% (370).*** During the same period the maintained and academy school population has increased by 8%.

6.11.1.7 Horizon scanning

Up until the end of March 2013 Buckinghamshire County Council provided additional resources for children and young people with SEN that required over 5 hours of support. This was well below the national average. From April 2013, in line with the High Needs Funding Reform, the High Needs Funding Block (HNFB) funded places in special schools, specialist units, alternative provision (Pupil Referral Until etc.); and top up funding for high needs pupils whose educational provision cost more than the basic entitlement plus £6,000; the equivalent of 13 ½ hours of support.

The Council have therefore a number of children and young people with statements of SEN, who do not receive any additional top up, as the number of hours they receive on their statement of SEN is less than 13 ½ hours.

For those children and young people with statement of SEN placed in mainstream schools (LA, Academies and Free School) approximately 20% are not receiving any additional funding and are a result of historical SEN statementing criteria being applied. This would seem to be the reason for the higher number of children and young people with statements or an EHC Plan in Bucks being 3.2% in comparison with its statistical neighbour average of 2.8%.

It should be noted that the overall numbers of children and young people with a statement of SEN or EHC Plan will rise overall in the coming years following on from the Children and Families Act 2014, where children and young people may hold an EHC Plan up until they are 25 if they are in education provision.

6.11.2 Autism Spectrum Disorder (ASD)

Autism is a lifelong developmental disorder / condition that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

Autism is typically considered to encompass three key areas of difficulty:

- *Social Communication*: difficulties understanding social use of language including metaphor and idiom and often finding extended conversation or instruction difficult to process.
- *Social Comprehension*: difficulties understanding social conventions and behaviours and often finding behaviour of others difficult to predict and sometimes threatening. This can lead to a range of responses including apparent passivity and social withdrawal or emotional and physical outbursts.
- *Social Imagination*: difficulties diverting attention from one task / activity to anther and sometimes 'fixating' on internally motivated stimuli; difficulties engaging in social play or activity including reciprocal and imaginative play and role play. Behaviours can present as 'rigid' and repetitive.

It is a 'spectrum' condition, which means that, while all people with autism can share certain difficulties, their condition can affect them in very different ways. Many people with autism are able to live relatively independent lives, however some may experience a level of severity and / or accompanying learning disabilities requiring long term specialist support.

Other factors to consider–

Children and young people on the autism spectrum may experience co-morbidities (co-occurring conditions and syndromes) which bring their own challenges and which may complicate the autistic characteristics. For example some have co-occurring:

- Developmental/neurological conditions (such as attention deficit hyperactivity disorder, dyspraxia and epilepsy).
- Gastro-intestinal problems including constipation, diarrhoea and indigestion.
- Genetic conditions (such as fragile X syndrome, tuberous sclerosis and Cornelia de Lange syndrome).
- Learning disabilities (although many individuals with autism have normal or above average intellectual ability).
- Mental health problems (such as anxiety, depression, and obsessive compulsions).
- Motor difficulties including major motor skills (such as standing upright) or fine motor skills (such as holding a pencil between their fingers and thumb).
- Sensory problems (such as hearing and sound sensitivity, visual disturbances).
- Adaptive and functional behaviour (such as sleep problems or difficulties eating and feeding).

6.11.2.1 The impact of having ASD

The impact of having autism for an individual means that they can experience difficulties in school and work situations. This can lead to lack of confidence and low self-esteem. For some this can manifest as high anxiety, depression and mental health issues. Some people with autism can be also very vulnerable to abuse because of their social comprehension and social communication deficit. Being bullied and taken advantage of by so-called “friends” is not unusual.

These challenges can often be felt by the wider family. Difficulties can include severely disrupted sleep for prolonged periods, as children with autism often have disturbed sleep patterns: “Autistic children appear to be especially prone to this problem, and in has been estimated that more than half exhibit some disturbance in sleep patterns. This suggests some form of deficit in the brain systems that normally promote sleep”.[iv] Siblings can also be affected, as much of the time and energy of parents is necessarily directed to the child with autism.

6.11.2.2 Intervention and Support

Early Intervention - Whilst there has yet to be a definitive comparative study of the various different early interventions available, there is general consensus amongst professionals that early identification and intervention is very important to help a child reach their potential and in some cases can reduce the need for services later on.[v]

Though education and health professionals are in agreement that early, intensive intervention greatly assists a child's development it can only be achieved with early diagnosis. Evidence shows that parents can experience considerable delays in diagnosis this may be because professionals involved in the assessment of a very young child will be tentative in their conclusions due to the similarity of aspects of autism with other conditions, including speech and language difficulties. The average age of a diagnosis for a child with autism is 6 years while for a child with Asperger syndrome the average age is 11.[vi]

6.11.2.3 Information on ASD

National Prevalence - A major difficulty in compiling a report of this type is that there are no accurate figures on the national prevalence of autism, and there is currently no requirement for health or education services to record new diagnoses.

The only figure available at present is that estimated by The National Autistic Society, which combines two studies. The first of these was conducted by Wing in 1979.[vii] It identified a prevalence rate for those with autism and accompanying learning disability as approximately 20 in every 10,000 children. A 1993 study in Gothenburg by Ehlers and Gillberg found a prevalence of high functioning autism and Asperger syndrome of 36 per 10,000, and another 35 per 10,000 with social impairments which fit into the autism spectrum. The two studies are combined to estimate prevalence of autism spectrum disorders in the United Kingdom at 91 per 10, 000 head of population, or 1 in 110.

Recent smaller scale studies have confirmed this - for instance Dr. Fiona Scott et al (Cambridge Autism Research Centre) conducted a survey of 5-11 year olds in Cambridgeshire (over 34 000 children). They found a prevalence rate of 1 in 175. Scott found 12.5% of the special needs population had diagnoses of autism spectrum disorder and about 50% of mainstream primary schools have at least one pupil with an autism spectrum disorder.[viii]

There is strong evidence to suggest that there are more boys with autism spectrum disorders (ASDs) than girls:

- Brugha (2009) surveyed adults living in households throughout England, and found that 1.8% of males surveyed had an ASD, compared to 0.2% of females.
- Wing (1981) found that among people with high-functioning autism or Asperger syndrome there were as many as 15 times as many males as females. On the other hand, when she looked at people with learning difficulties as well as autism the ratio of boys to girls was closer to 2:1. This would suggest that, while females are less likely to develop autism, when they do they are more severely impaired.

Local Data – One way of understanding how many CYP have ASD in Buckinghamshire is through the SEND data available locally:

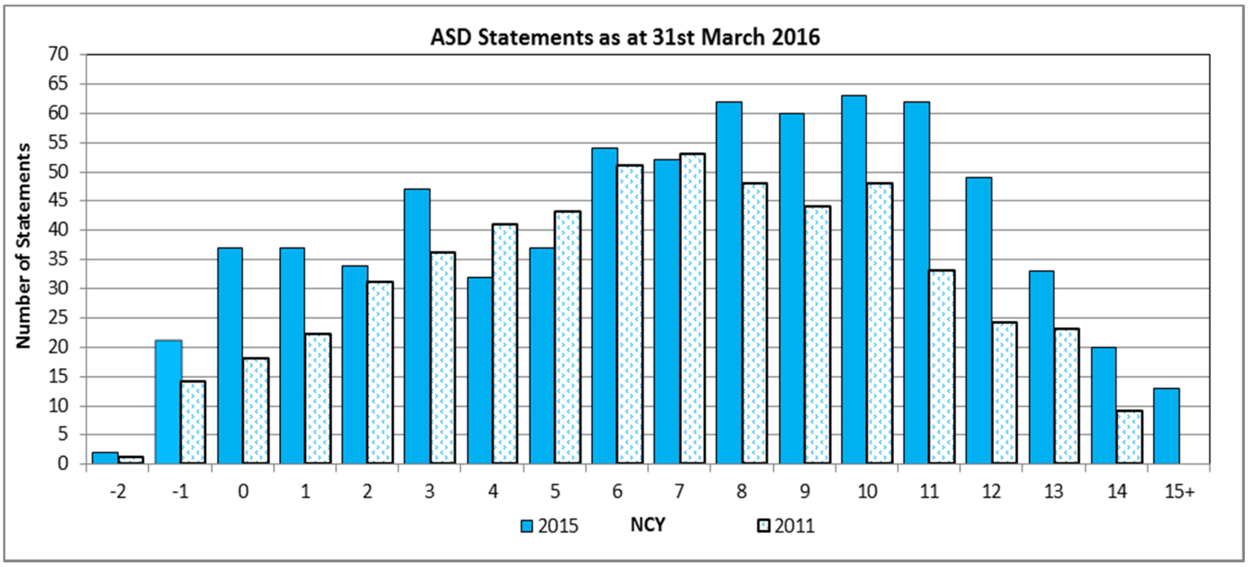
ASD Statements - As at 31st March 2016, BCC was financially responsible for 715 ASD statements of Special Educational Needs/Education Health and Care Plans and maintained 714 ASD statements/plans.

Additionally there were 11 pupils with statements maintained and financed by other local authorities attending BCC schools. The table below shows the number of ASD statements financed by BCC since March 2011:

Table 7 ASD statements financed by BCC since March 2011

	Mar 2011	Mar 2012	Mar 2013	Mar 2014	Mar 2015	Mar 2016
Autistic Spectrum Disorder	539	566	590	596	616	715

Figure 2 ASD statements as at 31st March 2016



715 statements/plans of ASD represent 4.3 in every 1,000 children/young people resident in Buckinghamshire (0-25 age population).

There are a number of pupils with statements of SEN that have secondary needs. At the 31st March 2016 there were 205 pupils with a primary need of ASD that had secondary needs recorded and 69 pupils with other primary needs that had a secondary need of ASD. Of the 205 ASD pupils with secondary needs, 44 had 2 secondary needs recorded, 7 pupils had 3 secondary needs recorded and 1 has 4 secondary needs recorded.

Below is a breakdown of these figures:

Table 8 Primary needs of pupils with ASD as secondary needs

	ASD	SEMH	HI	MLD	MSI	PD	SLCN	SLD	SPLD	VI	Misc.	DWN
Primary Needs of pupils with ASD as secondary needs	0	18	0	10	0	2	28	10	0	1	0	0
Secondary Needs of ASD pupils	0	57	2	32	1	7	84	9	9	3	0	1

A total of 58 BCC pupils with ASD statements are attending other local authority schools, 32 in mainstream (including 3 in departments) and 26 in special schools.

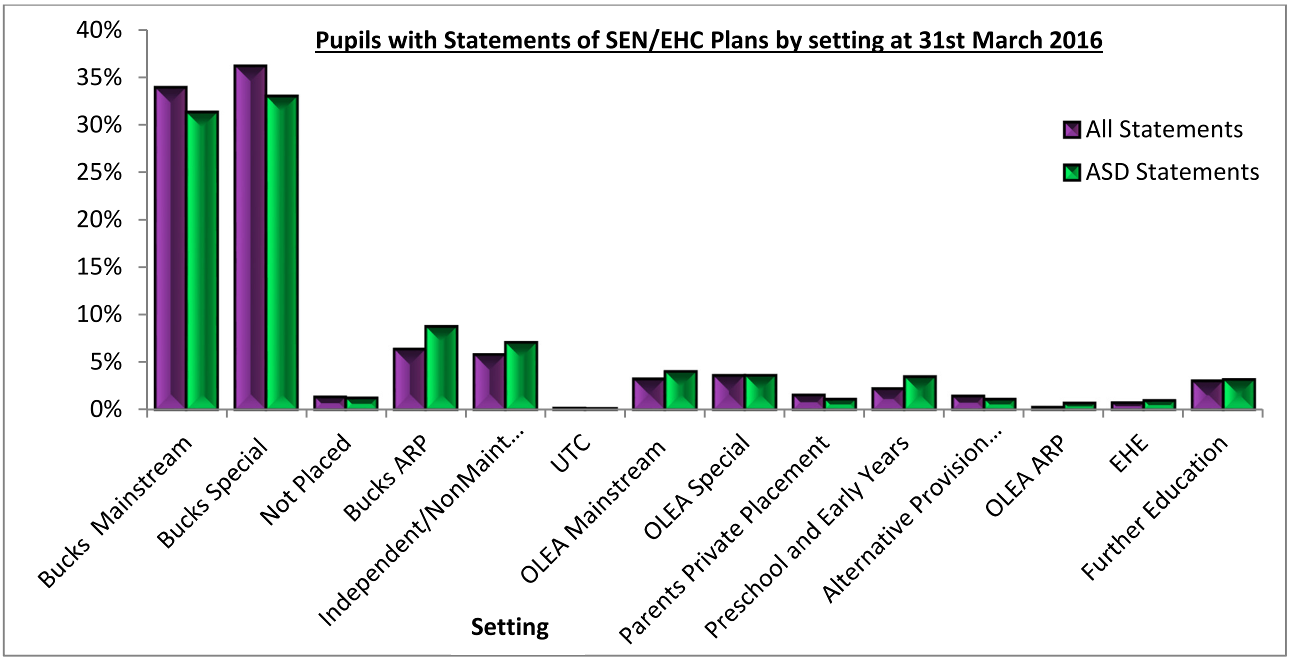
There are 55 ASD pupils funded by BCC in independent or non-maintained schools.

Table 9 Out of County pupils by school stage

	Pre School	**Primary School**	**Secondary School**	**Post 16**	**Total**
OLM	0	10	16	6	32
OLS	0	9	10	7	26
IND/NM	0	3	32	20	55
Total	**0**	**22**	**58**	**33**	**113**

38.8% (278) with statements for ASD are placed in mainstream settings (including Pre-Schools and OLEA Schools). This is a lower proportion to all pupils with statements at 31st July 2015 – 44%. This comparison is shown in the graph below:

Figure 3 Pupils with statements of SEN/EHC plans by setting at 31st March 2016



6.11.2.4 Trends

There has been an increase in the number of ASD Statements since March 2011; the number of statements has risen by 176 (33%) over the last 5 years:

6.11.2.5 Inequalities

Gender Inequalities - Girls may be better at hiding their difficulties. Attwood (2000), Ehlers and Gillberg (1993) and Wing (1981) have all speculated that many girls with Asperger syndrome are never referred for diagnosis, and so are simply missing from statistics. This might be because the diagnostic criteria for Asperger syndrome are based on the behavioural characteristics of boys, who are often more noticeably "different" or disruptive than girls with the same underlying deficits.

Girls with Asperger syndrome may be better at masking their difficulties in order to fit in with their peers, and in general have a more even profile of social skills. Gould and Ashton-Smith (2011) say that because females with ASDs may present differently from males, diagnostic questions should be altered to identify some females with ASDs who might otherwise be missed.

6.11.2.6 Geographical variations

Table 10 Pupils with SEN by their primary need

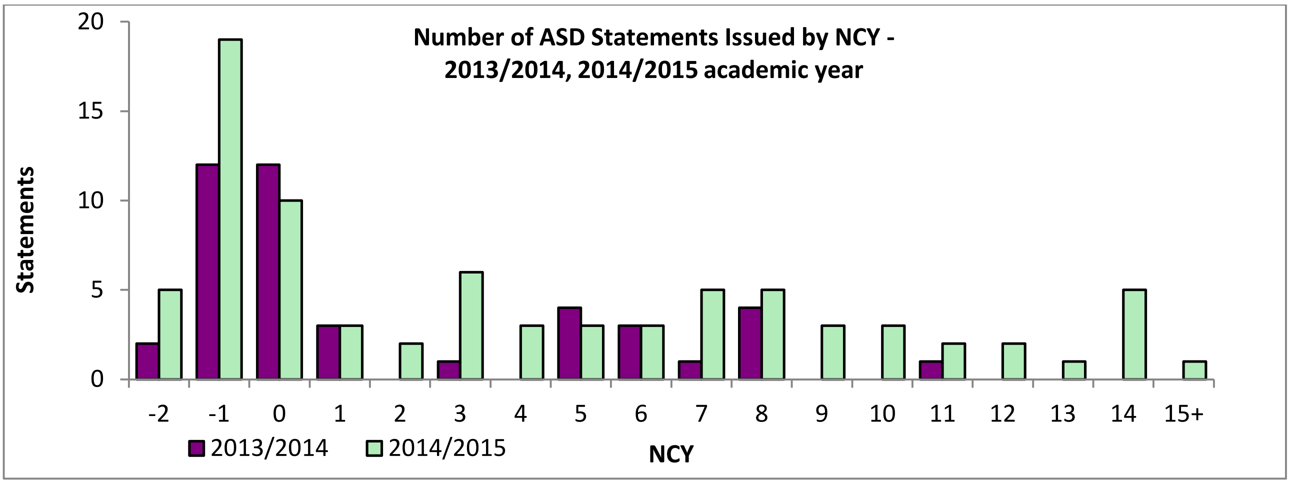
Pupils with SEN by their Primary Need	England	South East Group	Buckinghamshire
Speech Language & Communication Needs	27.7%,	27.5%	29.3%
Autism Spectrum Disorder	6.5%,	6.8%	5.1%

Source: SFR -2015 Tables LA

6.11.2.7 Demand

Below is a graph to show the National Curriculum Year (NCY) of pupils at the point an ASD statement was issued:

Figure 4 National curriculum year of pupils at the point an ASD statement was issued



During the 2014/15 Academic Year 81 ASD statements were issued. This is 45 more than the previous year (43) and 35 more than in 2012/13 (53).

6.11.2.8 Horizon scanning

In accordance with national figures, Bucks has seen a rise in the number of children and young people diagnosed with ASD. Although Bucks is 1.85 below the SE average for the number of children and young people with ASD, it is 1.7% higher for the number of children and young people with Speech Language & Communication Needs. This therefore puts Bucks broadly in line with national average.

6.11.3 Transitions

Transitions occur at various stages throughout a young person's life, from starting School, leaving Primary School and starting Secondary School, to preparing for independence and leaving home. This section will focus on transitions in relation to the Children and Family Act 2014 and SEND reforms in preparing for adulthood, which highlights the importance of working with young people with SEN or disabilities aged 14 and over.

Education, health and social care should support children and young people with special educational needs (SEN) or disabilities to prepare for adult life, and help them go on to achieve the best outcomes in employment, independent living, health and community participation. With discussions about longer term goals starting before Year 9 (age 13-14) at school.

6.11.3.1 The impact of transitions

Buckinghamshire have developed a "Multi Agency Protocol", to ensure positive outcomes for all Young People going through the transition process. The protocol sets out the roles and responsibilities for agencies/departments and representatives involved in the transition planning process and emphasises the holistic and multi-agency approach to transitions. The protocol has been signed up to across Buckinghamshire County Council and Buckinghamshire CCG's. Please see: www.bucksfamilyinfo.org/transitions

Adult Social Care have a Transitions Team monitoring all potential referrals to adult social care and provide an assessment to assess eligibility. Joint assessments are taking place between Adults and Family Well Being and Continuing Healthcare to help improve transition process.

The Care Act 2014 states A transition assessment must be conducted for all those who have likely needs, however, the timing of this assessment will depend on when it is of *significant benefit* to the young person or carer (significant benefit being at a time suitable to the young person). 100% referrals are now assessed by the time the young person is 18.

Information is also available now on the Local Offer website about "What to Expect from Adult Services"

6.11.3.2 Information on transitions

Key 1: EHC Plans/Statements types of need and categories on EHC Plans/ Statements

- Communication and interaction: ASD,SLCN
- Cognition and learning: MLD, SPLD, SLD

- Behaviour, emotional and social development /Social emotional and mental health difficulties: BESD
- Sensory and physical: HI, VI, PD

NOTE:
Behaviour, emotional and social development: Pre Children and Family Act 2014
Social emotional and mental health difficulties: Post Children and Family Act 2014

Key 2: Acronyms of Primary Need on EHC Plans/Statements

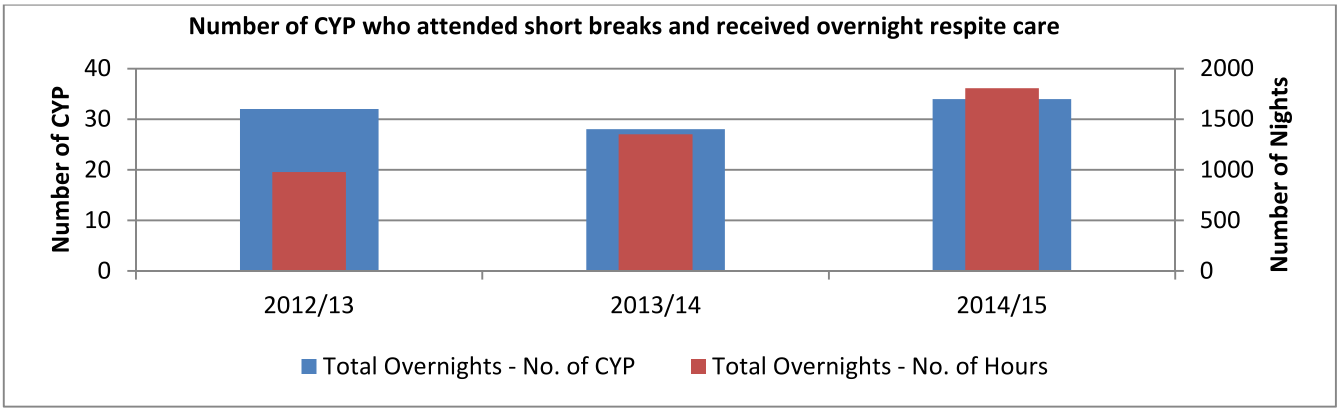
- ASD – Autism Spectrum Disorder
- BESD – Behavioural, Emotional & Social Difficulties
- MLD – Moderate Learning Difficulties
- PD – Physical Difficulties
- SLCN – Speech, Language & Communication Needs
- SLD - Severe Learning Difficulties
- SPLD – Specific Learning Difficulties
- HI – Hearing Impairment
- VI – Visual Impairment
- MSI – Multi Sensory Impairment
- PMLD – Profound and Multiple Learning Difficulties
- SMEH – Social Mental Emotional Health

Section 139/College Placements

Within 2013/2014 146 young learners had a completed Section 139 by Connexions, of these 7 young learners, did not go on to enrol at a higher educational establishment, therefore leaving 139 young learners enrolled on to higher education. Of these 50 young people continued into college and needed adult social care packages (89 students did not need adult social care packages). So of the 50 young people who started college 4 went into residential colleges and 46 attended general colleges.

6.11.3.3 Horizon scanning

Figure 5 The number of children and young people who attended short breaks, who received overnight respite care



Trends for future demand show that since 2012/2013 there has been an increase in young people being assessed as eligible for Short Breaks with overnight stays. These young people have traditionally then gone on to need adult social care support packages. Indicating there will be a higher demand in the future for adult social care services.

6.11.4 Short Breaks

Short breaks provide opportunities for children and young people with disabilities to spend time away from their primary caregivers giving them the opportunity for independence, to have fun with their peers, make new friends and have new experiences, and provide opportunities for their parents and carers to have a break from caring responsibilities.

Short breaks can include day, evening, overnight, weekend or holiday activities that take place in the child or young person’s own home, the home of an approved carer, a residential or community setting.

Short breaks range from supporting disabled children and young people to access universal services, through to providing specialist services at a local and regional level, where appropriate.

Section 25 of the Children and Young Persons Act 2008 requires that every local authority shall provide services designed to assist individuals who provide care for disabled children to continue to do so, or to do so more effectively by providing them with breaks from caring.

The Breaks for Carers of Disabled Children Regulations 2011 requires local authorities to not only provide crisis care, but to provide short breaks that help them care more effectively for their disabled children. Short breaks should enable family carers to study or undertake leisure activities, meet the needs of other children or carry out household tasks (Regulation 3).

Regulations also require local authorities to provide a range of services ‘sufficient to assist carers to continue to provide care or to do so more effectively’. This ‘sufficiency duty’ means local authorities must know the number of disabled children in their area and their level of need for short breaks, as well as the level of service available to meet that need, and exercise their judgement about whether provision is sufficient (Regulation 4).

Local authorities must also publish a ‘Short Breaks services statement’ setting out the range of services provided, any eligibility criteria and (importantly) ‘how the range of services is designed to meet the needs of carers in [the] area’. The statement must now be published on the website for the ‘local offer’ introduced under section 30 of the Children and Families Act 2014 (Regulation 5).

All Disabled Children and Young People, as defined by the Equality Act 2010[ix], are currently able to access Buckinghamshire County Council funded non-assessed Short Breaks Services (Short Break Local Offer). See Buckinghamshire County Council Short Break Statement:

https://search3.openobjects.com/mediamanager/buckinghamshire/fsd/docs/buckinghamshire_short_breaks_services_statement_v2_2015_16.pdf

The Short Breaks Duty does not create individual right to short breaks for disabled children and their families. An individual right to short breaks is only established under the Chronically Sick and Disabled Persons Act 1970, when they are assessed as necessary to meet that child's needs.

6.11.4.1 The Importance/impact of short breaks

The central purpose of short breaks is to improve outcomes for family carers and their disabled children:

- Reducing the risk of family breakdown
- Increasing family resilience
- Reducing the number of disabled children and young people going into long term care
- Increasing disabled children and young people's confidence, self-esteem, skills
- Increased self-resilience for both disabled children and young people and their families
- Disabled children and young people achieving individual outcomes' such as making friends, having fun, trying new opportunities and improving communication and self-help skills
- Increasing community inclusion and community cohesion
- Increasing children and young people's involvement in decision making

Short breaks have both a direct positive impact on the health and wellbeing of carers, and buffer the impact of important stressors on carers' health and well-being.

Short breaks support carers to continue caring effectively for their disabled child.

Short breaks have a role to play in reducing the impact of the disabled child's difficulties on the well-being of carers.

The overwhelming positive impact of short breaks on outcomes for disabled children and their families, and the resulting cost saving for the state, estimated to be up to £174 million annually[x], if all eligible children received them. This saving is based on:

- Decreased cost of long-term residential care: £135 million
- Decreased cost to health services from reduction in parents', families' and carers' stress: £18 million

- Decreased cost to schools of educating siblings with behavioural and emotional difficulties: £21 million

General Impact on families with disabled children whose short breaks would be reduced (Taken from Every Disabled Child Matters (EDCM) Short Breaks in 2015: An Uncertain Future) –

- 76% of parent carers experience stress or depression and 72% suffer from lack of sleep[xi]
- 80% of parent carers of children with learning disabilities say they have reached or are close to reaching 'breaking point'; a moment of emotional, psychological or mental crisis where they feel they can no longer cope with their caring responsibilities[xii]
- There is a direct relationship between the level and range of short breaks and 'lower levels of psychological distress, higher levels of life satisfaction and better health' **and**
- Short breaks have a direct positive impact on the disabled Children and Young People that benefit from them, leading to improved confidence and independence[xiii].

6.11.4.2 Information on short breaks

Based on short break data collected from providers or Buckinghamshire County Council Internal short break services for 2014/15 there were 1,252 disabled CYP recorded as having some form of short break.

Annual data is recorded by number of CYP and volume of service provided. As can be seen from the table below many CYP access more than one type of short break service.

It should be noted that the Aiming High for Disabled Children Short Breaks Transformation Programme came to an end 31/03/11. After this time data was no longer collected from providers of short break and targeted activities not funded by Buckinghamshire County Council or health, which accounts for the sharp drop in numbers of CYP accessing Group Based Specialist or Universal services.

Table 10 Number of CYP and volume of service provided

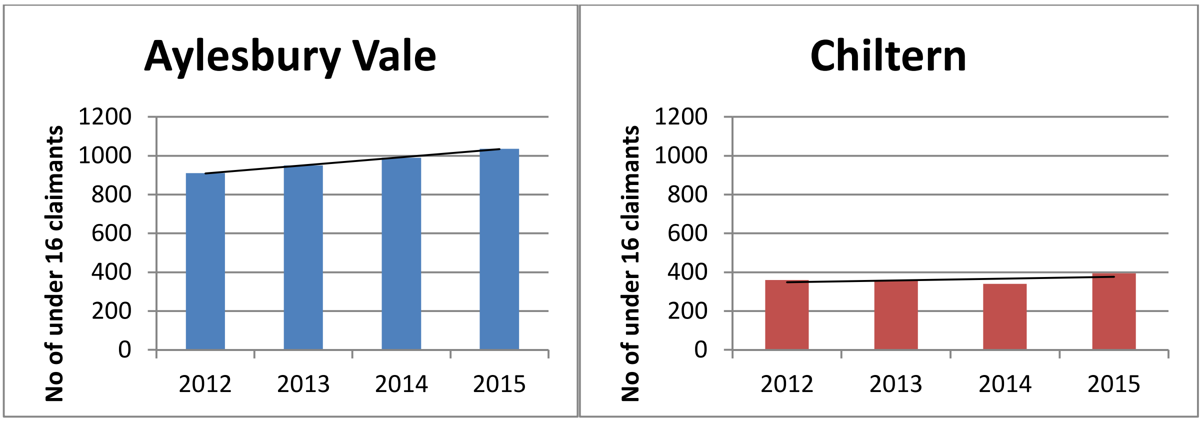
	Family Based or Individual Day Care		Overnight Care		Group Based Specialist and Group Based Universal services	
	No. of CYP	No. of Hrs	No. of CYP	No. of Overnights	No. of CYP	No. of Hrs
10/11	264	24493	153	5954	1663	80994
11/12	301	26915	178	5927	1402	85126
12/13	286	27709	145	5258	1390	89412
13/14	153[1]	15046[2]	113	5255	1055	85844[3]
14/15	135	5823[4]	111	5706	1044	75892[5]

6.11.4.3 Trends, including chart if data available

One indicator of the number of disabled CYP aged 0 – 16 years is the take-up of Disability Living Allowance. The following graphs show that the numbers of CYP receiving this welfare benefit is increasing year on year, with the largest rise in the Aylesbury Vale area. The exception to this is South Bucks where the number has remained static at approximately 250 children.

This population is one indicator of how many disabled CYP may be eligible for short breaks and as can be seen below on the Buckinghamshire graph has risen by 9% to 2,620 since 2012.

Figure 6 Numbers of CYP receiving Disability Living Allowance



---

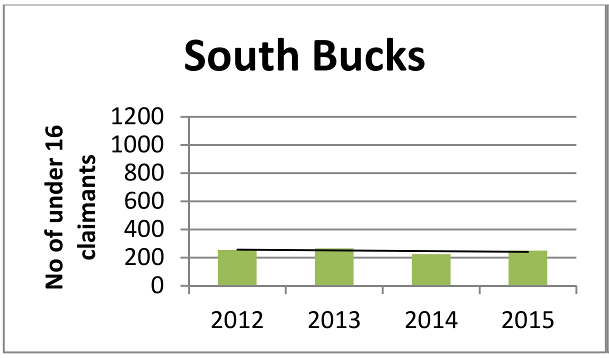
[1] No activity data collection for spot purchased domiciliary care, so less CYP recorded.

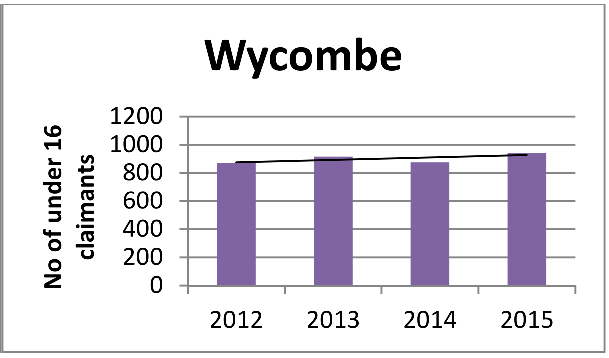
[2] The Council did not collect activity data from spot purchased domiciliary care – this would account for the 13/14 reduction in individual day care usually about 7,000 – 8,000 hours/year

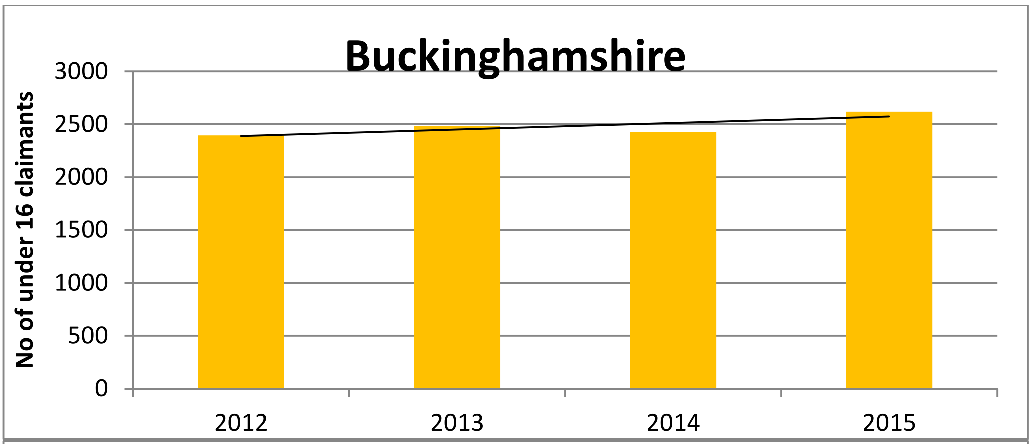
[3] Some providers have stopped providing data in regards to short breaks since 2012/13, which offers some explanation to the reduction of hours and CYP shown.

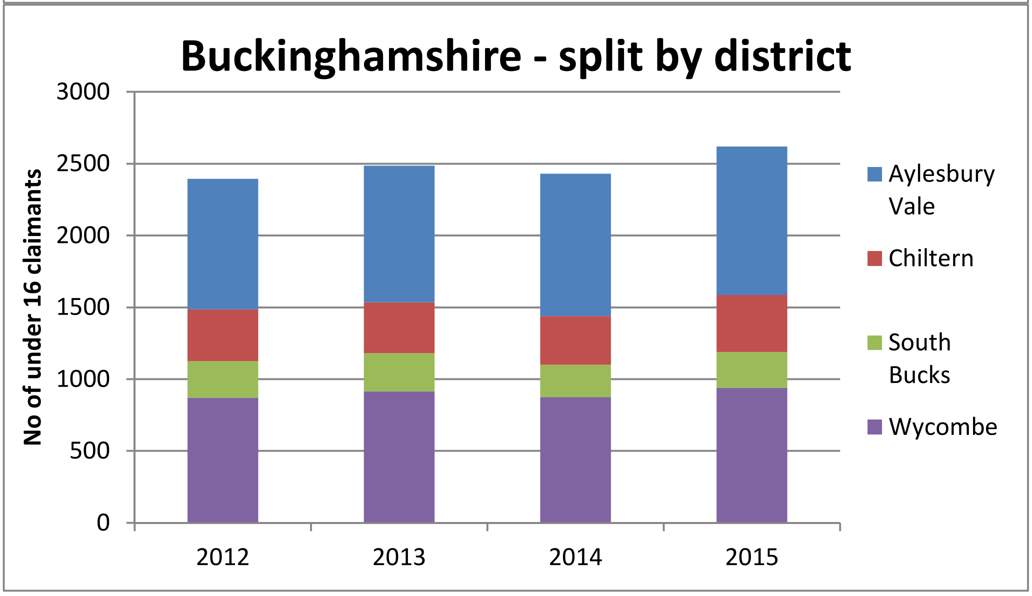
[4] The Council moved some of its contracted provision to spot purchase of domiciliary care and this activity data was not collected from providers. This would account for approximately 6,000 hours in this year together with non-collection of spot purchased domiciliary care, so in total approximately 13,000/year

[5] This activity data for group hours has not been confirmed by all providers so this is an estimated total.


South Bucks
No of under 16 claimants
1200
1000
800
600
400
200
0
2012
2013
2014
2015


Wycombe
No of under 16 claimants
1200
1000
800
600
400
200
0
2012
2013
2014
2015


Buckinghamshire
No of under 16 claimants
3000
2500
2000
1500
1000
500
0
2012
2013
2014
2015


Buckinghamshire - split by district
No of under 16 claimants
3000
2500
2000
1500
1000
500
0
2012
2013
2014
2015
Aylesbury Vale
Chiltern
South Bucks
Wycombe

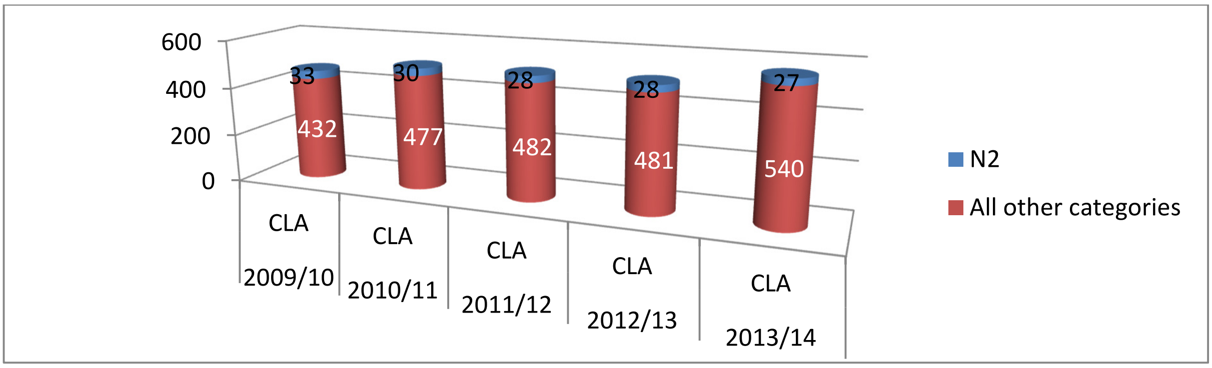
Short breaks support families to carry on caring for their disabled child at home. The following charts show the trends in disabled CYP (N2) becoming long term ‘Children Looked After’ (CLA) in comparison with all other CYP becoming CLA.

As can be seen from the graphs the proportion of disabled CYP as a total % of the CLA group of CYP has decreased by 2%.

Figure 7 Proportion of Children Looked After during the year by Need Code 2009 – 2014

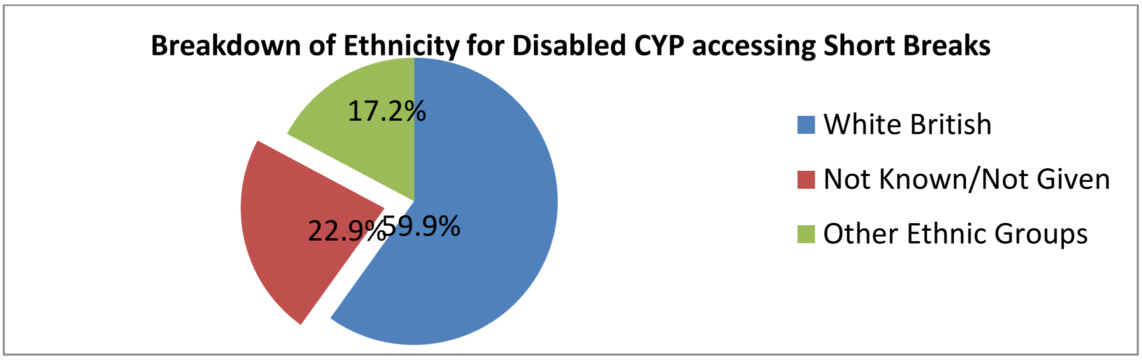
As can be seen from the chart below the numbers of disabled Children Looked After during the year (N2) have decreased from 2009/10 when there were 33 N2 CLA compared with 432 - all other CYP, to 2013/14 when there were 27 N2 CLA compared with 540 – all other CYP.

Figure 8 Children Looked After (CLA) during the year by Need Code 2009 – 2014



6.11.4.4 Inequalities, (e.g. deprivation, age, gender, ethnicity etc., based on local data or if not available national evidence), including chart if appropriate

Table 11 Breakdown of Ethnicity of all Buckinghamshire Disabled CYP Accessing Short Breaks



In view of the not known/not given level being so high, this may include Children and Young People from Other Ethnic Groups, so we are not able to say that the reach for short breaks is high enough for non-white ethnic groups. This is comparing to the table below showing national demographic characteristics with an average % of non-white ethnic groups would be 17%.

Table 12 National demographic characteristics

		TCRU survey Years %	Children in Need Census 2005 %	SEN statements 2007 %	Census 2001: All children %
Ethnic Group (n=66)					
	White	78	81	84	84
	Mixed	4	4	3	4
	Asian	8	6	6	7
	Black	6	5	4	4
	Other	4	1	1	1

As the 2011 Census data for Buckinghamshire (0 – 15 with Life Long Term Illness) suggests a 39% increase in both the following ethnic groups: Mixed/Multiple Ethnic Group Asian/Asian British, this emphasises the reach for these groups in accessing short breaks may not be high enough.

6.11.4.5 Demand

Increasing Buckinghamshire Demographics:

There are three simple basic indicators of the potential population of disabled Children and Young People who might be entitled to access short breaks: national formula for estimating demand for short break services for severely disabled children multiplies the total 0-19 population by 1.2%, Disability Living Allowance (DLA) rates and population of special schools –

- National formula for estimating demand for short break services for severely disabled children multiplies the total 0-19 population by 1.2%: 2016 estimated Buckinghamshire population 0 – 19 years estimated to be 131,059, which would indicate 1,573 children and young people likely to need short breaks.

- DLA rates for Buckinghamshire - This represents a 6% increase since 2013 and provides a potential demand for short breaks of 2,500 Children and Young People. N.B. The figure would be higher than this as 16+ age group are eligible for a different welfare benefit Personal Independence Payment (PIP) Source: DwP DLA Local Authority statistics: http://tabulation-tool.dwp.gov.uk/100pc/dla/tabtool_dla.html

- Special Schools Population – the pupil population has increased by 12% from 2011 to 2015 to 1,200. This is a greater % rise than the overall pupil population of 9% for the same period.

- Assuming the median figure as the group of Children and Young People that may be eligible to receive short breaks (1,757) Children and Young People Buckinghamshire recorded 1,252 unique Children and Young People accessing short breaks in 2014/15. It needs to be noted however that the 1,252 Children and Young People accessing services that are not directly or wholly funded by Buckinghamshire County Council Short Breaks funding.

This indicates Buckinghamshire is still not achieving a high enough reach for short breaks.

As the Local Authority is required to be able to demonstrate sufficiency of short breaks and that they are meeting the needs of local carers, any reduction to short breaks budget and contingent levels of service will have a **negative impact** when reviewing the Buckinghamshire Short Breaks Services Statement.

6.11.4.6 Horizon scanning

An assessment was undertaken by Buckinghamshire County Council CYP Commissioners in July 2015 revealed that more than half in the residential short breaks service (42 Children) were at some level of risk of becoming Looked After Children/entering full time boarding placements. There were 15 children where accommodation had specifically been avoided between 2013 – 2015; a potential minimum cost to Children and Young People social care of £930,000. This compares in cost if we assume the respite Children and Young People have an average 90.2 nights annually this is equivalent to an approximate cost of £43,386/ Children and Young People, so a cost avoidance of a minimum of £279,210.

The assessment also indicated there are 28 disabled Children and Young People that have been identified by Children with Disabilities teams as likely to be requiring residential short breaks in the future; 8 of which are 10 years and over meaning the need is more likely to be within the next year. This compares with 9 Children and Young People reaching age 18 and leaving the service in the next year and the service currently with a waiting list of 11 Children and Young People, waiting for a space.

6.11.4.7 Public views

Education, Health and Care (EHC) Plans – Academic Year 2014/15:

A questionnaire is sent out to parents and carers when a Final EHC Plan is issued. The overall results for the 2014/2015 academic year are very pleasing. 84% of parents and carers either strongly agree or agree that the information the SEN Team provide as part of the EHC assessment process is useful and accessible. The remaining neither agrees nor disagrees.

We are keen to ensure that parents and carers are feel valued through the EHC Needs assessment and results show that 76% parents strongly agree or agree that they felt valued with the remaining neither agreeing or disagreeing. 88% of parents reported that they found their SEN Officer or Assistant SEN Officer helpful. We asked parents and carers if there was anything else that we could do differently. The general opinion was that more information should be included in the EHC Plan and that plainer language would aid better understanding. The SEN Team will adjust the plans in the future, accordingly. One person also said that inaccurate and missing information had caused them some distress.

Education Psychology Support Case Study - Academic Year 2014/15:

A young person reported to the Educational Psychology Service t how she has turned her life around. She had by all accounts had a horrific upbringing with abuse and rejection being a part of it. She called in to say how an EP had made a significant difference to her life. The young person is now pursuing her aspiration of becoming a lawyer. She said the EP had given her hope, inspiration and was a great role model for her.

Local Offer

Local Authorities are required to publish feedback and comments on the Local Offer and show how these are being used to shape services and information.

Comments and resulting actions are published on the website using a 'you said, we did' format http://www.bucksfamilyinfo.org/kb5/buckinghamshire/fsd/advice.page?id=d5wypw22kDc

Examples are as follows:

You said: You wanted some information about what sort of things were included in the Local Offer. You said that you wanted to watch a film that would give you this information.

We did: We went away and worked with some young people in Buckinghamshire to find out what was important to them and asked them to help us make a film to tell you about their important things.

You said: I have been looking at lots of SEND local offers across England as to how well they were providing information about health services. I think yours is really good – however you have not included a link to your wonderful community nurses. Please could you add a link to them on your local offer?

We did: We have now added a page about the community nurses.

You said: Some schools had difficulty adding their Local Offer report to the website.

We did: This year we have offered to do this on behalf of schools to ensure all the information is available.

Short Breaks Case Study from a Disabled Children's Social Worker – October 2015:

This family have two children, one of whom receives a service from the Children with Disabilities Service. This young person has Rett Syndrome, which is a rare genetic postnatal neurological disorder affecting mainly girls.

People with Rett syndrome are prone to gastrointestinal disorders and up to 80% have seizures. They typically have no verbal skills, and about 50% of affected individuals do not walk. Scoliosis, growth failure, and constipation are very common and can be problematic.

This young person had a respite package at Merryfields; a residential short break service and throughout the assessment process I was of the agreement that this needed to be increased. The family have little sleep when this daughter is home due to her sleep patterns and seizures; the condition is showing signs of deterioration which has had an impact on her seizures. The need for respite is paramount for this family. This allows them to spend quality time with their other child (age 14), get sleep and have independent quality time for themselves; equally the respite is an opportunity for this young person to be with her friends, gain social skills and cognitive development with her peers in a different environment.

This package was increased from one evening a fortnight to one evening a week and from a weekend in every six to a weekend in every four. This is a reasonably small change but the impact has been significant for the family.

Annual Parent Survey re Short Breaks 2014/15:

There was a very low response rate to this annual survey so results are relevant but need to be treated with some caution:

- 92% of responders agreed/strongly agreed - There has been a positive impact on my disabled child's life since attending short breaks.
- 35% of responders disagreed/strongly disagreed - The short breaks we receive has provided me with a sufficient break to continue caring for my child.
- 58% of responders disagreed/strongly disagreed - The short breaks I receive allow me to undertake education, training or any regular leisure activity.
- 27% of responders disagreed/strongly disagreed - The short breaks I receive allow me to meet the needs of other children in the family more effectively.
- 92% of responders agreed/strongly agreed - The short breaks I receive allow me to carry out day to day tasks which I must perform in order to run my household.

The last four factors are cited in The Breaks for Carers of Disabled Children Regulations 2011 - Short Breaks Duty to Make Provision.

Short Breaks Case Study from a Disabled Children's Social Worker – October 2015:

A young person and his family were struggling to find the appropriate service promote their independence in preparing them for adulthood. Children With Disabilities Unit 4 considered short breaks and the young person was offered a place at Merryfields (short breaks residential unit). The young person was given lots of opportunities to improve their peer relationships, participating in lots of activities in the community and increased their confidence in developing life skills, affording them work experience with the local maintenance man. As the young person entered adult social care he was able to go shopping to buy the relevant equipment to carry out small maintenance tasks and able to maintain peer relationships.

Transitions - Parent Voice July 2014 . . . . .

"I have two teenage children, my eldest is currently in the sixth form of a local grammar school and my son has autism and is at a special school. When my son was diagnosed the one thing that I struggled with was that one day he was my son and the following day, when the letter arrived saying he was on the autistic spectrum, he was autistic. I did not know what that meant and in fairness I still do not know what that means.

"In the first instance, we attended many courses on autism, communication and the like and often people are convinced that I am an expert on autism, having lived with it for so many years. However, I am only an expert on how autism affects my son and my family. Early on I took inspiration from a poem called Welcome to Holland written by Emily Perl Kingsley and that has followed me through the times with my son. I have found that acceptance of what is can be enormously helpful and being in Italy and Holland together has rich and beautiful moments as well as the dark times. "Over the course of the last 10 - 12 years I have had the privilege to work with Parent Partnership and different professionals to help shape policies for children and young people with special educational needs and/or disability in Buckinghamshire. This has taken me in a whole new direction to that which I believed I would take when my children were very small. Some has been good and some bad, although the changes that I have seen are encouraging. Participation is much more on the map now and the County Council is committed to working with parents/carers and young people to help shape the services it provides. I am now looking forward to the next steps in transition – with both children – to adulthood, albeit in different guises. I expect some trauma and struggle but also look forward to the adventure that I hope they both face along the way."

Transitions Case Study 1 - 2013:

Student A joined Talkback in 2013. Student A is on the Autistic Spectrum and, at the time, suffered with difficulties relating to anxieties. As part of Student A's transition to Talkback, we were handed his s139a form, and attached to this form was a note from Student A's school explaining that student A had expressed inappropriate interests towards young children. The Equip Project Manager contacted the school to gather more information, and was given two scenarios which explained the note.

The challenge here was the lack of appropriately shared information. Student A continued to raise challenging questions while being supported by Talkback, and we tried to support by challenging and redirecting Student A. Talkback decided not to raise the subject with parents initially as there was no knowledge that the parents were aware of these events. It later transpired, after several difficult meetings, that not only were the parents aware of this, but Student A had been involved with CAMHS who had addressed these issues. If Talkback had been made aware of this, our approach to his support would have been very different.

Transitions Case Study 2 - 2015:

Student B joined Talkback in 2015. Student B had higher support needs than Talkback's Equip project had previously worked with, however, this was not made explicit in their EHC Plan. A week after half term, Student B had an accident relating to personal care. This was unexpected by the Talkback team as the EHC Plan had made it clear that there were no concerns relating to personal care.

When Talkback contacted Student B's family to discuss what had happened, Student B's parents were shocked that Talkback had not expected this as it was a part of Student B's plan at college.

EHC Plans need to be clearer in what is explicitly needed for a student, particularly one who has more complex needs.

Transitions Case Study 3 – 2015:

Student C joined Talkback in 2013. Talkback were given an assessment of needs for Student C that implied that they would struggle to succeed outside of the school environment, with particular difficulty relating to independent skills, in particular travelling independently. However, within two weeks of joining Talkback, Student C was not only travelling independently, but was communicating their whereabouts to family and supporters.

The concern here is around what is communicated from schools to Colleges/providers about a student's abilities and achievements. It is usually the case that a student's ability is undersold and this can create difficulties for providers in setting correct targets for people.

Speech and Language Therapy Provision Case Study 1 – 2015:

The speech and language service are developing their ways of working to be more focused on goals and outcomes and are trying to find ways that children can be involved in choosing these. One child who has been testing this out is a six year old girl with a language disorder and statement of Special Educational Needs who receives input from a speech and language therapist. The therapist and learning support assistant showed the child five activities and asked her to choose three that she wanted to work on. The therapist then carried out each activity with her and asked her to rate how hard she found it. The child enjoyed choosing the activities she wanted to do in therapy. She found using the rating scale difficult as she always wanted to choose the smiley face even when she found the activity hard. The learning support assistant said that having more emphasis on goals helped her focus on what she needed to with the child and to record progress. The learning support assistant was able to ask for further activities and goals as the child achieved the original ones. The child has made steady progress and the learning support assistant has been able to adapt skills to use with the child in the classroom.

June 2016

Appendix 1

SPECIAL EDUCATIONAL AND DISABILITY (SEND) REFORMS

Background

The enactment of the Children & Families Bill on 13th March 2014 requires radical changes to the Special Educational Needs and Disability (SEND) provisions, known as the SEND Reforms.

The Bill follows on from the SEN Green Paper, Support and aspiration: a new approach to special educational needs and disability published in March 2011. The SEND Code of Practice: 0 – 25 was published in July 2014 with an implementation date of 1 September 2014.

The main elements of the SEND Reforms are:

- Replacing statements of SEN and learning difficulty assessments (LDAs) (for older young people) with a single, simpler birth to 25 years assessment process; an education, health and care (EHC) plan from 2014. Parents/carers who have children with an EHC plan would have the right to a personal budget to fund their support.
- Providing statutory protections comparable to those currently associated with a statement of SEN to up to 25-years-old in further education.
- Requiring local authorities (LAs) and health services to link up services for disabled children and young people - so they are jointly planned and commissioned.
- Requiring LAs to publish a Local Offer showing the support available to disabled children and young people and those with SEN, and their families.
- Introducing mediation for disputes and trialling giving children the right to appeal if they are unhappy with their support.
- School Action/School Action Plus (and Early Years Action/Early Years Action Plus) categories of support for pupils and students without Statements/EHC Plans were renamed 'SEN Support' from September 2014. The change of name does not affect which children/young people need/receive support for their Special Educational Needs.

In order to implement the SEND Reforms and the recommendations from the recent SEN Review a SEND Board has been established. The specific function of the SEND Board is to assist/enable implementation of the recommended strands of the SEN reforms and to identify priorities, objectives and targets.

An overview of the main areas can be found below.

Education, Health and Care Plans (EHC Plans)

The Bill stipulates that EHC Plans replace statements. The current intention is for the threshold for these assessments to remain the same as for statements. The Government has extended EHC Plans to further education and training and to replace 139a assessments. There is a duty within the Bill to secure the education provision set out in EHC Plan. The rights of appeal remain the same as for a statement but include further education. Amended Regulations set out how assessments should be conducted and how it might be combined with other assessments.

Joint Commissioning and Personal Budgets

The Bill states that named partners will be required to cooperate in relation to meeting the education, health and care needs of children and young people with SEND. Partners include all special and mainstream schools and colleges, local authorities (including in relation to social services), providers of alternative provision and key health agencies. Local authorities and clinical commissioning groups must make arrangements for joint commissioning. This includes arrangements for considering and agreeing reasonable provision to meet the needs of all children with SEND in the area, and specifically for children with EHC plans. The Bill requires local authorities to prepare a personal budget in relation to an EHC plan and where a request has been made by parent or young person. This budget may include direct payments. The Regulations set out the provisions in more detail.

Local Offer

Local authorities must publish a Local Offer, setting out in once place information about provision they expect to be available across education, health and social care for children and young people 0 - 25 in their area who have SEN or are Disabled, including those who do not have EHC Plans. This includes services available outside of the local area. There is a duty to consult with parents, schools, colleges, other services when developing the local offer. The Regulations stipulate what the Local Offer should include.

The local authority must also set out in their Local Offer an authority-wide description of the educational and training provision children and young people with SEN or disabilities can expect to be provided from the funding provided to providers of relevant early years education, schools and the full range of post-16 providers in their area.

Preparing For Adulthood/ Transitions

The Preparing for Adulthood programme will provide knowledge and support to local authorities and their partners, including families and young people, so they can ensure disabled young people achieve paid work, independent living, good health and community inclusion as they move into adulthood.

Appendix 2

Glossary:

Acronyms of Primary Need on EHC Plans/Statements

ASD – Autism Spectrum Disorder
BESD – Behavioural, Emotional & Social Difficulties
MLD – Moderate Learning Difficulties
PD – Physical Difficulties
SLCN – Speech, Language & Communication Needs
SLD - Severe Learning Difficulties
SPLD – Specific Learning Difficulties
HI – Hearing Impairment
VI – Visual Impairment
MSI – Multi Sensory Impairment
PMLD – Profound and Multiple Learning Difficulties
SMEH – Social Mental Emotional Health

References

---

[i] Support and aspiration: A new approach to special educational needs and disability, DfE (March 2011) http://webarchive.nationalarchives.gov.uk/20130401151715/https://www.education.gov.uk/publications/eorderingdownload/green-paper-sen.pdf

[ii] Mooney, A, Own, C and Stratham, J (2008) Disabled Children: Number, Characteristics and Local Service Provision Research Report

[iii] Integrating Services for Children and Young People with Additional Needs and/or Disabilities in Buckinghamshire Version 1.2

[iv] Panksepp, J 'Melatonin. The sleep master . An Emerging role for this over-the-counter supplement in the treatment of autism' Lost and Found: Perspectives on Brain, Emotions, and Culture www.autism.org/melatonin.html

[v] Jordan, R, Jones, G and Murray, D (1998) Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research DfEE, Norwich

[vi] Howlin, P and Moore, A 'Diagnosis in Autism' Autism Vol 1 No 2 pp135-162 (Nov 1997) Sage NAS, London

[vii] Wing, L (1979) 'Mentally Retarded children in Camberwell (London)' in Estimating Needs for Mental Health Care ed H Hafner pp 107 – 112, Springer-Verlag, New York

[viii] Dr. Scott presented the findings of her research to the All Party Parliamentary Group in May 2000.

[ix] In the Act, a person has a disability if:

- they have a physical or mental impairment,
- the impairment has a substantial and long -term adverse effect on their ability to perform normal day-to-day activities

For the purposes of the Act, these words have the following meanings:

- 'substantial' means more than minor or trivial
- 'long-term' means that the effect of the impairment has lasted or is likely to last for at least twelve months

'normal day-to-day activities ' include everyday things like eating, washing, walking and going shopping

[x] The social and economic value of short breaks, nef consulting (2009)

[xi] No time for us. Relationships between parents who have a Disabled Child: A survey of over 2,000 parents in the UK, Contact a Family (2004)

[xii] Breaking Point reports, Mencap (2003, 2006, 2013)

[xiii] No time for us. Relationships between parents who have a Disabled Child: A survey of over 2,000 parents in the UK, Contact a Family (2004)