Bristol JSNA Chapter 2016-17

Children's Social Communication and Interaction Needs in Bristol

Chapter information	
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Linked JSNA chapters	Children and Young People's Mental Health

Executive summary

Introduction

'Social communication and interaction needs' (SCIN) is a term that covers a range of conditions and support needs including Autism Spectrum Disorder (ASD). Social Communication and Interaction Needs (including ASD) affect the way a person communicates with, and relates to, other people. SCIN is a spectrum of needs meaning each individual will have different needs.[1] For the purpose of this review, we will use the following definition "the support needs of children and young people whose social communication, interaction, understanding and imagination abilities, along with restricted and repetitive behaviours and interests, present difficulties to the individual and/or to others"[2]. This needs assessment will cover children and young people up to the age of 25, who have these needs.

Children and young people who have social communication and interaction needs and their families may experience a variety of difficulties, and require various types of support. The aim of this needs assessment is to inform how we provide that support across sectors – from education, social care and health, to the voluntary sector.

Recent studies have reported an increased prevalence of diagnosed ASD, and the condition is now thought to occur in at least 1% of children[3]. There are around 123,500 children and young people aged 5-24 living in Bristol[4]. On this basis, it is estimated that within this age group, there are likely to be around 1235 children and young people with Autism Spectrum Disorders (this figure does not include 0-4 year olds who are less likely to have been diagnosed). This figure relates to children and young people who have ASD, whether or not this is currently diagnosed. It is important to highlight that these figures relate to ASD only, and therefore figures relating to our wider definition of social communication and interaction needs will be higher. This rising prevalence has inevitably led to increased demand for diagnostic and support services for children and young people of all ages. This needs assessment will inform how we manage this increased need in the most effective way, while improving outcomes for children and their families.

There is no single database which records the number of children and young people with SCIN, or diagnosed ASD. We are therefore reliant on the collation of data from a number of sources. The main sources of this data are represented below in Figure 1.

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[1] Department of Health (2014). Fulfilling and Rewarding Lives, the Strategy for Adults with Autism in England: an update. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

[2] Bristol Social Communication and Interaction Needs Review Group

[3] Baird, G. et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet, 368 (9531), 210-5.

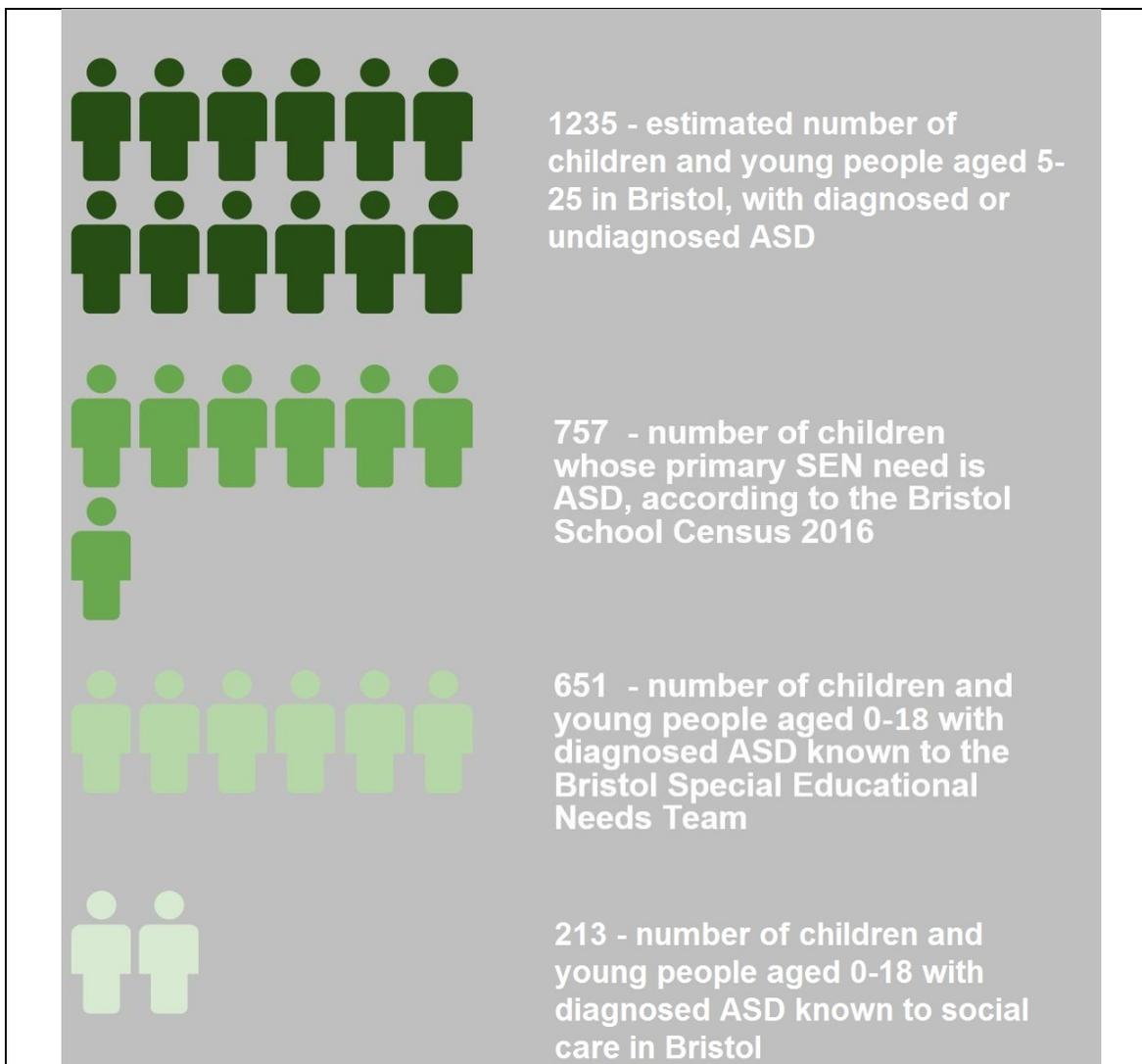[4] Bristol City Council (2015) The Population of Bristol. Available at: https://www.**bristol**.gov.uk/statistics-census.../**the-population-of-bristol** (Accessed: 08/09/16).

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1235 - estimated number of children and young people aged 5-25 in Bristol, with diagnosed or undiagnosed ASD

757 - number of children whose primary SEN need is ASD, according to the Bristol School Census 2016

651 - number of children and young people aged 0-18 with diagnosed ASD known to the Bristol Special Educational Needs Team

213 - number of children and young people aged 0-18 with diagnosed ASD known to social care in Bristol

Figure 1 - Summary ASD figures, Bristol 2016

A range of services are available to support families through identification of need, to assessment, possible diagnosis of ASD, and on-going support. However, feedback from parents, carers, children and other stakeholder suggest that there are areas where this could be improved. Furthermore, the information collected in this needs assessment suggest that a significant amount of funding is spent on the support needs of a small number of children in high cost education, social care and health placements.

Key issues and gaps (summary of section 8)

Needs led services for those with or without a diagnosis

The information gathered for this needs assessment has shown us that there is a significant number of children and young people in Bristol who have been diagnosed with ASD, and that there is likely to be a further group of children and young people who have a range of social communication and interaction needs. The needs of these children are diverse and vary in complexity and severity. For this reason, some children require much more intensive support

than others. At the highest end of the range of needs are those children who require support from social care and/or are accessing education, social care or health placements in Bristol, or sometimes outside Bristol.

Gender

While the prevalence of SCIN has not been recorded or measured locally to date, and we have therefore had to rely on data for ASD, this information does provide us with some useful knowledge. There are significantly more boys than girls who have been diagnosed with ASD, which reflects national patterns of diagnosis, although it is unclear whether this is due to a variation in prevalence or a lack of recognition of how symptoms may present differently in women and girls.

Additional needs

We also know that many of the children and young people this needs assessment is concerned with have additional needs such as speech, language and communication needs; social emotional and mental health needs; and learning difficulties. At the highest end of the needs spectrum, of those children supported by social care, two thirds have more than one disability.

ASD and Education and Health Care Plans

Nationally, Autism Spectrum Disorders are the most common need for those with a Statement of Educational Needs (SEN)or Education and Health Care (EHC) plan. More than a quarter of pupils (25.9%) with a statement of SEN or EHC plan in January 2016 had Autistic Spectrum Disorder listed as their primary type of need. This is reflected locally in Bristol where 21.3% of pupils with a statement of SEN or EHC plan in January 2016 had Autistic Spectrum Disorder listed as their primary type of need, and 4.8% of pupils with SEN support have this type of need. The majority (80.5%) of these pupils with a primary need of ASD are male.

Increase in need over time

We know that demand for service has increased over time, and the number of children identified by the School Census as having been diagnosed with ASD reflects this. With a growing child population, and increasing diagnoses of ASD, it is clear that demand for support services is going to continue to increase over the coming years. Based on Bristol's population projections and the estimated 1% of the population with diagnosed ASD, by 2037 it is projected that there will 1772 children and young people with diagnosed ASD in the city.

Complex landscape of support services

Services to support children and young people with ASD or undiagnosed social communication and interaction needs in Bristol are varied and diverse. Services cover different geographical areas, age ranges, and some require a diagnosis in order to be able to access them, while others don't. Furthermore, some services have thresholds or eligibility criteria in place to manage access, while others don't. Our analysis of the range of services available, alongside the

information gathered from parents, carers and other stakeholders highlighted a range of issues in relation to how services are currently provided. Information about the range of services is not readily available or clear enough for families to understand; communication with families throughout their diagnosis journey and beyond could be improved; professionals in mainstream services should have a comprehensive understanding of SCIN and the services available to support children with these needs; there is a real or perceived inconsistency in the support available across the different parts of Bristol which needs to be reviewed; and crucially, support should be available on the basis of identified need rather than simply whether or not a child has a diagnosis of ASD. As a result of this, we have identified a need to review children's journeys through services, and how they and their families are made aware of and can access services. It is clear that increasing demand for services is a further challenge which must be considered as part of this review.

Prevention of high cost placements

This needs assessment has also highlighted that a significant amount of funding is spent on the support needs of a small number of children with complex and severe needs in high cost education, social care and health placements. We therefore need to understand more about the needs of these children and the circumstances that led to their current situation in order to be able to propose ways that similar escalation of needs and costs could be avoided, and outcomes improved for children and young people in the future.

Recommendations (summary of section 10)

As a result of this needs assessment, and in particular the engagement activities that took place to understand how well services are currently catering to the needs of children with SCIN, the following principles have been developed which we believe represent the feedback received from parents, carers and other stakeholders. We anticipate using these principles as a guide as we begin the next stage of this review:

1. Services should be needs led, not diagnosis led
2. Information and communication with parents, service users and carers should be clear and accessible
3. Professionals should be knowledgeable about Social, Communication and Interaction Needs including ASD and the support available
4. Services should be joined up and work together wherever possible
5. Families need support throughout the journey: before diagnosis, during diagnosis, and after diagnosis
6. Available support for each age group, and pathways through services should be consistent across the city according to need
7. Appropriate support should be identified at the earliest opportunity to avoid escalation of needs

Further recommendations for consideration are:
   a) To explore the potential for a single database of children with ASD to be established in order to enable us to accurately project the number of children and young people requiring support across services

b)   That health services who do not currently collect data on this cohort of children begin to do so in order to inform the development of services

c)   That the broader definition of 'Social Communication and Interaction Needs' is considered alongside Autism Spectrum Disorders when designing services for this group of children and young people in order to ensure that services can become as needs led as possible

Next Steps:

The SCIN Review Group will be using the information collected in this document to inform the development of services and the way support is offered to children and young people with Social Communication and Interaction Needs.

Work is already underway to begin to make improvements to the support available, including:

- Community Children's Health Recommissioning – this service is being recommissioned, reflecting the principles outlined above
- A pooled budget between NHS Bristol CCG and Bristol City Council for Autism Support has been established to enable the joint commissioning and delivery of support to Parent/Carers of children with SCIN. These services have been recommissioned and are now provided within the birth to 25 service. Further review of the model of delivery is underway, with the aim of aligning with the above principles.

The following next steps have been identified to further the progress of this review:

a)   Undertaking a deep-dive exercise to identify the most costly education, social care and health placements, and the needs of those young people. The aim of this exercise will be to identify any opportunities for intervening earlier or differently with the objective of improving outcomes for individual children and young people, and reducing costs

b)   Identifying further opportunities for service redesign and improvement based on the above principles

c)   Developing a clear, comprehensive whole system pathway.

JSNA chapter report

A: What do we know?

1) Who is at risk and why?

Definition of Social Communication and interaction Needs:

'Social communication and interaction needs' is a term that covers a range of conditions and support needs including Autism Spectrum Disorder (ASD). Specific characteristics must be present in order to receive a diagnosis of ASD. In the UK, the main criteria for diagnosing autism are set out in the World Health Organisation's International Classification of Diseases (ICD). In the USA, the American Psychiatric Association (APA) produces its own diagnostic manual, the Diagnostic and Statistical Manual of Mental Disorders (DSM) which is also influential outside the USA, including in the UK[5]. However, this review covers the needs of those both with and without a diagnosis. For the purpose of this review, we will use the following definition "the support needs of children and young people whose social communication, interaction, understanding and imagination abilities, along with restricted and repetitive behaviours and interests, present difficulties to the individual and/or to others"[6].

Purpose of this document:

This needs assessment aims to outline the current and projected levels of need in relation to children and young people from birth to the age of 25, who have social communication and interaction needs (SCIN). This needs assessment will inform the review of SCIN support in Bristol for children and young people between 0 and 25. The scope of this review will cover the whole system of support, including health, education, and social care services, as well as support provided by the voluntary sector. This review will consider how well support services meet the needs of children and young people with social communication and interaction needs, how accessible services are, and how easy it is to navigate the pathways through services.

Background:

Social Communication and Interaction Needs (including ASD) affect the way a person communicates with, and relates to, other people. SCIN is a spectrum of needs meaning each individual will have different needs.[7] People with SCIN also frequently experience a range of cognitive, learning, language, medical, emotional and behavioural difficulties. These difficulties can substantially affect a person's quality of life and lead to social vulnerability[8]. These needs can also impact the families of those experiencing them profoundly which will have support implications. Autism Spectrum Disorders are considered to be lifelong developmental disabilities that affect how individuals make

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[5] National Autistic Society. (2016). Autism profiles and diagnostic criteria. Available at: http://www.autism.org.uk/labels (Accessed: 21/03/16).

[6] Bristol Social Communication and Interaction Needs Review Group

[7] Department of Health (2014). Fulfilling and Rewarding Lives, the Strategy for Adults with Autism in England: an update. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

[8] National Institute for Health and Care Excellence. (2014). *Autism.* NICE Quality Standard 51 (QS51) Available at: http://guidance.nice.org.uk/qs51

sense of the world around them.

People with SCIN can have a variety of very complex needs, including; profound difficulties relating to other people, and to the world in general, very high levels of social exclusion, very low rates of employment, high vulnerability to exploitation, and high rates of co-morbidity (depression, anxiety, OCD, transient psychotic episodes).

Children, young people and adults on the autism spectrum are often affected by other mental health conditions, such as attention deficit hyperactivity disorder (ADHD), anxiety or depression. About half also have varying levels of learning difficulties. However, with appropriate support many people can be supported to become independent. Children with more severe symptoms and learning difficulties are likely to need more care and assistance to live independently as adults[9].

National SCIN data
There are no studies looking at the prevalence of SCIN, and relatively few looking at the prevalence of ASD in children in the UK. Estimating the prevalence of Social Communication and Interaction Needs is almost impossible, considering that this is not a widely used definition for the purposes of monitoring and data collection. Furthermore, estimating the prevalence of autism spectrum disorders is difficult because of the absence of long term studies and inconsistencies in the use of definitions over time. Diagnoses of 'autism', 'high-functioning autism', 'autistic traits' and 'Asperger's syndrome' are still not clearly defined[10]

Baird et al state that the prevalence of ASD is "substantially greater than previously recognised", with children with ASD constituting 1% of the child population[11]. It is unclear whether this increase is due to better awareness, wider diagnostic criteria or increased incidence. A systematic review of prevalence studies of Autism Spectrum Disorders showed that published studies of autism found an estimate of prevalence of ASD of 20.0 per 10 000, but the 95 % confidence interval ranged from 4.9 to 82.1[12].

Risk factors:
A comprehensive review of the causes of autism stated that most researchers believe that ASDs have a variety of causes[13]. They could perhaps all affect the same brain systems, or they could impede development through disruption of the different functions necessary for social and communicative development. It is well established that there is a genetic component to ASDs, although it remains unclear how many genes may be involved. It is thought that several genes may be operating together to confer susceptibility. In a small proportion of cases, various single gene disorders and chromosomal abnormalities have been reported in individuals with ASDs. It is entirely plausible that the autism phenotype might be derived from a number of different genetic

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[9] NHS Choices. (2016). Autism Spectrum Disorder (ASD). Available at:
http://www.nhs.uk/Livewell/Autism/Pages/Autismoverview.aspx (Accessed: 14/06/16).
[10] National Autistic Society. (2016). Autism profiles and diagnostic criteria. Available at:
http://www.autism.org.uk/labels (Accessed: 21/03/16).
[11] Baird, G. et al (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet, 368 (9531), 210-5.
[12] J. G. Williams, J. P. T. Higgins and C. E. G. Brayne (2006) Systematic review of prevalence studies of autism spectrum disorders. Archives of Disease in Childhood 91:8-15
[13] MRC (2001) Review of Autism Research: Epidemiology and Causes. Available at:
https://www.mrc.ac.uk/documents/pdf/autism-research-review/

components. How environmental factors interact with genetic susceptibility is as yet unclear. The National Autistic Society notes that the difficulty of establishing gene involvement is compounded by the interaction of genes and by their interaction with environmental factors[14].

Gender:

Prevalence figures would suggest that men and boys are more at risk of developing ASD than women and girls. An NHS Information Centre Study found prevalence of 2.0% in men and 0.3% in females[15]. It has been suggested that men's symptoms are more frequently found on the autism spectrum than women's, who are more likely to internalise their symptoms. This raises the possibility that ASD may be under-diagnosed in women and girls.

Ethnicity:

There is little national research on the difference in prevalence and experience of ASD between ethnic groups. However, research in America suggests that identification and diagnosis of ASD in some ethnic groups may be delayed for various reasons, for example, differing cultural interpretations of some developmental issues which may signal possible ASD, such as avoidance of eye-contact. Potential stigma surrounding disability, a reluctance to 'label' a child, and an understanding of the causes of the condition can be influenced by cultural beliefs. This can play a role in preventing early diagnosis, in treatment choice and in accessing support services[16].

Migration:

Although evidence is limited and inconsistent, research suggests some correlation between maternal immigration and diagnosis of ASD. In a study from 2010, mothers born outside Europe had a significantly higher risk of having a child with an autism spectrum disorder (ASD) than mothers born in the UK[17]. Some research suggests that Somali immigrants are one of the groups that have specific needs around the diagnosis and support of children with autism[18]. The experiences of Somali families, living in Bristol, who have a child with autism, have been explored by the University of Bristol, alongside Autism Independence in order to understand how autism is understood in their community, and how health and social care services can be best delivered to support them[19]. This research shows the importance of understanding cultural views of autism and the need to raise awareness, reduce stigma and provide support to encourage families not to delay seeking help for their children.

Co-morbidity:

Mental illness can be more common for people with ASD than in the general population, however the mental health of people on the spectrum is often overlooked. Anxiety disorders are very

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[14] National Autistic Society. Position Statement on the Causes of Autism. http://www.autism.org.uk/get-involved/media-centre/position-statements/causes.aspx (Accessed 16/11/2016)

[15] Brugha T, et al (2012) Estimating the Prevalence of Autism Spectrum Conditions in Adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: The NHS Information Centre.

[16] Mandell, D et al (2009) Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders, Am J Public Health. March; 99(3): 493–498

[17] Keen DV, Reid FD, Arnone D. (2010) Autism, ethnicity and maternal immigration. Br J Psychiatry; 196: 274–81.

[18] Kuenzli, Jessica, "The Somali Community's Experiences with Autism: An Exploratory Study" (2012).Master of Social Work Clinical Research Papers. Paper 50. http://sophia.stkate.edu/msw_papers/50

[19] Fox, F. et al. J Autism Dev Disord (2016). doi:10.1007/s10803-016-2952-9

common amongst people with ASD. Roughly 40% have symptoms of at least one anxiety disorder at any time, compared with up to 15% in the general population. It is thought that a combination of factors, leading to vulnerability to stress, is likely to explain why anxiety disorders are so common in people with ASD[20].

2) What is the size of the issue in Bristol?

Local SCIN data:

The prevalence of SCIN has not been recorded or measured locally to date, and we must therefore rely on data for ASD. While estimates of ASD prevalence differ considerably, it seems to be widely agreed that it is realistic that around 1% of the population has ASD, diagnosed or undiagnosed. On the basis that there are around 123,500 children and young people aged 5-24 living in Bristol, we estimate that within this age group, there are likely to be around 1235 children and young people with Autism Spectrum Disorders (this figure does not include 0-4 year olds who are less likely to have been diagnosed). This figure relates to children and young people who have ASD, whether or not this is currently diagnosed. It is important to highlight that these figures relate to ASD only, and therefore figures relating to our wider definition of social communication and interaction needs will be higher.

There are a number of sources of data about children with ASD in Bristol, although none of them will provide a full and accurate picture. We must therefore use these different sources together to establish as accurate a picture as possible. We are currently unable to provide an accurate figure of the number of children and young people living with ASD in Bristol, we must therefore rely on the estimate of 1235 outlined above.

School Census:

The School Census is a statutory data collection for all maintained nursery, primary, secondary, local authority maintained special and non-maintained special schools, academies including free schools, studio schools and university technical colleges and city technology colleges in England. This data set does not currently include information from private schools, or about home educated children. This information from January 2016 identified 757 pupils in Bristol schools whose primary Special Educational Needs (SEN) need is ASD. This figure represents 8.6% of all pupils with an SEN need, and 1.3% of all pupils, with or without a SEN need[21] .

Gender:

The breakdown of School Census data shows a marked difference between the gender of pupils identified as having ASD, and that this difference has persisted over time:

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[20] Robertson, D., Galanopoulos, A., Spain, D. and Murphy, C (2014). Making Sense of anxiety and OCD. Your Autism Magazine, Vol 8(4), Winter.
[21] Bristol City Council. (2016). Bristol School Census. Available at: https://www.gov.uk/government/publications/school-census-2016-to-2017-guide-for-schools-and-las (Accessed: 03/10/16).
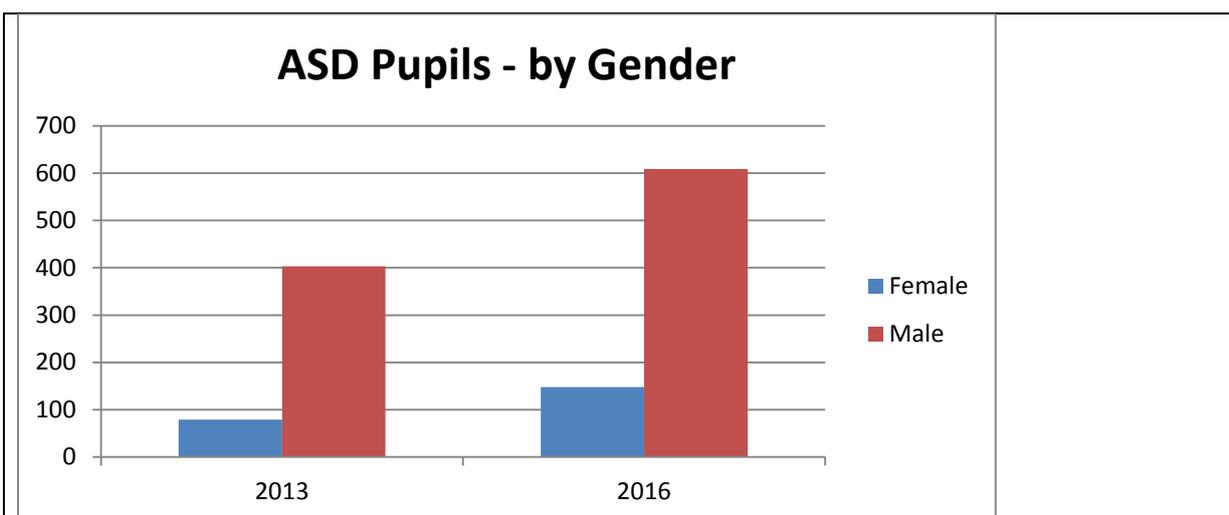
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Figure 2: Schools Census data 2013-16, ASD pupils by gender

Ethnicity:

The School Census data can be further broken down by ethnicity as demonstrated below:

Number of pupils with ASD by Ethnicity		
	2013	**2016**
Asian	27	44
Black	45	86
White	360	547
Mixed	37	58
Other	5	16

Table 1: ASD pupils by Ethnicity, Bristol School Census 2013-16

ASD as secondary need:

There are a further 105 children who have ASD recorded as their secondary need. The primary needs of those children are diverse and include speech, language and communication needs; social emotional and mental health needs; and learning difficulties.

Special Educational Needs Team:

The Bristol Special Educational Needs (SEN) team holds information about all children attending schools who have identified Special Educational Needs, which includes diagnosed ASD. These figures are likely to be a sub-set of the School Census figures covered above. The following figures show the number of school aged children with diagnosed ASD as their primary difficulty known to the SEN team in 2015-16:

	Number of children with ASD
Attending Bristol Schools (mainstream or special school)	592
Attending Out of Local Authority Area Schools	59
Total known children with ASD diagnosis	**651**

Table 2 Children with diagnosed ASD known to Bristol SEND team 2015-16

There are a further 431 children with Speech, Language and Communication Needs who may or may not fall into our definition of Social Communication and Interaction Needs.

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Table 5 does not include children attending Early Years settings across the city. Bristol City Council is aware of 47 children within this category, but it is worth highlighting that there may be further children of this age who have not yet received a diagnosis, or who are not attending an Early Years setting.

Nationally, Autism spectrum disorder is the most common need for those with a statement or EHC plan. More than a quarter of pupils (25.9%) with a statement of SEN or EHC plan in January 2016 had Autistic Spectrum Disorder listed as their primary type of need. This primary type of need is much less common in pupils with SEN support, with only 4.7% of pupils with SEN support having this type of need. This is reflected locally in Bristol where 21.3% of pupils with a statement of SEN or EHC plan in January 2016 had Autistic Spectrum Disorder listed as their primary type of need, and 4.8% of pupils with SEN support have this type of need. The majority (80.5%) of these pupils with a primary need of ASD are male.

The Hope Virtual School:
The Hope Virtual School looks after the education and learning of Bristol's children in care, and enables support to be put in place where needed. The HOPE school is aware of 28 Children in Care with SEND category 'Communication and Interaction'. These include 7 whose primary need is something else but secondary need is 'Communication and Interaction'.

Of these 28 children, 15 are at Bristol schools and 13 are in Out of Authority schools, 17 are at Special schools and 11 are in mainstream schools; and 17 are male and 11 are female.

Social Care:
In March 2016, there were 213 children with an ASD diagnosis receiving support from social care. Of these, the vast majority (178) are boys. This figure includes children whose disability means that they require support from social care, as well as children who are known to social care for other reasons, but happen to have ASD. It is likely that this figure is a sub-set of the SEN figure covered above, as fewer children reach the thresholds for requiring support from Social Care.

Youth Offending Team:
A study by the British Institute for Brain Injured Children found that "nearly 37% of youngsters in the sample of youth offending teams questioned were found to have conditions such as autism, attention-deficit hyperactivity disorder (ADHD) or a low learning age"[22] In Bristol's Youth Offending Team, there are currently 5 cases were the young person has a diagnosis of ASD, which represents 2.75% of the total caseload. However, it is likely that this is an under-estimate and the team are working on ensuring that this data is as accurate as possible.

Vulnerability:
A recent analysis[23] of the most vulnerable disabled children in Bristol, found that there were 124 children who had both special educational needs, and received free school meals. The primary needs of these 124 children were predominantly ASD and SLD (severe learning difficulties). In relation to income deprivation, 90 children (73%) are in the bottom 30% of comparable geographical areas in

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[22] BIBIC. (2007). BIBIC research on ASBOs and young people with learning difficulties and mental health problems. Available from: http://www.bibic.org.uk/newsite/general/pdfs/ASBOandYOTsummary.pdf (Access 29/08/16).
[23] Analysis of School census data, unpublished, Bristol City Council, 2016

England. Reflecting the gender breakdown above, 87 of those 124 are boys and 37 are girls.

Continuing Health Care:
A small number of social care or education placements are joint funded by health through continuing health care funding, alongside social care and/or education. A March 2016 snapshot of children and young people who are NHS CAMHS in-patients, showed that at that point in time, this cohort included fewer than 5 children with ASD.

3) What are the relevant national outcome frameworks indicators and how do we perform?

Unlike other areas of health and social care, there are no known national indicators covering this specific area for benchmarking purposes. ASD is not included is the Public Health Outcome Framework, NHS Outcome Framework, or the Adults Social Care Outcomes Framework.

The Autism Self-Assessment Framework looks at the progress being made in implementing the Adult Autism Strategy. Local authorities are asked to co-ordinate local responses, and are asked to seek views from local partners, particularly health care partners, and include people with autism and their families. This Self-Assessment is very heavily focussed on the response to the needs of adults, rather than children and young people.

4) What is the evidence of what works (including cost effectiveness)?

When an autism spectrum disorder is diagnosed, families and carers and the child or young person themselves can experience a variety of emotions, shock and concern about the implications for the future. They may also have a profound sense of relief that others agree with their observations and concerns. Diagnosis and the assessment of needs can offer an understanding of why a child or young person is different from their peers and can open doors to support and services in education, health services and social care, a route into voluntary organisations, and contact with other children and families with similar experiences. All of these can improve the lives of the child or young person and their family.[24] It is therefore important to recognise that the support needs of those who have not received a diagnosis will be different, and may be compounded by a feeling of not having had their concerns validated. Nevertheless, the majority of guidance relating to this area of work relates specifically to the diagnosis and support of those who have received a diagnosis.

NICE guidance
The National Institute for Health and Clinical Excellence (NICE) is responsible for providing national guidance on treatments and care for people using the NHS in England and Wales. NICE have published two sets of guidance relevant to this review: Autism in under 19s: recognition, referral and diagnosis. [CG128] Sept. 2011 and Autism in under 19s: support and management [CG170] August 2013; which set out good practice in the recognition and support for children with Autism. A third

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[24] NICE guidelines [CG128]; Autism in under 19s: recognition, referral and diagnosis, 2011

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set of guidelines relating to autism and behaviour that challenges s is also available and relevant to this review[25].

5) What services / assets do we have to prevent and meet this need?

Services to support children and young people with ASD or undiagnosed social communication and interaction needs are varied and diverse. Services cover different geographical areas, age ranges, and some require a diagnosis in order to be able to access them, while others don't. The majority of non-statutory services do not require a diagnosis, although there are some notable exceptions, specifically those offering more targeted support. Geographically, our research suggests that the majority of services offer a citywide service, although their physical location may still be a barrier to access.

Education – Early Years
Support for children in Early Years includes Early Years Practitioners, Early Years Inclusion & Portage support, Early Support Development Workers, Speech & Language Therapy Service, and Specialist Children's Centres. A snapshot of Early Years settings in April 2016, showed that there were at that point 47 children in early years settings with diagnosed ASD. The total budget for supporting all children (not specifically ASD) in Early Years settings with SEN in 2015-16 was £1,476,700.

A small number of children in Early Years settings with high levels of SEND may not make reasonable progress despite support through arrangements made as part of core funding (Element 1 and Element 2). All Early Years Settings may apply for additional funding for consideration by the Early Years Special Educational Needs Panel. The panel meet on a monthly basis and includes representatives from the Early Years Service, SEN Team, Educational Psychologist, Health Colleagues, Early Years SENCO and Specialist Children's Centres.

Education – Schools:
Funding allocated to schools enables early intervention and appropriate provision for all pupils with Special Educational Needs and Disabilities. In exceptional circumstances, there may be a need to apply for additional funding (Top up) or an 'Education Health and Care Plan (previously referred to as a 'Statement of SEN') in order to support the learning needs of the child or young person.

When a school can demonstrate that they have made effective use of funding available through Element 1 (school's core budget) and Element 2 (school's notional SEN budget) and that a pupil still requires additional support, they may apply for High Needs Band Funding, Element 3, in order to provide the additional support required. Based on the individual child's needs, a Band is assigned. Regular monitoring of pupil progress, and evaluation of effectiveness of support must be evident against all bands.

The following figures show the number of school aged children with diagnosed ASD known to the SEN team in 2015-16:

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[25] Local Government Association. (2014). Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges. Available at: http://www.local.gov.uk/documents/10180/12137/L14-105+Ensuring+quality+services/085fff56-ef5c-4883-b1a1-d6810caa925f (Accessed: 11/07/16).

	Number of children with ASD
Attending Bristol Schools (mainstream or special school)	592
Attending Out of Local Authority Area Schools	59
Total known children with ASD diagnosis	**651**

Table 3 Number of school aged children with diagnosed ASD known to the SEN team in 2015-16

The total amount spent in 2015-16 on this cohort of children attending Bristol schools was £5,652,332. The average funding amount per pupil was £9,547. Around 60% of these children fall within Bands 0-3, and their education setting was therefore entitled to up to £10,000 per child. There are however, a handful of children whose education setting receives a much higher amount of funding towards their support.

During this year, 15 children's education placements cost in excess of £25,000. These ranged between £30,179 and £186,698. In 2015-16, there were 59 children with ASD attending schools outside Bristol. The total amount spent on children with ASD attending schools outside Bristol was £1,852,421. The average funding amount per pupil was £31,396.

Social Care:
The ASD specific elements of Bristol's Social Care support include the Bristol Autism Team, Courses for parents of children with ASD, ASD related direct payments, and the Bristol Autism Project home support and short breaks service. The total cost of these aspects in 2015-16 was £957,977.

Based on a snapshot of Bristol City Council's social care database (LCS), in March 2016, there were 13 children who were Looked After Children (LAC) and also had diagnosed ASD. It is likely that this is an under-representation and that in reality more Looked After Children have ASD, but that these cases have not been recorded accurately on LCS. These 13 children were placed in a mixture of residential schools, foster care placements, group homes, and NHS in-patient provision. The cost of accommodating children in residential schools costs between £3,779 and £4,905 weekly. The cost of foster care placements depends on the individual arrangements.

Health and Mental Health:
The support available through health and mental health services for children with ASD includes Paediatrics, Speech and Language Therapy, Occupational Therapy, Physiotherapy, Specialist Service for Children with Learning Difficulties (SSCLD), Bristol Autism Spectrum Service, and CAMHS.

A March 2016 snapshot of children and young people who are NHS CAMHS in-patients, showed that at that point in time, this cohort included fewer than 5 children with ASD. The in-patient day rate is estimated to be around £547. Based on the length of stay of the identified children, the combined estimated cost of these placements to March 2016 was around £700,000.

Non-statutory services:
There are various non-statutory services that can support children and young people with ASD and their families, largely provided by voluntary sector organisations. These include Bristol Parent Carers, National Autistic Society (NAS) Bristol Branch, Supportive Parents, Bristol Autism Support, Butterflies Haven, Autism Independence, Contact A Family, Time2Share, KIDS, and a range of short breaks.

The table below shows the money spent on targeted short breaks for disabled children by Bristol

City Council. As these services are not ASD specific, the estimated amount of that funding spent specifically on children with diagnosed ASD is also shown, based on the percentage of children with ASD accessing those services between June and December 2015. This will not be an accurate representation of spend as funding is not utilised as simply as this portrays, it should therefore be used as an estimate only:

Provider	Service	Annual funding 2015-16	% children with ASD	£ on ASD CYP
Action for Children	Residential Holidays	£75,000	56%	£42,000
WECIL Consortium	Activities, Befrienders & BME Services	£230,000	40%	£92,000
Barnardos	School Based Holidays	£100,000	13%	£13,000

Table 4 Funding for Short Breaks for Disabled Children

It is not possible to accurately calculate the total amount of money spent diagnosing and supporting this cohort of children. However, the information we have collected demonstrates that across education, social care, and health, a significant amount of funding is being spent on a small number of children. While these children may have significant support needs which require this level of funding, it is also worth questioning whether support at an earlier stage could have avoided some of these costs.

More information about services and how to access them can be found on the Findability website http://www.findabilitybristol.org.uk/

6) What is on the horizon?

Population change
With a growing child population, and increasing diagnoses of ASD, it is clear that demand for support services is going to continue to increase over the coming years. Based on Bristol's population projections and the estimated 1% of the population with potentially diagnosable ASD, by 2037 it is projected that there will 1772 children and young people with diagnosable ASD in the city.

School places
Schools are feeling particularly stretched by this increase and have experienced a particular growth in numbers of children with Social, Emotional and Mental Health needs; Autism Spectrum Disorders; Speech, Language and Communication needs (SLCN); complex needs and Multi-Sensory Impairment (MSI). As a result the current 'maintained' capacity is already full and by 2019 there is a projected shortfall of 128 specialist places (12%) across all need types and ages, and a predicted shortfall of 52 specialist places for children with ASD[26]. This is being addressed by the Integrated Education and Capital Strategy[27].

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[26] Bristol City Council. (2015). The Integrated Education and Capital Strategy (2015-2019). Available at: http://bristollearningcity.com/wp-content/uploads/2016/02/BD7807-Education-Strategy-Summary-WEB.pdf (Accessed: 15/03/16).
[27] Ibid

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7) Local views

The review of services and pathways for children and young people with Social Communication and Interaction Needs is governed by a multi-agency stakeholder group who have informed the direction of the review, and ensured that the voice of various different stakeholders is heard including parents, carers, schools, voluntary and public sector organisations. This group's aim is to improve the experience and outcomes of Bristol's children and young people with social communication and interaction needs including autistic spectrum conditions who require support and services. By ensuring that the governance of this review is a multi-agency project, local views have been included throughout the process.

Analysis of the feedback gained through a variety of engagement activities (including a participation event with parent carers specifically for the purpose of this review, and engagement undertaken for the Teenage Life review; Speech, Language and Communication Therapy Review; Early Bird and Early Bird+ review; Bristol Autism Support Member's Autism Diagnosis Experience Survey; Bristol Parent Carer's 'South Asian' day and re-commissioning of Community Children's Health Service) highlighted the following common priorities across different service areas:

- Training for professionals across sectors to improve awareness and knowledge of ASD/SCIN

- Information for parents of available services, suitability for individual children, how to access them, pathways into and through services

- Communication with parents

- Support for parents and wider families pre/during/post diagnosis

- Geographical consistency of services

- Needs led services, not diagnosis led

B: What does this tell us?

8) Key issues and gaps

Needs led services for those with or without a diagnosis
The information gathered for this needs assessment has shown us that there is a significant number of children and young people in Bristol who have been diagnosed with ASD, and that there is likely to be a further group of children and young people who have a range of social communication and interaction needs. The needs of these children are diverse and vary in complexity and severity. For this reason, some children require much more intensive support than others. At the highest end of the range of needs are those children who require support from social care and/or are accessing education, social care or health placements in Bristol, or sometimes outside Bristol.

Gender
While the prevalence of SCIN has not been recorded or measured locally to date, and we have therefore had to rely on data for ASD, this information does provide us with some useful knowledge. There are significantly more boys than girls who have been diagnosed with ASD, which reflects

national patterns of diagnosis, although it is unclear whether this is due to a variation in prevalence or a lack of recognition of how symptoms may present differently in women and girls.

Additional needs

We also know that many of the children and young people this needs assessment is concerned with have additional needs such as speech, language and communication needs; social emotional and mental health needs; and learning difficulties. At the highest end of the needs spectrum, of those children supported by social care, two thirds have more than one disability.

ASD and Education and Health Care Plans

Nationally, Autism Spectrum Disorders are the most common need for those with a statement or Education and Health Care (EHC) plan. More than a quarter of pupils (25.9%) with a statement of SEN or EHC plan in January 2016 had Autistic Spectrum Disorder listed as their primary type of need. This is reflected locally in Bristol where 21.3% of pupils with a statement of SEN or EHC plan in January 2016 had Autistic Spectrum Disorder listed as their primary type of need, and 4.8% of pupils with SEN support have this type of need. The majority (80.5%) of these pupils with a primary need of ASD are male.

Increase in need over time

We know that demand for service has increased over time, and the number of children identified by the School Census as having been diagnosed with ASD reflects this. With a growing child population, and increasing diagnoses of ASD, it is clear that demand for support services is going to continue to increase over the coming years. Based on Bristol's population projections and the estimated 1% of the population with diagnosed ASD, by 2037 it is projected that there will 1772 children and young people with diagnosed ASD in the city.

Complex landscape of support services

Services to support children and young people with ASD or undiagnosed social communication and interaction needs in Bristol are varied and diverse. Services cover different geographical areas, age ranges, and some require a diagnosis in order to be able to access them, while others don't. Furthermore, some services have thresholds or eligibility criteria in place to manage access, while others don't. Our analysis of the range of services available, alongside the information gathered from parents, carers and other stakeholders highlighted a range of issues in relation to how services are currently provided. Information about the range of services is not readily available or clear enough for families to understand; communication with families throughout their diagnosis journey and beyond could be improved; professionals in mainstream services should have a comprehensive understanding of SCIN and the services available to support children with these needs; there is a real or perceived inconsistency in the support available across the different parts of Bristol which needs to be reviewed; and crucially, support should be available on the basis of identified need rather than simply whether or not a child has a diagnosis of ASD. As a result of this, we have identified a need to review children's journey through services, and how they and their families are made aware of and can access services. It is clear that increasing demand for services is a further challenge which must be considered as part of this review.

Prevention of high cost placements

This needs assessment has also highlighted that a significant amount of funding is spent on the

support needs of a small number of children with complex and severe needs in high cost education, social care and health placements. We therefore need to understand more about the needs of these children and the circumstances that led to their current situation in order to be able to propose ways that similar escalation of needs and costs could be avoided, and outcomes improved for children and young people in the future.

9) Knowledge gaps

- ASD data - there is no single definitive database of children and young people with a diagnosis of ASD in the city. All figures are therefore estimates only
- Lack of data held by health services - diagnostic health services do not currently collate the number of children referred to them for ASD assessments, or the number of diagnoses made
- CAMHS have told us that they don't record the number of children currently being supported with ASD, or the number of children referred to them with ASD
- Need for an outcomes framework - as ASD is not part of a national outcome framework, comparative data from local authorities is not routinely published, making benchmarking challenging
- No data relating to this review's wider definition of SCIN is collected; we have therefore had to extrapolate from the various sources of data relating to ASD.

C: What should we do next?

10) Recommendations for consideration

As a result of this needs assessment, and in particular the engagement activities that took place to understand how well services are currently catering to the needs of children with SCIN, the following principles have been developed which we believe represent the feedback received from parents, carers and other stakeholders. We anticipate using these principles as a guide as we begin the next stage of this review:

1. Services should be needs led, not diagnosis led
2. Information and communication with parents, service users and carers should be clear and accessible
3. Professionals should be knowledgeable about Social, Communication and Interaction Needs including ASD and the support available
4. Services should be joined up and work together wherever possible
5. Families need support throughout the journey: before diagnosis, during diagnosis, and after diagnosis
6. Available support for each age group, and pathways through services should be consistent across the city according to need
7. Appropriate support should be identified at the earliest opportunity to avoid escalation of needs

Further recommendations for consideration are:

a) To explore the potential for a single database of children with ASD to be established in order to enable us to accurately project the number of children and young people requiring support across services

b) That health services who do not currently collect data on this cohort of children begin to do so in order to inform the development of services

c) That the broader definition of 'Social Communication and Interaction Needs' is considered alongside Autism Spectrum Disorders when designing services for this group of children and young people in order to ensure that services can become as needs led as possible

Next Steps:

The SCIN Review Group will be using the information collected in this document to inform the development of services and the way support is offered to children and young people with Social Communication and Interaction Needs.

Work is already underway to begin to make improvements to the support available, including:

- Community Children's Health Recommissioning – this service is being recommissioned, reflecting the principles outlined above

- A pooled budget between NHS Bristol CCG and Bristol City Council for Autism Support has been established to enable the joint commissioning and delivery of support to Parent/Carers of children with SCIN. These services have been recommissioned and are now provided within the birth to 25 service. Further review of the model of delivery is underway, with the aim of aligning with the above principles.

The following next steps have been identified to further the progress of this review:

a) Undertaking a deep-dive exercise to identify the most costly education, social care and health placements, and the needs of those young people. The aim of this exercise will be to identify any opportunities for intervening earlier or differently with the objective of improving outcomes for individual children and young people, and reducing costs

b) Identifying further opportunities for service redesign and improvement based on the above principles

c) Developing a clear, comprehensive whole system pathway.

11) Key contacts

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