Croydon Joint Strategic Needs Assessment 2009-10

Children with special educational needs & disabilities

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Summary of key findings

With over 58,000 pupils, Croydon has the highest school population of the London boroughs, with 22.6% of pupils in primary schools and 18.5% of pupils in secondary schools known to be eligible for free school meals.

Croydon has a very ethnically diverse school population, with 54% of pupils in primary schools and 51% of pupils in secondary schools coming from black and minority ethnic groups. There are links between deprivation and special educational needs and disability, which has implications for focusing service delivery.

A higher percentage of children and young people in Croydon's mainstream primary and secondary schools require additional support for special educational needs than the England average. This is particularly the case in secondary schools.

Croydon has 1,669 pupils with statements of special educational needs. A large number of children with special educational needs are placed in schools outside the borough, often with higher placement costs. Capacity needs to be increased to help meet these needs in local schools.

The most prevalent type of primary need amongst pupils with statements of special educational needs or at *school action plus* in maintained primary schools, is speech, language and communication needs; in maintained secondary schools it is behaviour, emotional and social difficulties. In out of borough independent and non-maintained special schools, severe learning difficulties are the most common need.

A significant number (almost 1000) of Croydon's children and young people in the mainstream school system have speech, language and communication as their primary areas of need. Other children and young people have speech, language and communication needs but their primary need may be a physical disability or sensory impairment. This may mean that their speech, language and communication needs are not identified or addressed.

1.3% of the child population of Croydon is registered as disabled, most commonly for communication disorders including autistic spectrum disorders. The incidence of some disabilities is increasing, particularly the number of children with autistic spectrum disorders, complex health needs and palliative care needs.

Children and young people with autistic spectrum disorders form a significant group of approximately 700 in Croydon, with varied and complex needs which require multiagency support. The prevalence of autistic spectrum disorders in the UK child population is estimated to be about 1%.

A study undertaken by the Thomas Coram research unit (2008) estimated that 1.2% of England's child population has severe and complex disability. This includes severe learning and physical disability, autism, challenging behaviour, or a serious chronic health condition. This would equate to approximately 1000 children in Croydon. This is the group targeted through the *aiming high for disabled children* short breaks programme.

Children with disabilities and complex health needs, supported through the *continuing care* and the *early support* programmes, are increasing in number and require a multi-agency approach.

Children and young people with mental health needs, attention deficit hyperactivity disorder or challenging behaviour with disabilities, have considerable needs which can result in their being excluded from school, or ending up in high cost, distant, residential care. A virtual team approach is being implemented to help meet these needs.

There is a challenge to ensure high quality transition for children with special educational needs and disabilities when they move from children's services into adulthood and the need for adult services. This is being addressed by the *transitions transformation* programme.

A significant number of disabled children who are looked after by the local authority are placed in residential provision or foster placements which are out of borough. The aim of all services should be to prevent accommodation in residential or foster care. For those children where remaining at home is not possible, alternative provision within the borough needs to be developed.

Parents, children and young people have been asked for their views on service provision in a number of ways. Parents stressed the importance of information; access to support services, especially therapies; the need for better service integration; short breaks; and transport. Children and young people wanted access to a range of activities; to feel safe; and to be treated the same as other children.

Recommendations

Croydon's Children's Trust should:

1. Develop a joint commissioning strategy which focuses on meeting the therapy needs of children and young people.
2. Make therapies more available, more accessible and more ordinary by developing the skills of the workforce to identify and meet the therapeutic needs of children and young people.
3. Ensure service development focuses on building capacity through the *transforming Croydon schools* programme, to help families, schools and other community settings play a proactive role in meeting the speech, language and communication needs of their children. This would help reduce dependence on the medical model of specialised one to one treatment by experts, and support a more inclusive user friendly approach, enabling homes, schools and other settings to become language friendly environments.
4. Respond to the *Bercow review* on children and young people with speech, language and communication needs, by working on a joint action plan. This may also help improve outcomes for children and young people who present as having challenging behaviour or are not currently in education, training or employment.
5. Develop a joint action plan to meet the needs of children and young people with very complex and palliative care needs.
6. Develop a joint children and adolescent mental health strategy linked to targeted mental health promotion and service provision in schools.
7. Jointly develop a systematic approach to information systems to enable comprehensive data sharing and provide tools to monitor and evaluate performance.
8. Ensure the *aiming high for disabled children* transformation programme entails joint work and match funding to implement the *aiming high* project for short breaks and extended activities and the *early support* programme. It should also involve joint work to progress the *every disabled child matters* charter.
9. Develop a strategy for children and young people with autism.
10. Develop joint provision that is focused on early intervention and prevention in order to enhance the five outcomes for babies, children and young people set out in *every child matters*.
11. Develop and promote the use of the *common assessment framework* across the children's workforce and strengthen integrated working in line with the children's trust.
12. Enhance and develop additional school and recreational provision for children and young people with special educational needs and disability.

13. Work with schools and in other settings to enable them to build their capacity to be more inclusive of children with special educational needs and disability.
14. Work with parents and families through the *parental support* strategy, to enhance parental confidence and opportunities to become engaged and participate in service development, delivery and review.
15. Work on engaging children and young people in strategic design and delivery of provision.
16. Continue to develop the virtual team approach for children and young people with autistic spectrum disorders, learning disabilities with challenging behaviour and attention deficit and hyperactivity disorders.
17. Develop a transition policy and strategy to ensure that all young people who require transition planning from 14 years old (school year 9) onwards know what goals, actions and progress need to be achieved in the immediate and longer term.

Families, carers and teachers should:

18. work in partnership with therapists to develop relevant interventions in the school and home setting, enabling a seamless approach to meeting children and young people's needs.

Introduction

This chapter presents an assessment of the needs of children and young people with special educational needs and disabilities in Croydon in order to improve their outcomes and experiences. It aims to:

- Provide evidence of unmet need which will be used to influence Croydon's inclusion strategy and future action plans.
- Identify existing services and the way they are used.
- Identify the future needs of the community.
- Provide a framework for the commissioning of services across Croydon children's trust.

The overall aim is that children and young people with special educational needs and disabilities will have improved health, independence and wellbeing so that they will enjoy childhood, achieve their potential and make a positive contribution in their community by having timely access to local support and local schools which meet their needs.[1]

Definitions

Special educational needs

Children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them.

Children have a learning difficulty if they:

a) have a significantly greater difficulty in learning than the majority of children of the same age; or

b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority

c) are under compulsory school age and fall within the definition at (a) or (b) above or would so do if special educational provision was not made for them.[2]

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[1] Department of Health (2006). Our health, our care, our say: a new direction for community services. DOH: London.

[2] Department for Education and Skills (2001). Special educational needs code of practice. London: DfES Publications.

Special educational provision means:

a) for children of two or over, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of their age in schools maintained by the local education authority, other than special schools, in the area.

b) for children under two, educational provision of any kind.[3]

Around one child in five will have a special educational need at some point during their education, but not all need the same level or kind of support.[4] Some children may be able to catch up with their peers with extra help in the form of short term targeted interventions or a differentiated curriculum, but may not have a special educational need. It is when this support does not help a pupil to progress that he or she will need to be assessed further and support planned, in liaison with parents, carers and other professionals. The child should have a voice in this process. There is a graduated approach to identifying and providing support to meet these needs.

- *School action:* the school is able to meet the pupil's needs with in house interventions, staff and resources.
- *School action plus:* the school is able to meet the pupil's needs with in house resources but has support from outside agencies, for example, the local authority's educational psychologist.
- *Statement of special educational needs:* the pupil's needs are severe or complex enough to require additional funding and resources to supplement the school's support.

Referrals for statutory assessment can be made by the child's school or setting, a parent, or an agency such as a health authority or social services department, and the process is described in the special educational needs code of practice.[5]

Disability

An impairment that has a long term and substantial effect on a child's ability may amount to a disability.[6] This may include sensory impairments, such as those affecting sight or hearing, or hidden impairments such as dyslexia, autism, speech and language impairments, and attention deficit hyperactivity disorder.[7]

Children or young people with medical needs such as diabetes or epilepsy would also be considered to have impairment and therefore be disabled if he or she:

a) relies on medical treatment or aid in order to able to be able to carry out normal day to day activities (except needing to wear glasses or contact lenses).

b) has a progressive condition (such as cancer, multiple sclerosis, muscular dystrophy or infection); or

c) has a severe disfigurement which affects normal day to day activities.[8]

Government guidance states that, 'for planning purposes and for avoidance of discrimination, it may be helpful to think of more pupils with special educational needs being included within the definition of disability rather than fewer. It is likely that many of the pupils who have special educational needs and a statement, or who are at *school action plus*, will count as disabled.'[9]

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[3] Department for Education and Skills (2001). *Special educational needs code of practice.* London: DfES Publications.

[4] ibid.

[5] ibid.

[6] Department for Children, Schools and Families (2006). *Implementing the Disability Discrimination Act in schools and early years settings.* Nottingham: DCSF Publications.

[7] Disability Rights Commission (2006). *The Duty to promote disability equality.*

[8] ibid.

[9] Department for Children, Schools and Families (2006). Implementing the *Disability Discrimination Act in schools and early years setting,* Nottingham: DCSF Publications.

Legal entitlements

The rights of children and young people with special educational needs and disability are set out in the Disability Discrimination Act 2005[10]. This includes the right to have their needs met without having to wait for a diagnosis. Equally a diagnosis alone does not mean that a child is covered by the act. It is the effect on a child's ability to carry out day to day activities that has to be considered.

The Special Educational Needs and Disability Act (2001)[11] strengthened the right of children and young people with special educational needs to equality of access to education, and in particular, to a mainstream school. It conferred a statutory duty on local authorities and schools:

- not to treat disabled pupils less favourably for a reason related to their disability.
- to make reasonable adjustments for disabled pupils, so that they are not at a substantial disadvantage to those who are not disabled.
- to plan strategically and make progress in improving accessibility for disabled pupils over time, by:
    - increasing access to the curriculum
    - making improvements to the physical environment of the school to increase access to education and associated services
    - making written information accessible in a range of different ways for disabled pupils, where it is provided in writing for non-disabled pupils.

Local authorities and schools are required to develop accessibility strategies and plans to demonstrate this.

Children and young people with special educational needs and disability also have a right to have their disability equality positively promoted. Local authorities, schools and educational settings have a duty to 'take a more proactive approach to promoting disability equality and eliminating discrimination.'[12] With this came the requirement to publish disability equality schemes and measure their impact, engage disabled stakeholders, and audit the needs of disabled children and adults within the community.

National context

National evidence shows that despite their legal entitlements, the needs of many children and young people with special educational needs and disability are not being met. This evidence includes:

- Every child matters, 2003
- Removing barriers to achievement, 2004
- Report of the Education and Skills Select Committee on special educational needs, 2006
- Aiming high for disabled children 2007 to 2011
- The Bercow review of children with speech, language and communication needs, 2008
- The Lamb inquiry, 2009.

Further details are contained in Appendix 1.

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[10] *Disability Discrimination Act* (2005). The Stationery Office.

[11] Special Educational Needs and Disability Act (2001). The Stationery Office.

[12] Disability Discrimination Act (2005). The Stationery Office.

These reviews highlight three key issues for children and young people with special educational needs and disability:

1. The links to social disadvantage.
2. Implementation of the special educational needs code of practice.
3. Difficulties with access to services.

Links to social disadvantage

According to the Bercow review approximately 50% of children and young people in socio-economically disadvantaged populations have speech, language and communication skills that are significantly lower than those of other children of the same age.[13]

National research and surveys such as *Improving life chances of disabled people*[14], and Mencap's *Breaking point*[15] highlight the difficulties experienced by families with disabled children.

Children with disabilities have poorer outcomes across a range of indicators. These include lower educational attainment, poorer health, more difficult transitions to adulthood and poorer employment outcomes. Families of disabled children are less likely to have one or both parents in work, and are more likely to suffer family break up. Siblings of disabled children may be more likely to suffer from emotional and behavioural problems.[16]

Families with disabled children are also more likely than other families to be living in bad housing.[17] This can mean that they are left unable to meet the child's basic needs, such as playing, joining in with family life and moving around the house and make them more dependent on external care and support services.[18]

A recent SCOPE survey investigating the experience of families with disabled children concluded that 'without support, all families with disabled children are currently fated to remain at a disadvantage.'[19]

The reports above highlight the need for improved opportunities for inclusion in a range of activities taken for granted by non-disabled children, particularly for children with complex health needs and challenging behaviour. These include having equal access to play, leisure, cultural and social activities; being able to express their views, make informed choices, and participate in decisions that affect their care.

Implementation of the special educational needs code of practice

Although outcomes for children feature in the special educational needs code of practice, the actual implementation of the code has been based on the process of identifying and responding to needs, rather than focusing on progress and outcomes for the child.

However, with the *every child matters*[20] agenda, there has been a shift to focus on children's outcomes. This sits alongside the refocus within education from process to progress and the desire to situate the needs of children and young people with special educational needs and disability at the heart of school improvement.[21]

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[13] Bercow, J. (2008). The Bercow Report: *A review of services for children and young people (0-19) with speech, language and communication needs.* Nottingham: DCSF.

[14] Prime Minister's Strategy Unit (January 2005) *Improving the life chances of disabled people - final report.*

[15] Mencap (2003). *Breaking point; a report on caring without a break for children and adults with severe or profound learning disabilities.* Mencap, London.

[16] ibid.

[17] Every disabled child matters (2008). *Disabled children and housing,* EDCM: London.

[18] Prime Minister's Strategy Unit (January 2005). *Improving the life chances of disabled people - final report.*

[19] Scope (2009). *Disabled families in flux: removing barriers to family life; disablism audit 2009,* Scope: London.

[20] Department for Education and Skills (2003). *Every child matters.* London: DfES Publications.

[21] Department for Education and Skills (2009). *Lamb inquiry special educational needs and parental confidence.* Nottingham: DCSF Publications.

The Lamb inquiry was established following the recognition of the lack of parental confidence in the special educational needs system. Its purpose was to investigate a range of ways in which parental confidence in the special educational needs system of assessment and provision might be improved. It found a thin evidence base when Ofsted inspectors made judgments about how well a school was meeting the needs of children and young people with special educational needs and that parents had little access to information and difficulty in getting provision for their children. It recommended that parents should have more input into Ofsted inspections and a wider remit to make complaints and that the Department for Children, Schools and Families should bring together information on the effectiveness of provision and parental satisfaction from a wide range of sources.

The Lamb inquiry focused on the quality and clarity of statements of special educational needs. It concluded that 'the education system as a whole is insufficiently focused on objectives and outcomes for disabled children and children with special educational needs. This is a long standing and deep seated cultural problem that has its origins in an era before all our children were entitled to education in schools.'[22]

The Bercow review of provision for children and young people with speech, language and communication needs has also highlighted the fact that parents experience difficulties in getting their child's needs met.[23]

Access to services

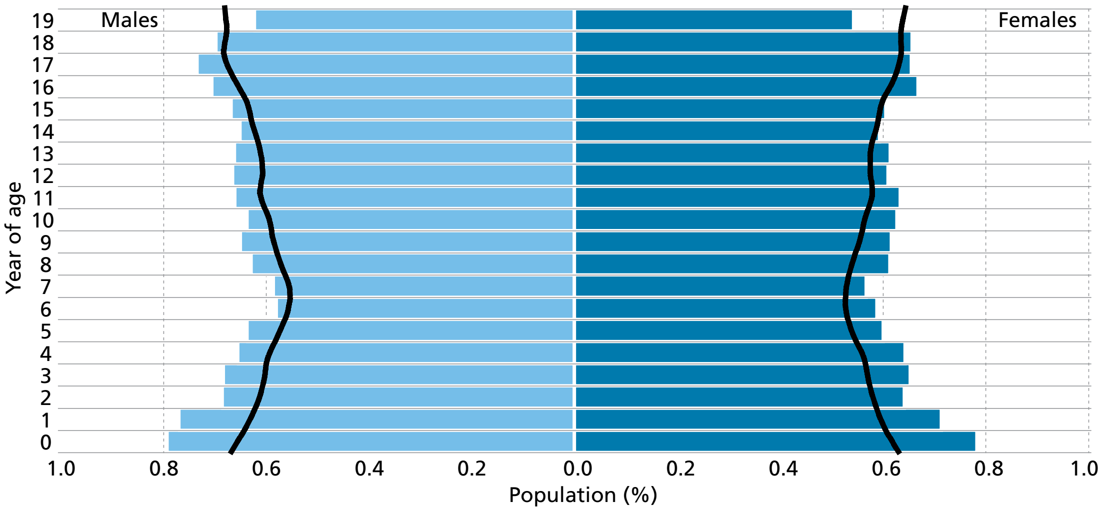
Removing barriers to achievement (2004)[24] highlights the inaccessibility of services for children and young people with special educational needs. Specifically that:

- too many children wait too long to have their needs met
- families face unacceptable variations in the level of support available from their school, local authority or local health service.

Croydon context

In 2008 there were 88,878 children and young people aged 0 to 19 years living in Croydon. This is 26% of the total population and the largest population of children and young people in London.[25] Figure 1 shows the age distribution of children in Croydon in comparison to England (represented by black lines).

Figure 1: Distribution of children in Croydon in comparison to England, 2008



Source: Office for National Statistics (ONS) mid-2008 population estimates, August 2009

[22] ibid.

[23] Bercow, J. (2008). The Bercow report: a review of services for children and young people (0-19) with speech, language and communication needs. Nottingham: DCSF Publications.

[24] Department for Education and Skills (2004). Removing barriers to achievement: the Government's strategy for special educational needs. Nottingham: DfES Publications.

[25] Office for National Statistics (ONS) mid-2008 population estimates, August 2009.

The index of child wellbeing was created by the Department of Communities and Local Government to measure how well children are doing in the major areas of a child's life that have an impact on child wellbeing.[26] The index is comprised of seven domains with equal weightings:

1. Material wellbeing; this domain aims to capture the proportion of children aged 0 to 15 who are living in low income households.
2. Health; focuses on illness, accidents and disability as represented by the use of health services and uptake of disability benefits.
3. Education; includes a variety of education outcomes including attainment, school attendance and destinations at age 16.
4. Crime; represents a measure of personal or material victimization.
5. Housing; represents the housing circumstances of children in terms of access to housing and quality of housing.
6. Environment; captures aspects of the environment that affect children's physical wellbeing (health, exercise, and safe, independent mobility).
7. Children (at risk of being) in need; reflects the expected rate of children in need.

Figure 2 shows the distribution of child wellbeing across Croydon. The most deprived 15% of super output areas in terms of the index of child wellbeing are in the north and south east of the borough. This link between deprivation and special educational needs[27] and disability, has implications for service delivery. There is a need to focus resources to help counteract social and economic disadvantage in the more deprived areas of the borough.

With over 58,000 pupils Croydon has the highest school population of the London boroughs, and 22.6% of primary school pupils and 18.5% of secondary school pupils are known to be eligible for free school meals.[28] Entitlement for free school meals is used as a proxy indicator for deprivation.

Croydon has a very ethnically diverse school population, with 54% of pupils in primary schools and 51% of pupils in secondary schools coming from black and minority ethnic groups[29].

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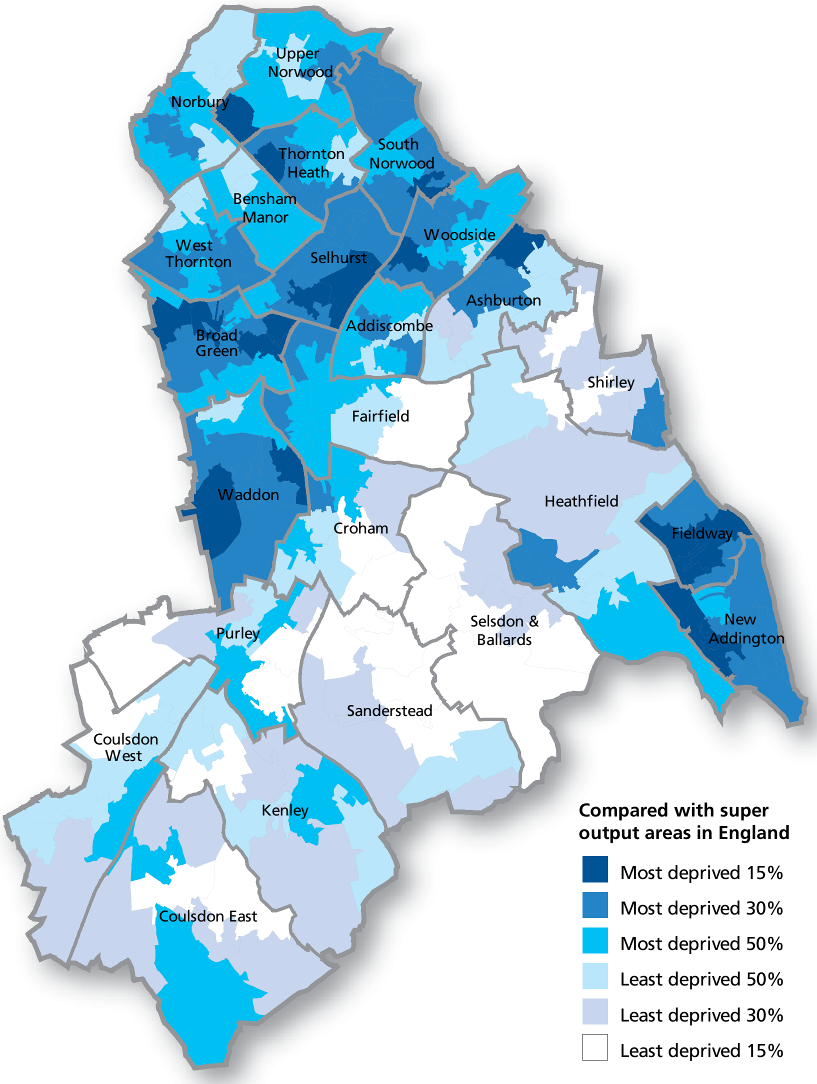
[26] Department of Communities and Local Government, Local index of child wellbeing 2009.

[27] Bercow, J. (2008). *The Bercow report: a review of services for children and young people (0-19) with speech, language and communication needs.* Nottingham: DCSF Publications.

[28] Department for Children, Schools, and Families (2009). *Special educational needs in England statistical first release 14, January 2009.* Includes pupils aged 15 or under who have full time attendance and pupils who have part time attendance and are aged between 5 and 15.

[29] Ibid.

Figure 2: **Index of child wellbeing 2009, Croydon super output areas**



Source: Department of Communities and Local Government, local index of child wellbeing 2009

Children and young people with special educational needs

Children and young people with special educational needs in Croydon schools

At January 2009 there were over 11,000 children and young people with special educational needs registered in Croydon schools,[30] and almost 200 placed outside the borough in day and residential schools.[31]

At January 2009 Croydon maintained 1,669 pupils with statements of special educational needs.[32] This includes children with statements in all educational provision including non-maintained, independent, special, and out of borough schools. The figures below relate only to those pupils in maintained primary and secondary schools.

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[30] Department for Children, Schools, and Families (2009). *Special educational needs in England statistical first release 14, January 2009.*

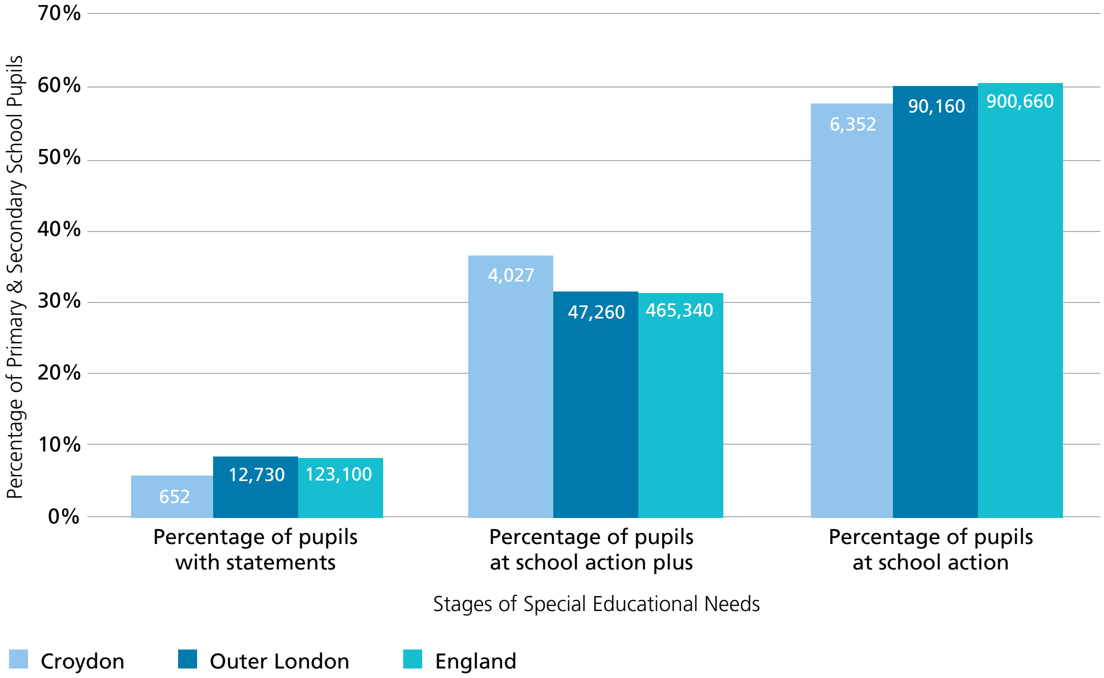
[31] London Borough of Croydon 'ONE System' educational data, May 2009.

[32] Department for Children, Schools, and Families (2009). *Special educational needs in England statistical first release 14, January 2009.*

Figure 3 shows that of the pupils with special educational needs:

- 57.6% (6,352 pupils) were at the *school action* stage of the special educational needs code of practice. This compares with 60% in outer London and 60.5% in England.
- 36.5% (4,027 pupils) were at the *school action plus* stage of the special educational needs code of practice. This is higher than the 31.5% in outer London and 31.2% in England.
- 5.9% (652 pupils) had statements of special educational needs. This proportion is lower than that of both outer London (8.5%) and England (8.3%).

Figure 3: Pupils with special educational needs in Croydon maintained primary schools and maintained secondary schools[33]



Source: Department for Children, Schools and Families, Special educational needs in England: January 2009

In Croydon's maintained primary schools, 22.2% of pupils have special educational needs. This proportion is higher than outer London (20.4%) and England (19.7%).[34]

Figure 4 shows that in Croydon's maintained primary schools, 1.2% (359) of all pupils had statements of special educational needs. This is slightly lower than the 1.6 percent of pupils with statements in outer London and 1.4% in England. The percentage of pupils at the *school action plus* stage of the special educational needs code of practice was higher in Croydon (7.8%) than in outer London (6.6%) and England (6.4%). The percentage of pupils at the school action stage (13.1%) was also higher than both the outer London (12.3%) and England averages (11.8%). This means a greater percentage of primary age pupils in Croydon require external support for their special educational needs than at a regional or national level.

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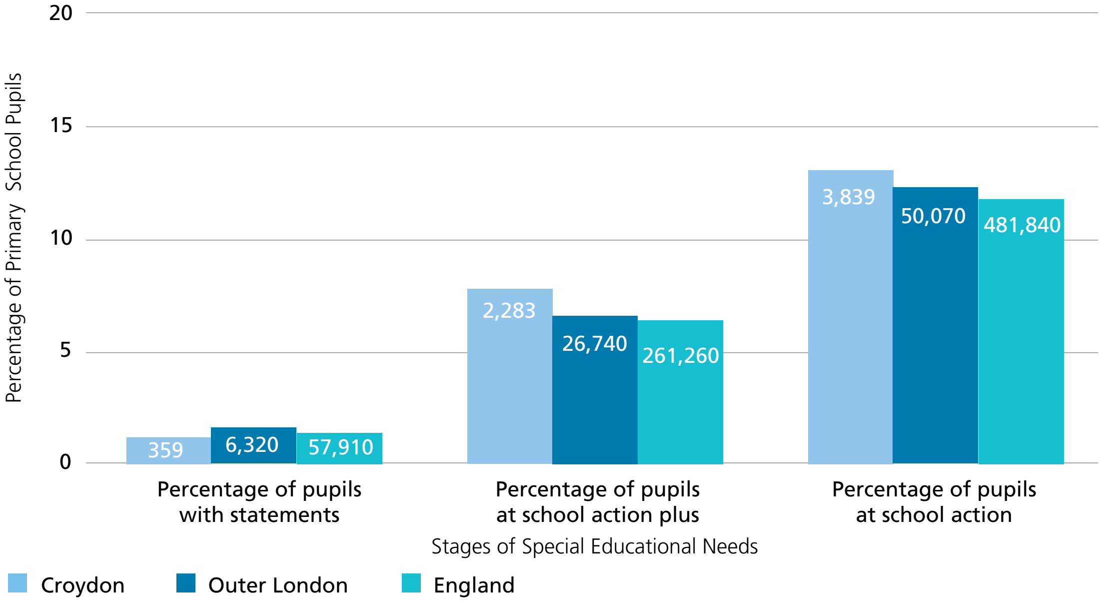
[33] Denominator is total number of special educational need pupils in all maintained primary schools and secondary schools. Excludes dually registered pupils (those registered with more than one special educational need). Numbers in bars represent number of pupils.

[34] Department for Children, Schools, and Families (2009). *Special educational needs in england statistical first release 14, January 2009.*

Figure 4: Maintained primary schools – percentage and number of pupils with special educational needs[35]

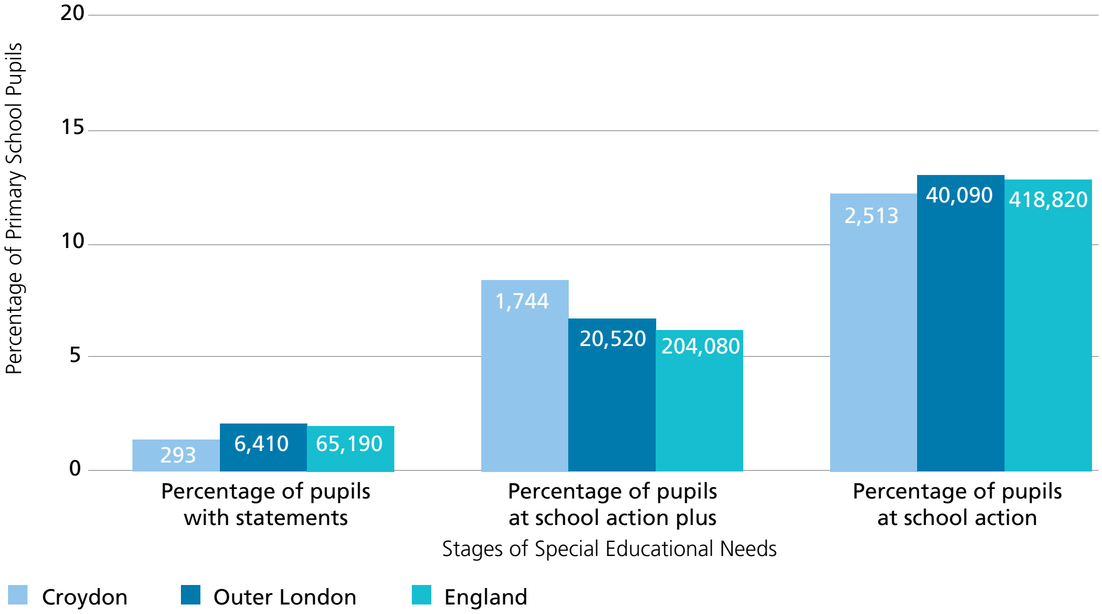


Source: Department for Children, Schools and Families, Special educational needs in England: January 2009

In Croydon's maintained secondary schools, 22% of pupils have special educational needs. This proportion is slightly higher than outer London (21.8%) and England (21%).[36]

Figure 5 shows that the proportion of Croydon pupils in maintained secondary schools with statements of special educational needs (1.4%) was lower than the average for both outer London (2.1%) and England (2%). The percentage of Croydon secondary pupils at *school action plus* (8.4%) was higher than in outer London (6.7%) and England (6.2%). However, there were fewer pupils in Croydon at the *school action stage* (12.2%) than the average for outer London (13%) or England (12.8%).

Figure 5: Maintained secondary schools – percentage and number of pupils with special educational needs[37]



Source: Department for children, schools and families, Special educational needs in England: January 2009

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[35] Denominator is total number of pupils in all maintained primary schools. Excludes dually registered pupils (those registered with more than one special educational need). Numbers in bars represent number of pupils.

[36] Department for Children, Schools, and Families (2009). *Special Educational Needs in England Statistical First Release 14, January 2009.*

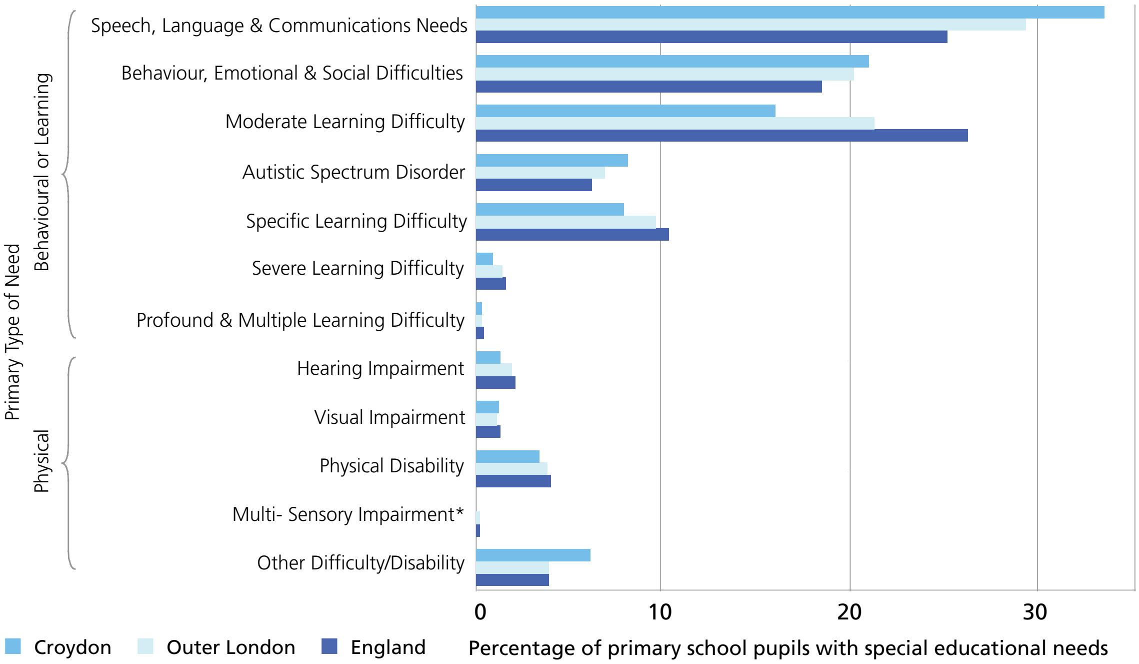
[37] Denominator is total number of pupils in all maintained secondary schools. Excludes dually registered pupils (those registered with more than one special educational need). Numbers in bars represent number of pupils.

Prevalence of different types of special educational need in children and young people

Data in this section are taken at January 2009 from the Department for Children Schools and Families *Special educational needs in England statistical first release 14* (January 2009). It represents only those children who have statements of special educational needs or those who are at *school action plus* level of the special educational needs code of practice.

In maintained primary schools, the most prevalent type of primary need amongst pupils with statements or at *school action plus* is speech, language and communication needs, representing 33.6% of pupils. This is also the most prevalent need in outer London at 29.4%, and the second most prevalent need in England at 25.2% (Figure 6).

Figure 6: **Maintained primary schools - percentage of pupils at school action plus and with statements of special educational needs, by primary type of need, 2009**[38]



Source: Department for Children, Schools and Families, Special educational needs in England: January 2009

*Numbers less than 5 or percentage based on a number fewer than 5.

In Croydon maintained secondary schools, the most prevalent type of primary need amongst pupils with statements or at *school action plus*, is behaviour, emotional and social difficulties (35.8%). This is also the most common need in both outer London (33.2%) and England (30.6%) (Figure 7). Figure 7 also shows that moderate learning difficulty is the second most prevalent pupil need in outer London (24.5%) and England (25.2%), however it represents only 19.9% of pupils in Croydon.

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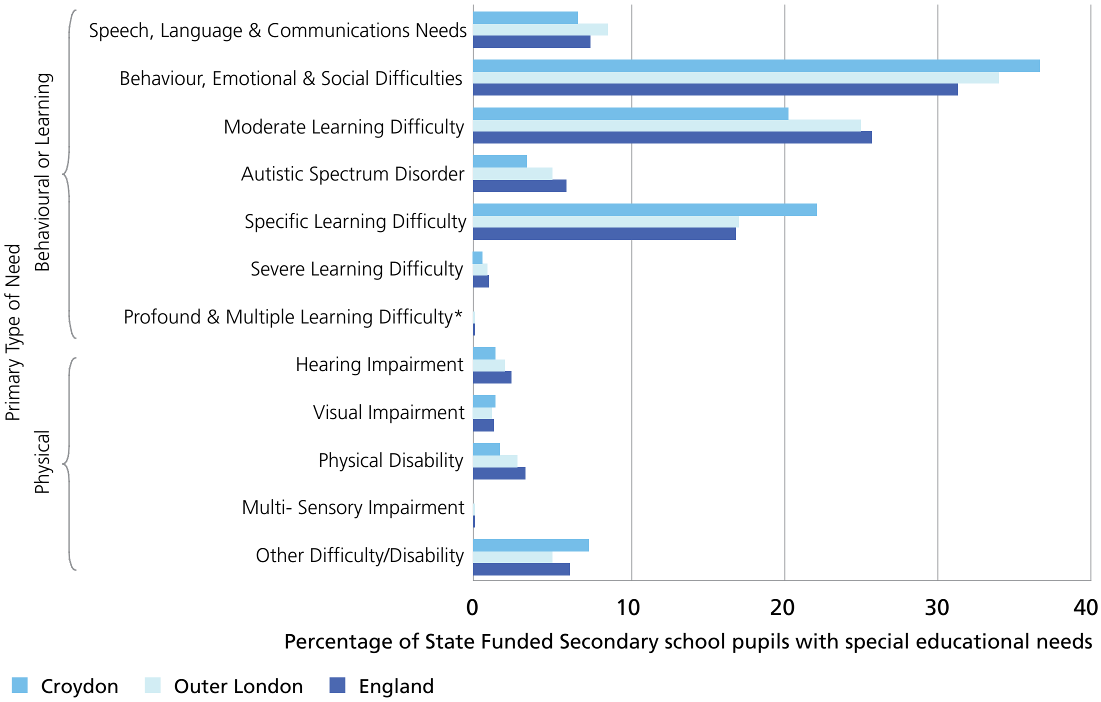
[38] Denominator is total number of *school action plus* and statement pupils in all maintained primary schools. Excludes dually registered pupils; categories are mutually exclusive and are with respect to pupils education needs.

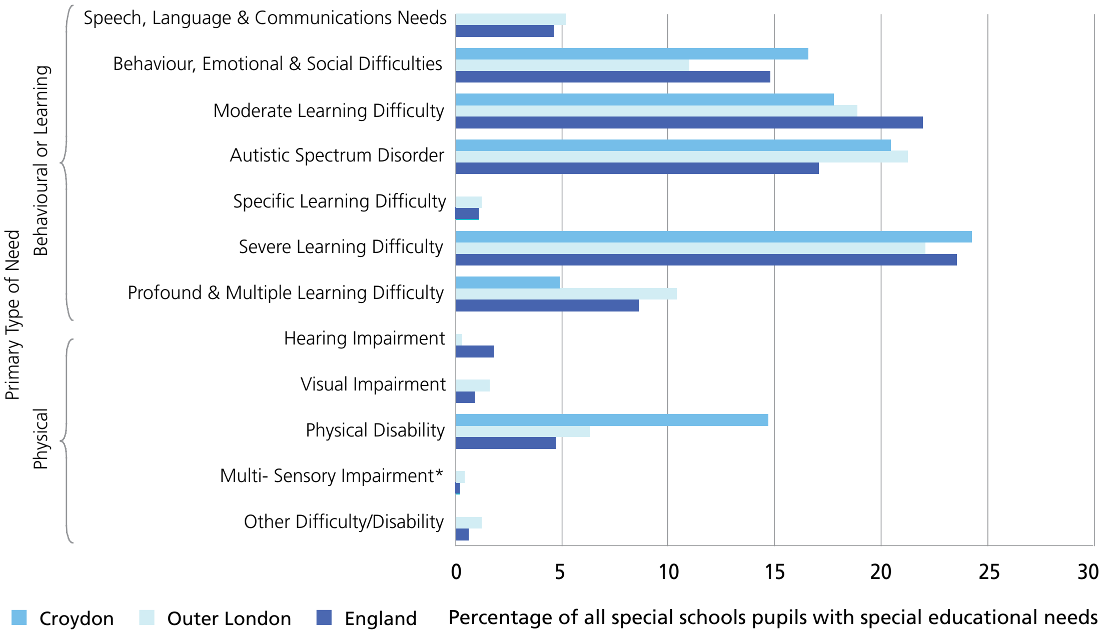
Figure 7: **Maintained secondary schools - percentage of pupils at school action plus and with statements of special educational needs, by primary type of need, 2009**[39]



Source: Department for Children, Schools and families, Special educational needs in England: January 2009
*Numbers less than 5 or percentage based on a number fewer than 5.

In maintained and non-maintained special schools in Croydon, the most prevalent type of special educational need for those with statements or at *school action plus* is severe learning difficulty (24.3%), followed by autistic spectrum disorders (20.5%). This is also the case for outer London. In England the most prevalent need is severe learning difficulty (23.6%) followed by moderate learning difficulty (22%) (Figure 8).

Figure 8: **Maintained and non-maintained special schools - percentage of pupils at school action plus and with statements of special educational needs, by primary type of need, 2009**[40]



Source: Department for Children, Schools and Families, Special educational needs in England: January 2009
*Numbers less than 5 or percentage based on a number fewer than 5.

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[39] Denominator is total number of *school action plus* and statement pupils in all maintained secondary schools. Excludes dually registered pupils; categories are mutually exclusive and are with respect to pupils education needs.

[40] Excludes dually registered pupils – categories are mutually exclusive and are with respect to pupils education needs.

Placement of children and young people with statements of special educational needs

At January 2009 Croydon maintained 1,669 pupils with statements of special educational needs.[41]

In England, at January 2009, 54.5% of pupils with statements of special educational needs were placed in ordinary mainstream settings. These include early years settings, maintained mainstream schools, resourced provision in maintained mainstream schools, and special educational needs units in maintained mainstream schools.

In Croydon, 41.4% of the 1669 pupils with statements were placed in mainstream settings. This is 15.1% lower than the outer London average (56.5%) and 13.1% lower than the England average.

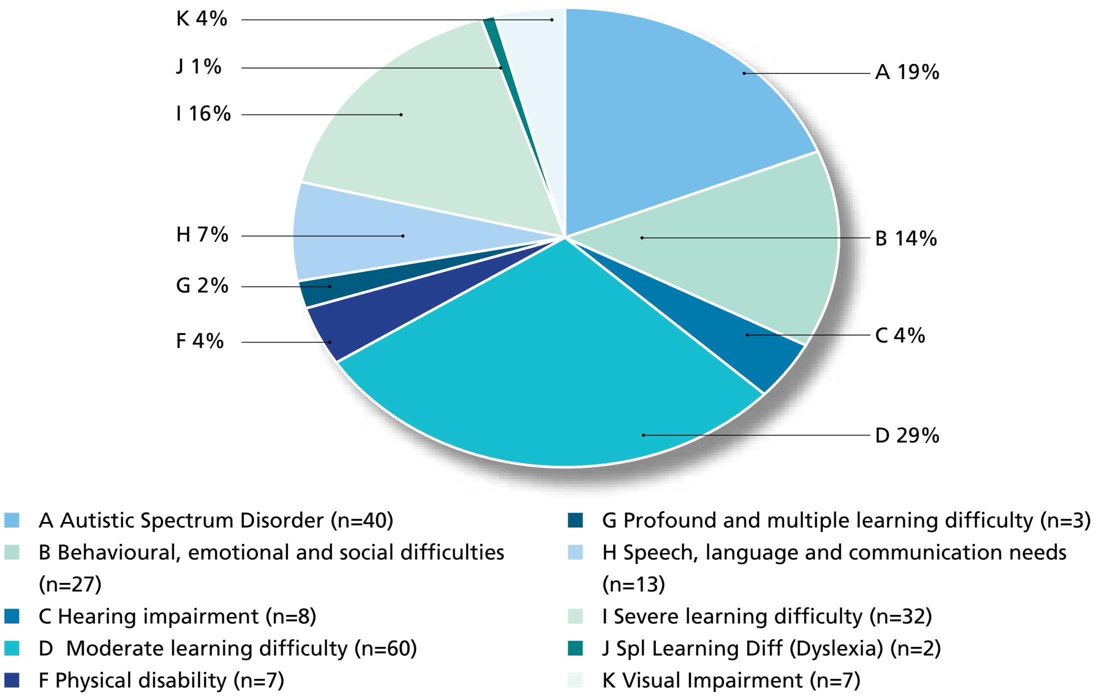
Children and young people with special educational needs in out of borough schools

Children and young people with special educational needs who are provided for outside the borough, are placed in either maintained (state funded) or non-maintained (independent sector) schools. Places at these schools are provided either on a day or a residential basis.

At May 2009, 199 children (12%) with a statement of special educational needs were placed in day and residential schools outside the borough for their education.[42]

Figure 9 shows the primary special educational need of those 199 children placed in out of borough schools. The largest proportion (29%) had moderate learning difficulties followed by 19% with autistic spectrum disorders.

Figure 9: Percentage of children and young people with a statement of special education needs placed in day and residential schools outside the borough, by type of need, 2009[43]



Source: London Borough of Croydon 'ONE System' educational data, May 2009

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[41] Department for Children, Schools, and Families (2009). *Special educational needs in England statistical first release 14,* January 2009

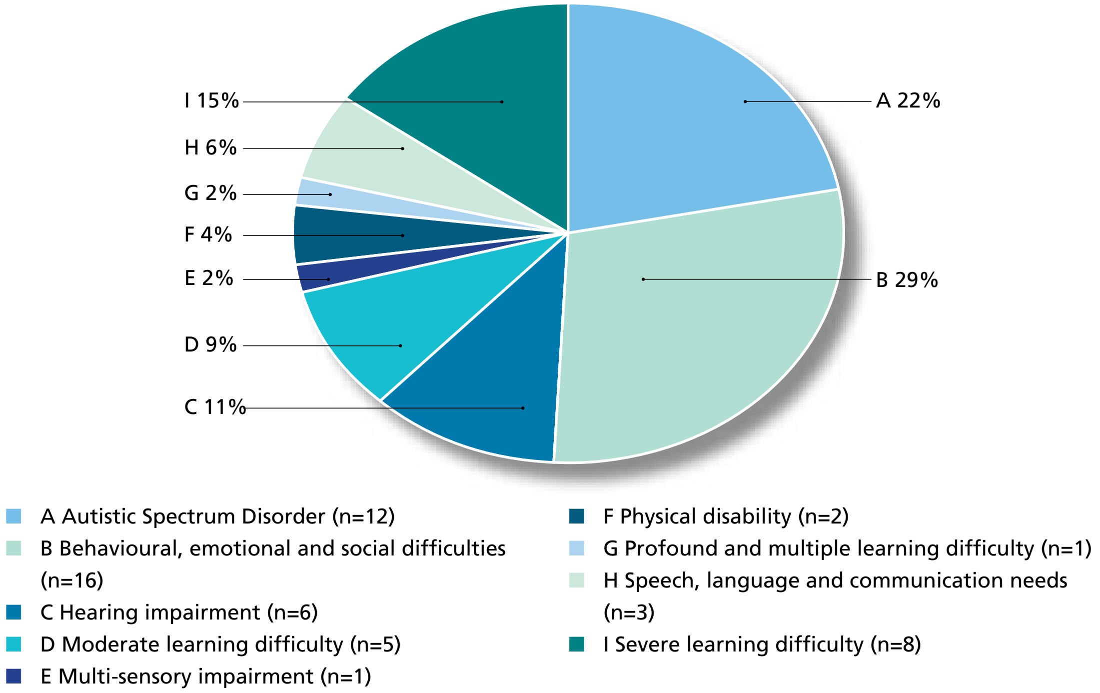
[42] London Borough of Croydon 'ONE System' educational data, May 2009.

[43] Numbers quoted in key (n=) represent number of children with special educational needs.

73% (145 pupils) of the pupils placed out of borough for their education are placed in day schools, whilst 27% (54) are placed in out of borough residential schools.[44]

Figure 10 shows that of those who are placed in out of borough residential schools, 29% have behavioural, emotional and social difficulties, 22% autistic spectrum disorders and 15% a severe learning difficulty.

Figure 10: Percentage of children and young people with statements of special educational needs placed in residential schools outside the borough, by type of need, 2009[45]



Source: London Borough of Croydon 'ONE System' educational data, May 2009.

There are four times as many male children and young people with a statement of special needs placed in residential schools out of borough than female. More than half of the male pupils either have behavioural, emotional and social difficulties or are identified as having autistic spectrum disorders (Table 1).

Table 1: Gender of pupils with a statement of special educational needs placed in out of borough residential schools

Statement category by gender	Female	Male	Total
Autistic spectrum disorders	1	11	12
Behavioural, emotional and social difficulties	2	14	16
Hearing impairment	2	4	6
Moderate learning difficulty	0	5	5
Multi-sensory impairment	1	0	1
Physical disability	1	1	2
Profound and multiple learning difficulty	0	1	1
Speech, language and communication needs	2	1	3
Severe learning difficulty	1	7	8
Total	**10**	**44**	**54**

Source: London Borough of Croydon 'ONE System' educational data, May 2009

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[44] London Borough of Croydon 'ONE System' educational data, May 2009.

[45] Numbers quoted in key (n=) represent number of children with special educational needs.

The highest percentage of children and young people placed in out of borough independent and non-maintained special schools were identified as having autistic spectrum disorders by primary need (27.6%). The next highest need was behavioural, emotional and social difficulty (17.6%) followed by speech, language and communication need (14.1%), moderate learning difficulty (12.9%), and severe learning difficulty (11.1%). These placements were most frequent for children and young people at Year 6.[46]

In common with other London boroughs, there is a shortage of in borough provision. This information may be used to signpost where Croydon needs to increase capacity so that more pupils can have their needs met in local schools. However, there is also a need to explore the reasons why these children and young people are being placed out of borough, based on the interventions that they require, rather than a primary need diagnosis alone.

Children and young people with therapy needs

Children and young people with speech, language and communication needs

At January 2009 there were almost 1000 pupils in the mainstream school system (133 pupils in secondary schools and 830 in primary schools) with identified speech, language and communication needs who had statements of special educational needs or were at the *school action plus* level of the special educational needs code of practice.[47]

The Bercow review of services for children and young people with speech, language and communication needs in 2008 highlighted the problems around the development of language skills in early years and at each school phase.[48]

The review found that approximately 50% of children and young people in deprived populations have speech and language skills that are significantly lower than those of other children of the same age. They need access to early years provision which is specifically designed to meet their language learning needs, and they may also benefit from specific targeted intervention at key points in their development.[49]

The review also found that in England approximately seven per cent of five year olds entering school have significant difficulties with speech and language. In Croydon this would be equivalent to approximately 296 children.[50] In addition, approximately one per cent of the five year olds entering school have the most severe and complex speech, language and communication needs. In Croydon this would be equivalent to approximately 42 children.[51]

In Croydon, speech, language and communication needs are the most prevalent primary special educational need for primary age pupils. Speech, language and communication needs are also associated with many other special educational needs and disabilities; however, they will not be registered as the primary need. The challenge is the early identification and prevention of speech, language and communication problems, which may become apparent only as the school curriculum becomes more demanding, for example at secondary school. It is at this stage when children and young people may have difficulties with reading, writing and accessing the curriculum. They also commonly display poor behaviour and may find it hard to socialise with their peers.[52]

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[46] London Borough of Croydon 'ONE System' educational data, May 2009.

[47] Department for Children, Schools, and Families (2009). *Special educational needs in england statistical first release 14, January 2009.*

[48] Bercow, J. (2008). *The Bercow report: a review of services for children and young people (0-19) with speech, language and communication needs.* Nottingham: DCSF Publications.

[49] ibid.

[50] Based on Office for National Statistics (ONS) mid-2008 population estimates, August 2009.

[51] ibid.

[52] Bercow, J. (2008). *The Bercow report: a review of services for children and young people (0-19) with speech, language and communication needs.* Nottingham: DCSF Publications.

If a child does not benefit from early intervention there are multiple risks, which may become apparent over a number of years. These can include lower educational attainment, behavioural problems, emotional and psychological difficulties, poor employment prospects, challenges to mental health, or criminality.[53] There is a need to put in place responsive teaching and classroom strategies which help with early identification and prevention of speech, language and communication needs.

The input of a speech and language therapist can promote the psychological, social and physical wellbeing of those children requiring such interventions, by enabling them to reach their maximum potential for communication, swallow functions, health, and independence, as well as prevent mental health problems.

In Croydon, long waiting times for children and young people directly overseen by the NHS speech and language therapy service have not been uncommon. Significant service redesign reduced the overall waiting times to within 18 weeks by September 2008; however this has not been maintained due to an increase in demand for the service. Despite threshold systems being in place, referral rates have risen by an average of 8% each year, and the total number of referrals for 2008 to 2009 was 1180.[54] Table 2 shows that at August 2009 a total of 2367 children and young people were overseen by the service. The increasing complexity of children's difficulties also impacts on the amount and type of intervention required.

Table 2: Number of children and young people overseen by the speech and language therapy service, 2009

Service & age group	Number of children
Specialist placement – all ages (including schools and resource centres)	608
Pre-school age (up to and including nursery age)	500
Primary school age	1153
Secondary school age	106
Total	2367

Source: Croydon paediatric speech and language therapy service data, August 2009

Consultation with parents has also highlighted the issue of inadequate access to speech and language therapy services[55] and a number of children have to be sent out of borough to have their speech, language and communication needs met.

The service has moved to working in a more consultative way for some individuals, to enable those who have regular and meaningful contact with the children and young people to apply activities and strategies to help them develop. This has been supported with formal and informal training for school staff, written care plans and activity sheets. Whilst this approach initially resulted in a reduction in demand for direct therapy intervention, the number of children requiring additional therapy intervention has risen.

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[53] ibid.

[54] Croydon paediatric speech and language therapy service data, 2008-2009.

[55] London Borough of Croydon, *parents in partnership consultation,* July 2009.

There is a need to increase the capacity and change the type of input from speech and language therapy services. Service development should focus on building capacity within the community to help families, schools and other community settings play a proactive role in meeting the speech, language and communication needs of their children. This would help reduce dependence on the medical model of specialised one to one treatment by experts, and support it through a more inclusive user friendly approach, enabling homes, schools and other settings to become language friendly environments. This requires families, carers and teachers to work in partnership with therapists to develop a seamless approach to meeting children and young people's needs.

A clear commissioning strategy needs to be developed which is needs led, not demand led or provider driven. Children and their families should be stakeholders in this development.

Children and young people with occupational therapy needs

Children and young people who have difficulties with the practical skills necessary for everyday life, require occupational therapy input to enable them to be as independent as possible at home and school. They may have a wide range of conditions including physical disabilities, autistic spectrum disorders and developmental coordination difficulties, the impact of which may range from mild to significant.

NHS Croydon's occupational therapy service has been working on behalf of Croydon Council since 1998 and was one of the first in the country to deliver an integrated service across health and social care. This enables the occupational therapist to work with children in their own homes and in educational and health settings to promote and enable access, independence and safe care.

There has been a significant increase in demand for the occupational therapy service in recent years and a resulting increase in the number of children waiting to access the service.[56]

Referrals in 2008 to 2009 were 73% above the target level, and audit results indicate an increase in complexity of the needs of children referred to the service, necessitating a greater level of both direct and indirect input.[57]

Figure 11 shows that the key types of intervention provided for children and young people are minor and major adaptations, housing assessments and equipment provision; assessment and provision of equipment accounts for about 75% of referrals.

The equipment budget had remained static for many years with funding levels insufficient to meet essential equipment needs. An additional £40,000 has been identified for 2009 and 2010, however ongoing funding needs to be identified.

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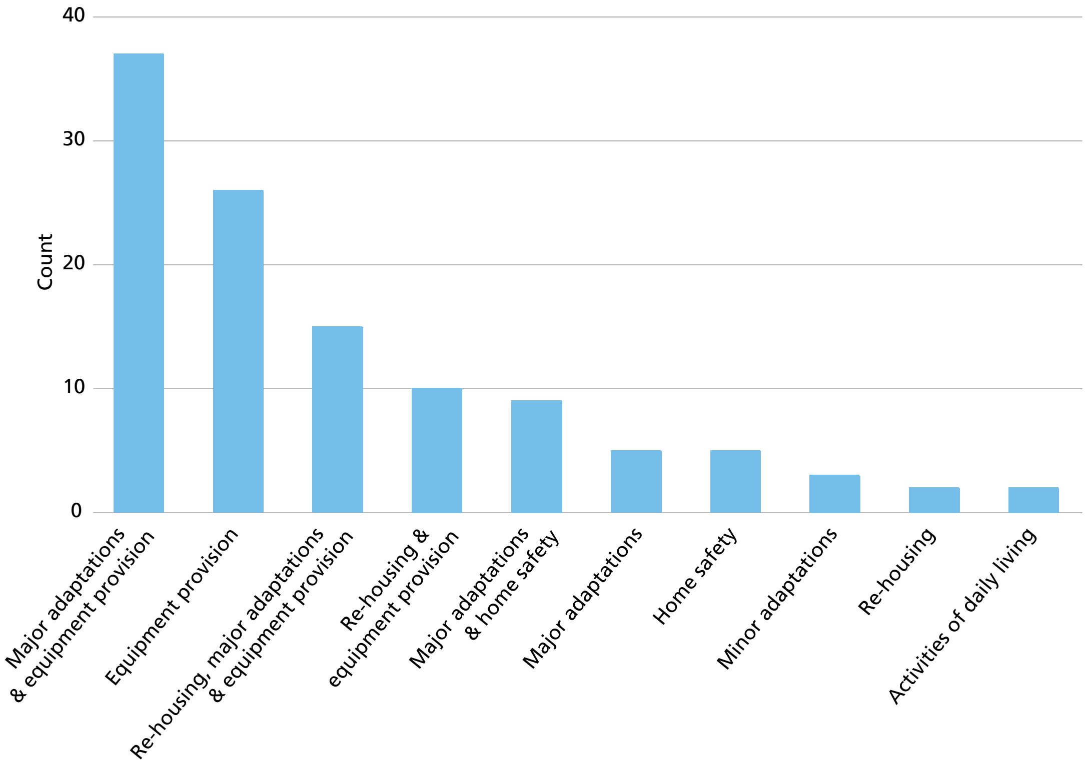
[56] Croydon paediatric occupational therapy service data, June 2009.

[57] Croydon paediatric occupational therapy service data, 2008 and 2009.

Figure 11: Occupational therapy intervention types for children and young people



Source: Croydon paediatric occupational therapy service data, June 2009

Following a change in the means testing for disabled facilities grants in 2005, there has been an increase in the number of private sector housing adaptations.[58] Housing adaptations are generally the most complex and time consuming aspect of the work undertaken on behalf of the local authority, and account for a large proportion of interventions (Figure 11).

Challenging behaviour was the primary reason given for almost 20% of referrals for equipment, rehousing and adaptations in 2008 to 2009. This is an area of increasing demand on the service.

Children and young people with physiotherapy needs

Children and young people who have motor delay or motor disability of a neurological cause, for example, cerebral palsy or spina bifida, have need of physiotherapy input up to 16 years of age. In the third quarter of 2009, about 400 children and young people were on the active case load of the physiotherapy service. In 2009 there were about 220 referrals, and waiting times for the service ranged between 6 and 19 weeks.[59] There is a need to explore the extent to which contact with this service represents all of the children and young people who have these needs.

Children and young people with disabilities

To gather information on the disabled child population, that is, those who have more severe needs and are registered as disabled, Croydon commissions *ICount* Register services to collate and analyse data. The data collected supports the identification and analysis of need and enables services to be effectively planned and targeted.

Croydon's *ICount* register is a joint project between health, social care, education, the voluntary sector and parents. It contains data on children and young people with a range of disabilities. It includes those with permanent and substantial disability of over two years' duration, and those who have a diagnosed mental health problem or a disabling chronic health problem.

[58] Croydon paediatric occupational therapy service data 2005 to 2009.

[59] Croydon physiotherapy service data 2009.

Categories of registration include:

- Physical disability
- Severe or moderate learning disability
- Sensory impairment
- Communication disorder
- Visual impairment
- Serious mental health problem
- Profoundly multiple disabled
- Serious chronic medical condition
- Behaviour

The *ICount* register is a voluntary register and therefore does not hold data on all disabled young people in the borough. The response rate for the register was 82% in 2009.[60] Work continues to increase registration which will result in a more complete picture of need.

The following information is taken from the *ICount* annual report 2009.[61]

At April 2009 there were 1153 children and young people aged 0 to 19 with disabilities registered (Table 3). This equates to 1.3% of the child population of Croydon.

Table 3: Number of children and young people (0 to 19 years) registered as disabled in Croydon, 2009

Age	Female	Male	Persons
0-4	40	77	117
5-9	83	239	322
10-14	116	294	410
15-19	92	212	304
0-19	331	822	1153

Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

Figure 12 shows the age and gender distribution of children and young people registered disabled in Croydon at April 2009. There were more male (71.3%) than female (28.7%) children registered as disabled.

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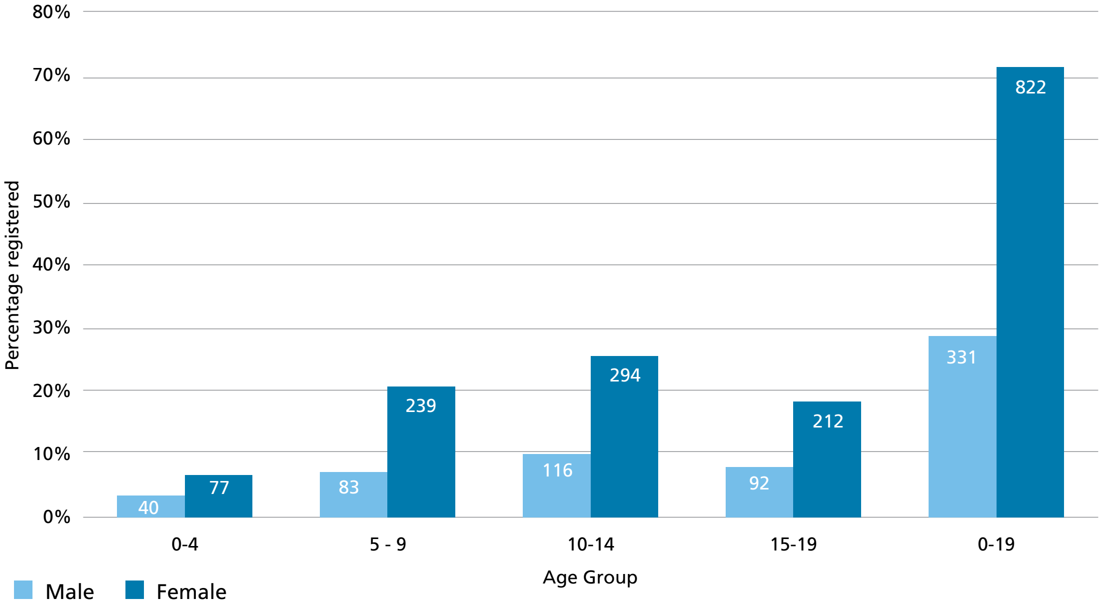
[60] Croydon register for children and young people with disabilities, *ICount* annual report, April 2009.

[61] ibid.

Figure 12: Distribution of children and young people (0 to 19 years) registered disabled in Croydon, 2009[62]



Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

Table 4 shows the numbers of children and young people registered as disabled by ward. Generally, the wards in the north of the borough have the greater numbers of disabled children. This has implications for service delivery, for example, planning transport services for disabled young people.

Table 4: Number of disabled children and young people (0 to 19 years) on the *ICount* register by ward, 2009

0 – 30 Children	31 - 40 Children	41 - 50 Children	51 - 60 Children	61 - 70 Children	71 -80 Children
Fairfield	Coulsdon East	Addiscombe	Kenley	Broad Green	Ashburton
Sanderstead	Croham	Bensham Manor	New Addington		Waddon
	Purley	Coulsdon West	South Norwood		
	Selsdon & Ballards	Fieldway	Upper Norwood		
	West Thornton	Heathfield	Woodside		
		Norbury			
		Selhurst			
		Shirley			
		Thornton Heath			

Source: Croydon Register for Children and Young People with Disabilities, *ICount* Annual Report, April 2009

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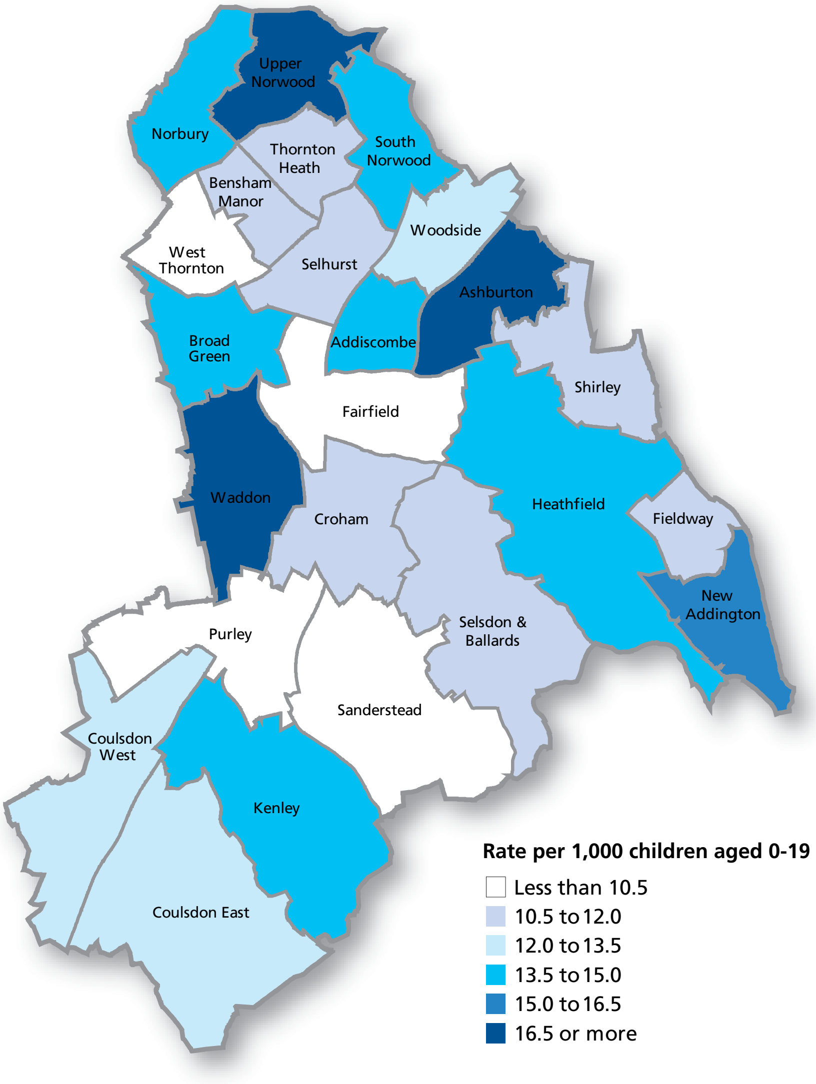
[62] Numbers in bars represent number of children and young people.

Figure 13 shows the proportion of registered children with disabilities in each ward, as a rate per 1,000 children[63]. Waddon and Ashburton wards have the highest rates of children registered as disabled.

Figure 13: Distribution of children and young people (0 to 19 years) on the *ICount* register, rate per 1,000 children, Croydon wards, 2009



Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

At April 2009, the highest percentage of children registered with a disability came from a white ethnic background (55%), mainly white British. Almost 22% of 0 to 19 year olds registered with a disability came from a black ethnic group: African (9%), Caribbean (8%) and white and black Caribbean (5%). Registrations of children from an Asian and mixed background were both 11%. The majority of children from an Asian background were Pakistani (4%) or Indian (4%) (Figure 14).

If these figures do not reflect the ethnic breakdown of the child population of Croydon then it may indicate that some ethnic groups are less likely to register as disabled than others.

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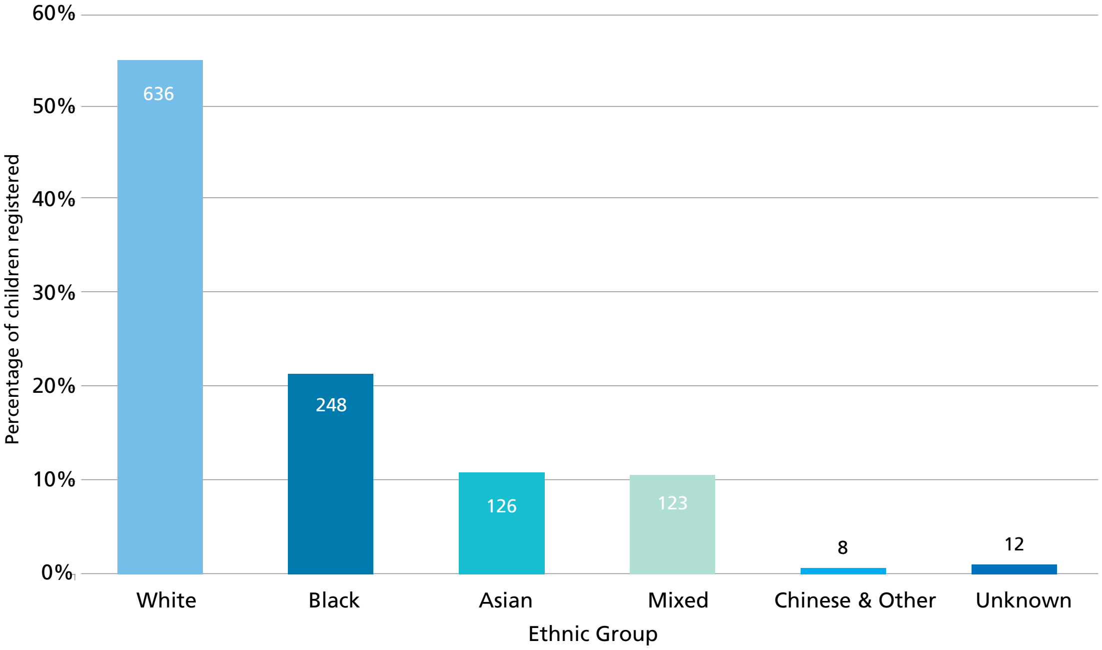
[63] Denominator based on Greater London Authority, PLP 2007 Low projection for Croydon.

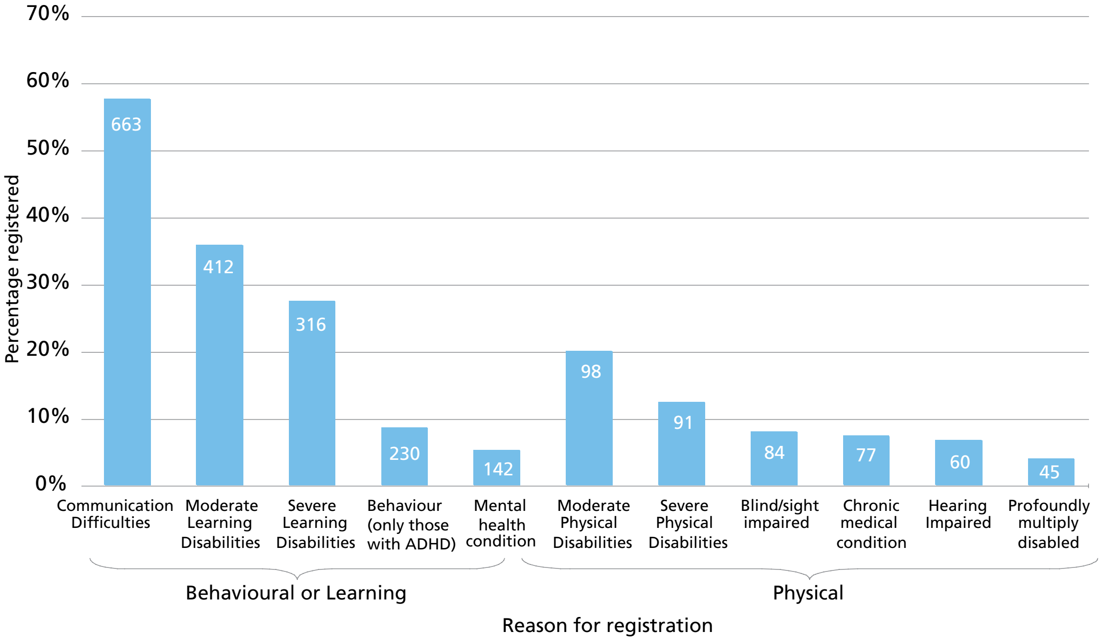
Figure 14: Ethnic origin of children and young people (0 to 19 years) registered with a disability, 2009[64]



Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

Figure 15 shows that the most common reason for registering a child as disabled was communication disorders (including autistic spectrum disorders), followed by moderate and severe learning difficulties.[65] A child may be registered in more than one category because they have a disability which requires the use of more than one service, for example a child who is deaf and blind. Registering a child in this way helps build a picture of service needs.

Figure 15: Reasons for registering as disabled in children and young people (0 to 19 years), 2009



Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

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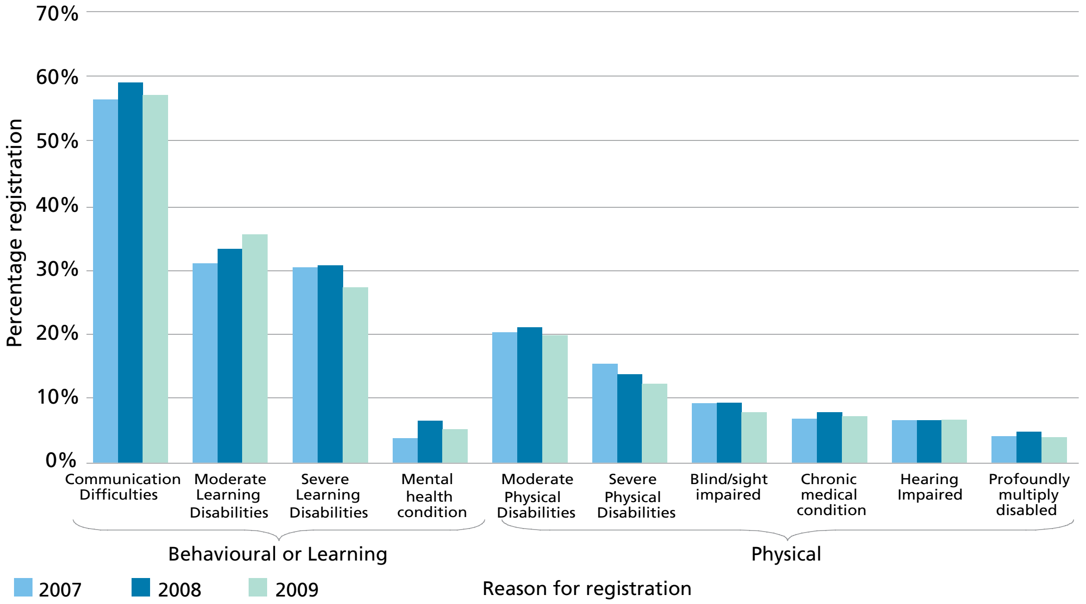
[64] Numbers in bars represent number of children and young people.

[65] Denominator is total number of 0-19 year olds registered (1153) in 2009; Categories are not mutually exclusive.

Figure 16 shows the changes in the reasons for registration from 2007 to 2009. As registration numbers increase, a more accurate picture can be built of the disabled child population, their specific needs, and changes in those needs over time.

Figure 16: Trend in reason for registering children and young people (0 to 19 years) as disabled, 2007 to 2009[66]

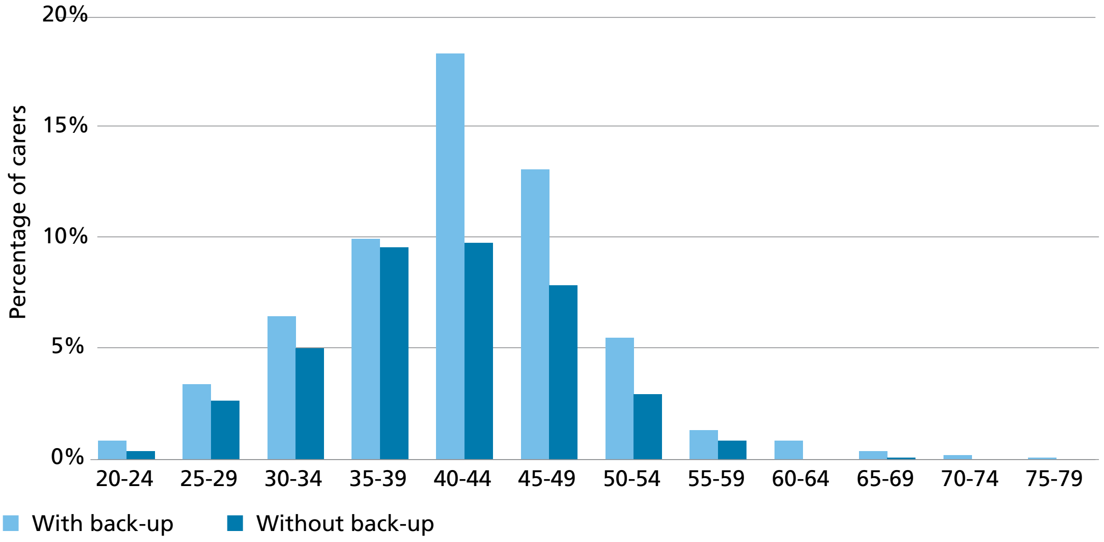


Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

61% of all primary carers of children and young people who were registered disabled had backup or support, whilst 39% were lone carers and had no backup.[67] The majority of primary carers (with and without backup) were between the age of 35 and 49 years but a few were between 65 and 79 years old (Figure 17). Lone carers (without backup) include single parents.

Parents of 7.7% (89) registered disabled children said that they themselves were disabled, with 33.7% (30) of these being lone carers. This has economic and social implications for families of disabled children.

Figure 17: Primary carers or parents of children and young people (0 to 19 years) registered with disabilities, with and without backup support in Croydon, 2009[68]



Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

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[66] A child may be registered within more than one category (denominator is total number of 0-19 year olds registered in 2007, 2008, and 2009). Numbers in bars represent number of children and young people.

[67] Croydon register for children and young people with disabilities, *ICount annual report*, April 2009.

[68] Values under 5 are not shown.

Children and young people with complex needs

Within the group of children with special educational needs and disability are those with more complex needs. A child with complex needs may have multiple special educational needs or disability, which are complex in nature and may include diagnoses such as autism, challenging behaviour, a serious chronic health condition, or moving and handling needs.[69] Support is required from a range of agencies working closely together to support the holistic needs of the child.

Children and young people with complex disabilities and significant conditions

A national study by Thomas Coram[70] estimated that 1.2% of the child population of England may have complex needs and disability. This would equate to approximately 1000 children in Croydon.

To address gaps in service, and improve outcomes and opportunities for children and young people with complex needs and disability the *aiming high for disabled children*[71] agenda is currently being implemented in Croydon. This requires that all services should plan for, and respond to, the needs of this group of children and young people. It includes early years provision, out of school provision and youth services, in addition to health and education provision.

The *aiming high for disabled children* short breaks programme specifically targets children and young people with complex needs and disability. The aim is to provide short breaks on a preventative basis and not just in times of crisis. Short breaks include a range of services such as residential respite, home based or domiciliary care, direct payments, activity schemes, youth schemes and access to universal provision.[72]

Government funding has been given to local authorities from 2008 to 2011 in order to transform short break provision. This resulted in a review and evaluation of Croydon's short break provision in 2008. Using data from the review and information gathered from consultation with users, families and other agencies, proposals were developed to extend and enhance local short break provision. These service developments were further supported by additional funding from NHS Croydon. Newly commissioned provision will require ongoing funding once the current funding ceases in 2011.

Children and young people who are disabled and have complex health needs require coordinated, high quality child and family centred services which are based on assessed needs, promote social inclusion and, where possible, enable them and their families to live ordinary lives. The *early support* programme has been created to help achieve this by providing early and preventative support. It targets families with children aged 0 to 3 years who have a minimum of three agencies supporting their child, in addition to universal services.

The programme ensures:

- The introduction and development of a lead professional or key worker services to improve the continuity and coordination of support available to families.
- Better joint assessment and planning processes for individual children and their families.
- Better coordination of service provision to families where many different agencies are involved.
- Better information for families.
- Better exchange of information about children and families between agencies and at points of transition.
- Joint review of multi-agency service provision and joint planning for service improvement at a strategic level.

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[69] Moving and handling needs relate to young people with physical difficulties, primarily with mobility. They may include wheelchair users, but not necessarily.

[70] Thomas Coram Research Unit (June 2008), *Disabled children, numbers, characteristics and local service provision.* Institute of Education, University of London.

[71] Department for Education and Skills (May 2007). *Aiming high for disabled children: better support for families, DES: Runcorn.*

[72] Universal services or provision are those which are available to all.

- The development of family-held, standard material to monitor children's development which can be shared across agencies.

Since January 2008 there have been 42 referrals to the programme, and in July 2009 there were 21 children receiving the programme, supported by 17 key workers.[73] The programme is being phased in, and will be rolled out to all children who currently meet the criteria for support. The aim is for the programme to be offered to all disabled children under five who meet the criteria.

In May 2009 NHS Croydon had 2380 children and young people in Croydon with significant conditions on their register.[74] The register is a means of identifying children with special needs to paediatricians, and helps to ensure that they have a plan of support in place. There are currently 220 different significant conditions which include both health conditions and disability, for example Down's Syndrome. Further analysis of this data will allow the identification of needs and trends relating to children and young people with disability.

Children and young people with complex health needs including life limiting conditions

This group of young people is supported primarily by the NHS Croydon children's hospital at home team who provide acute and palliative nursing care for children who would otherwise receive treatment in hospital. The current caseload is about 120, although numbers are increasing.[75] These young people require significant support to ensure positive outcomes, so services are extremely resource intensive.

Children and young people with continuing care needs

At August 2009 there were 23 children and young people in Croydon receiving continuing care support.[76] This support is a tailored package of care needed over an extended period of time for children with complex health needs which arise because of disability, accident or illness including life limiting or threatening conditions. It is for children whose health needs cannot be met by existing local health services. The aim is to support children and young people and their carers to manage their care at home and in other settings.

Packages can include day care on a weekly basis, short breaks away from home, night nursing support and education in a residential school. Numbers of referrals have grown significantly from six in April 2002 to 23 in August 2009.[77] Reasons for this increase include medical advances, an increase in multiple births and better survival rates for premature births. It is anticipated that numbers requiring support will continue to increase, which will have an impact on demand for all the service areas involved.

Children and young people with palliative care needs

Children and young people with life limiting or life threatening conditions have specific and often unique care needs. As well as offering care to the child or young person, support is also offered to their families, including siblings.

Further work needs to be undertaken to identify the current trends in relation to the number of young people likely to require this support in future years. The expectation is that numbers requiring palliative support will increase for various reasons, for example medical advances, and so services will need to respond to the needs of these children and their families.

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[73] NHS Croydon, Early support programme data, 2008-2009

[74] NHS Croydon, EPEX data base, May 2009.

[75] NHS Croydon, children's hospital at home team data, January 2010.

[76] Croydon NHS, EPEX data base, August 2009

[77] Croydon NHS, EPEX data base, August 2009

Children and young people with autistic spectrum disorders

Children and young people with autistic spectrum disorders have varied and complex needs which require multi-agency support.

At January 2009 there were 213 pupils in maintained primary schools and 70 in maintained secondary schools that had identified autistic spectrum disorders at *statement* and *school action plus* levels of the special educational needs code of practice.[78]

There are problems in establishing prevalence rates for autistic spectrum disorders. These include the absence of reliable long term data, and differences in definitions over time.[79]

A recent study in south east London,[80] estimated the prevalence of childhood autism at 38.9 per 10,000 and that of other autistic spectrum disorders in childhood at 77.2 per 10,000, making the total prevalence of all autistic spectrum disorders in children and young people 116.1 per 10,000 or approximately 1%. If the 1% prevalence rate found by this study is applied to the population of 5 to 16 year olds in Croydon, the estimated numbers with autistic spectrum disorders would be approximately 500 cases.

At April 2009, the number of children and young people with autistic spectrum disorders aged 5 to 16 registered on the Croydon's *ICount* register for disabilities was 487[81], a 0.9% prevalence rate.[82] This is similar to the estimated rate above.

Table 5 shows that the number of children and young people aged 0-19 years with autistic spectrum disorders registered on Croydon's *ICount* register for disabilities between 2003 and 2009 has increased annually. In Croydon, staff working with children and young people who have autistic spectrum disorders have been active in advocating the register to parents and carers in recent years. Numbers may also have increased due to improved diagnosis, with clinicians having a greater awareness of autistic spectrum disorders and better data recording systems in place.

Half of all disabled children and young people registered on the *ICount* register were registered with autistic spectrum disorders. There were more male registrations (85%) than female (15%).[83] This reflects the fact, as with many other disabilities, that autistic spectrum disorders are more prevalent in males, however it does have implications for service delivery.

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[78] Department for Children, Schools, and Families (2009). *Special educational needs in England statistical first release 14, January 2009.*

[79] Wing, L. and Potter, D. (2002). The epidemiology of autistic spectrum disorders: is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews,* 8(3), pp. 151-161.

[80] 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). The Lancet,* 368 (9531), pp. 210-215.

[81] croydon register for children and young people with disabilities, *ICount annual report,* April 2009.

[82] Based on Office for National Statistics (ONS) mid-2008 population estimates, August 2009

[83] Croydon register for children and young people with disabilities, *ICount* annual report, April 2009.

Table 5: **Number of children and young people (0 to 19 years) with autistic spectrum disorders registered in Croydon on the *ICount* register between 2003 and 2009**

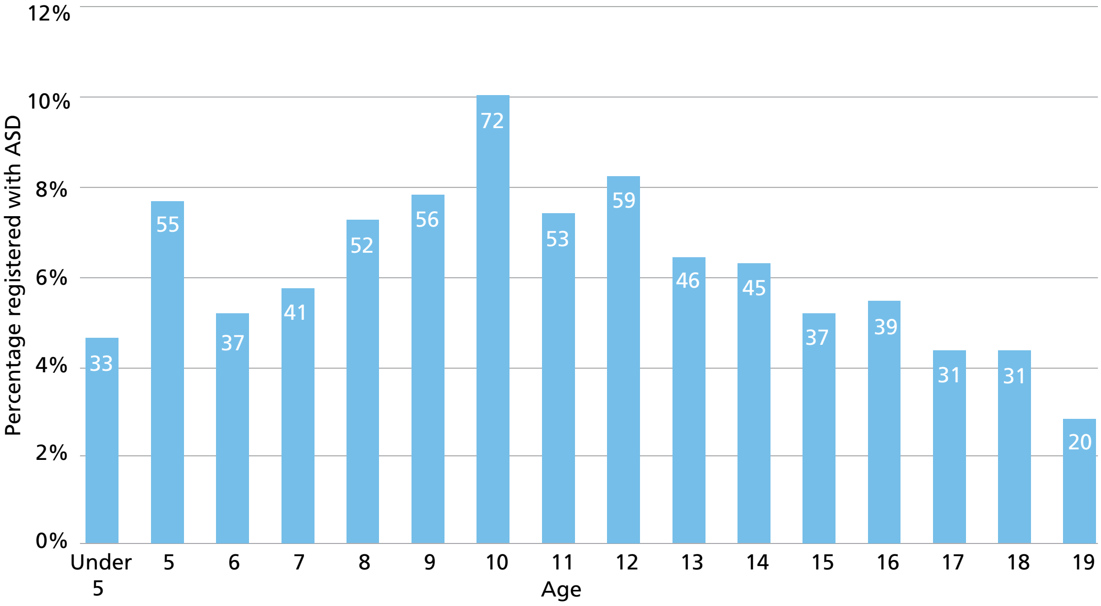
Year	Number of registered children	Number of children with autistic spectrum disorders	Percentage of registered children diagnosed with autistic spectrum disorders	Percentage of Croydon population* with autistic spectrum disorders
2003	487	98	20.1%	0.11%
2004	555	136	24.5%	0.15%
2005	582	235	40.4%	0.26%
2006	695	334	48.1%	0.38%
2007	810	397	49.0%	0.45%
2008	950	491	51.7%	0.55%
2009	1153	589	51.1%	0.66%

*Population denominator (88,878) based on ONS mid-2008 estimates for 0 - 19 year age group

Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

General practices in Croydon also register children with autistic spectrum disorders. At December 2009 there were 707 children registered with autistic spectrum disorders at general practices in Croydon. This is higher than the number on the *ICount* register. One reason for this difference could be that the *ICount* register is voluntary and so may well not reflect all diagnosed cases. Figure 18 shows the age distribution of these children.

Figure 18: **Age distribution of children and young people (0 to 19 years) registered in Croydon general practices with autistic spectrum disorders, 2009**[84]



Source: Croydon General Practice data at 31 December 2009

This general practice data can also help us to estimate the incidence of autistic spectrum disorders in Croydon, that is, the number of new cases diagnosed in the last year. In 2009 there were 110 new diagnoses in children aged less than 19 years; 83 were male and 27 were female. All new diagnoses of autistic spectrum disorders were in children aged 5 to 14 years.[85]

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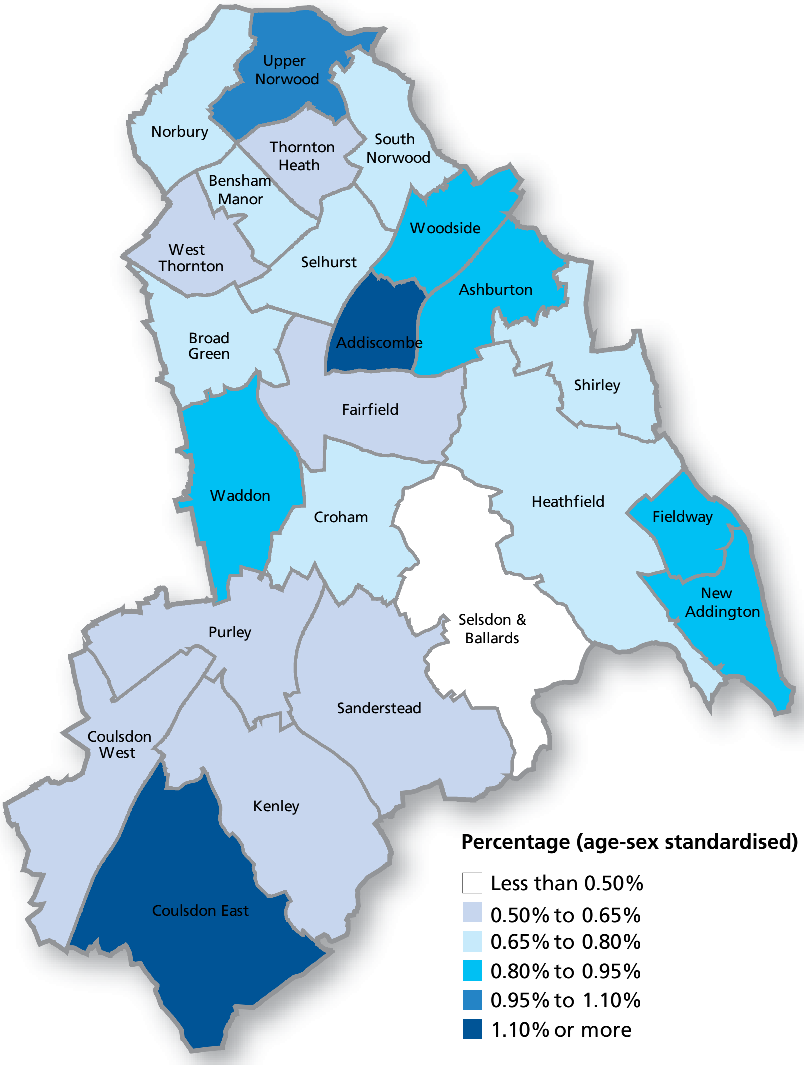
[84] Denominator is total of those with autistic spectrum disorders on general practice register (707). Numbers in bars represent numbers of children with autistic spectrum disorders.

[85] NHS Croydon, General practice data, 31 December 2009.

Figure 19 uses the data from the general practices to show the prevalence of children with autistic spectrum disorders by ward. Identifying the highest concentrations of children and young people with autistic spectrum disorders may help to plan service delivery more effectively.

Figure 19: General practice recorded prevalence of autistic spectrum disorders, children and young people (0 to 19 years), Croydon electoral wards, 2009[86]



Source: Croydon General practice data at 31 December 2009

Figure 20 shows the prevalence of children and young people registered at Croydon general practices with autistic spectrum disorders, by their ethnic origin. A larger number of children registered with autistic spectrum disorders are from a white British background. Almost 50% of the Asian ethnic group is made up of those with an Indian origin, 25% are from a Pakistani background, 10% are Bangladeshi and the remaining individuals are of 'other' Asian background. Black Caribbean and black African make up the majority of those from a black ethnic background, whilst 22% are from 'other' black backgrounds.

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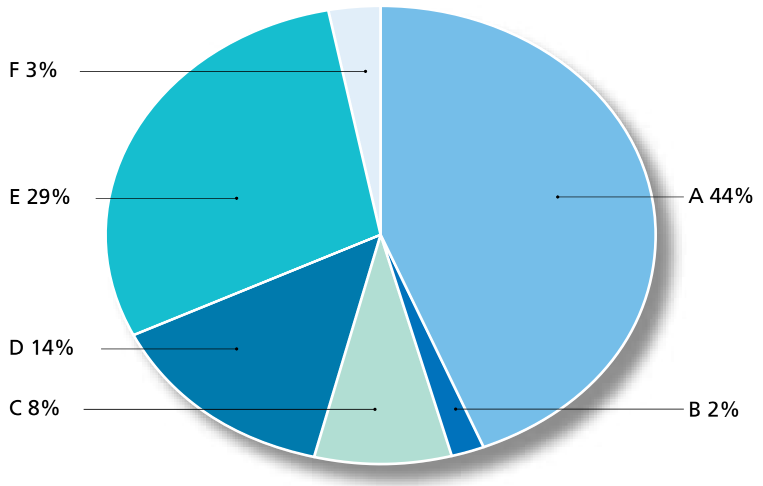
[86] Denominator based on Greater London Authority, PLP 2007 Low projection for Croydon.

Figure 20: **Percentage of children and young people (0 to 19 years) registered with autistic spectrum disorders at Croydon general practices, by ethnic origin, 2009**

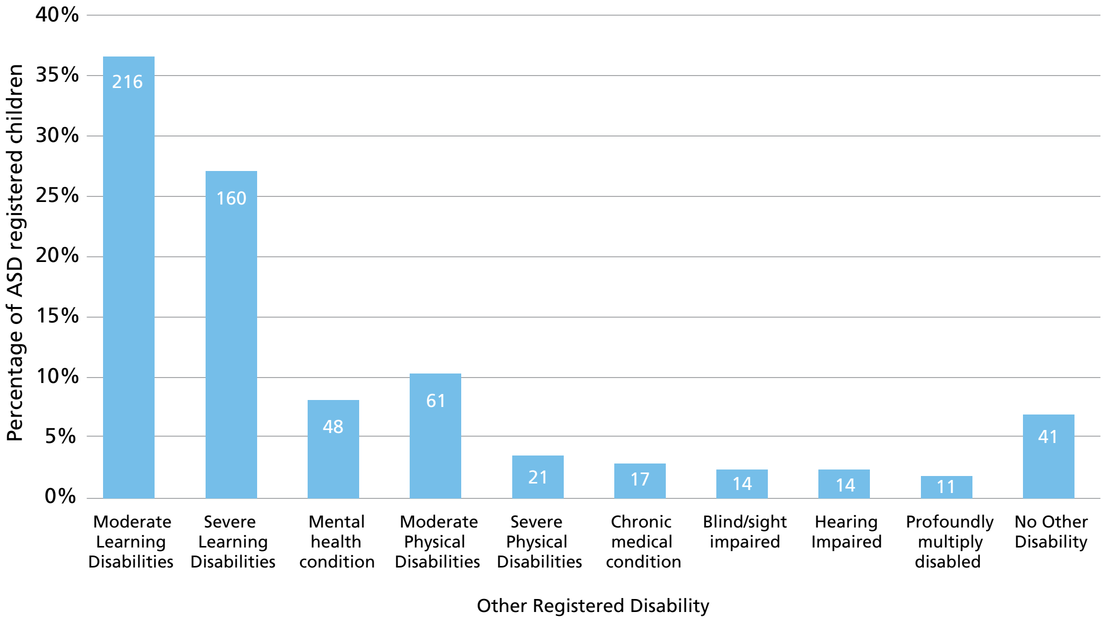


Source: Croydon General practice data at 31 December 2009

■ A White British (n = 161)
■ B White Irish or White Other (n = 7)
■ C Mixed (n = 28)
■ D Asian (n = 51)
■ E Black (n = 107)
■ F Other ethnic groups (n = 11)

Figure 21 shows the prevalence of other disabilities in children and young people registered on the *ICount* database with autistic spectrum disorders. Over 60% of children with autistic spectrum disorders also have severe or moderate learning disabilities.

Figure 21: **Children and young people (0 to 19 years) with autistic spectrum disorders registered with other disabilities in Croydon, 2009**[87]



Source: Croydon register for children and young people with disabilities, *ICount* annual report, April 2009

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[87] A child may be registered within more than one category (denominator is total number of 0-19 year olds registered with autistic spectrum disorders in 2009). Numbers in bars represent numbers of children and young people.

Children and young people with mental health needs, attention deficit hyperactivity disorder or challenging behaviour with disabilities

This group of children and young people has considerable needs and can present challenges to families and service provision across sectors. Early preventative work and ongoing support at various stages of the child's life is crucial to delivering positive outcomes and future wellbeing for young people with these difficulties. It is recognised as an area requiring further investigation and analysis to develop a cross service response. Work has begun to identify the needs of this group in order to develop a strategy and service development plans.

Children and young people with these needs are more likely than other children of the same age to be excluded from school.[88] Data shows that in Croydon secondary schools, 60.7% of pupils who were given fixed term exclusions had some level of special educational need,[89] of which 6.4% had statements of special educational needs. 46.8% of pupils who were permanently excluded had some level of special educational needs, of which 7.8% had statements of special educational needs.[90] Croydon is putting into place strategies in response to this association between the number of children and young people excluded from school and those who have special educational needs.

The aim is to improve joint working between children's services and health professionals to:

- Develop training in schools on the identification of health needs in children and young people which might contribute towards their disaffection from school.
- Increase input from the child and adolescent mental health service.
- Increase input from, and change the approach to, meeting the speech, language and communication needs of these children and young people.
- Implement 'Team around the Child' working, based on the *common assessment framework*, so that the child is at the centre, supported by a range of agencies as required. For those requiring more specialist support, care pathways are used to refer the child to appropriate agencies.

Children and young people with mental health needs in Croydon

The scope of this section focuses on the areas of mental health need which relate mainly to learning disability.

Using outer London prevalence rates from a study by Meltzer et al in 2000,[91] it is estimated that, of children and young people aged 5 to 15 living in Croydon, about 10% will have a specific mental health disorder:[92]

- 4.5% (2,107) will have conduct disorders
- 4.2% (1,966) will have emotional disorders
- 0.9% (421) will be hyperactive
- 0.5% (234) will have less common disorders

The most prevalent condition is conduct disorders.

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[88] Croydon school census, January 2009

[89] At *school action, school action plus*, or statement levels of the special educational needs code of practice.

[90] Croydon school census, January 2009

[91] Meltzer H, Gatward R, Goodman R, Ford T (2000) *The mental health of children and adolescents in Great Britain* HMSO: London.

[92] Croydon number based on Office for National Statistics (ONS) mid-2008 population estimates, August 2009.

Child and adolescent mental health services (CAMHS) offer a range of services that help meet the mental health needs of children and young people. These services are divided into tiers which offer different types and levels of service:[93]

Tier 1 services: Sometimes called universal services, whose primary function is not mental health care; they include general advice and identification of mental health problems early in their development by, for example, teachers, general practitioners and voluntary agencies.

Tier 2 services: More specialist services provided by a network of professionals such as educational psychologists and paediatricians. Functions include assessment, care and treatment for children and young people, and consultation and advice to professionals in Tier 1.

Tier 3 services: A specialised service for more severe, complex or persistent mental health problems. Assessment and treatment is the core function by teams of professionals such as clinical child psychologists and nurses.

Tier 4 services: Tertiary level services such as day units, highly specialised outpatient teams and inpatient units. Assessment and treatment is the core function by professionals such as occupational and speech and language therapists.

The 1996 publication *Treating children well*[94] provides an estimate of the number of children and young people who may experience mental health problems which would require a response from child and adolescent mental health services at Tiers 1, 2, 3 and 4.

For the population of Croydon aged 17 and under, this would equate to:[95]

- Tier 1: 12,040 children and young people (15% estimated prevalence)
- Tier 2: 6,020 children and young people (7.5% estimated prevalence)
- Tier 3: 2,007 children and young people (2.5% estimated prevalence)
- Tier 4: 377 children and young people (0.47% estimated prevalence)

Children with learning disabilities and mental health problems

Estimation of the population prevalence of learning disability is problematic and should be treated with caution. There is no unified approach to estimating prevalence and variations can occur, for example, due to methodological difference or differences in definitions of learning disability. Estimates of prevalence in the UK vary, ranging from 0.23% to 3% depending on the definition of learning disability.[96]A 2004 study by Emerson and Hatton estimated the prevalence of learning disability in the population at 2%.[97]

This study also calculated age related prevalence.[98] If these prevalence estimates are applied to Croydon the number of children with learning disability is estimated as follows:[99]

- 5 to 9 years: 201 children and young people (0.97% estimated prevalence)
- 10 to 14 years: 491 children and young people (2.26% estimated prevalence)
- 15 to 19 years: 598 children and young people (2.67% estimated prevalence)

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[93] Department for Education and Skills & Department of Health (2004). *National service framework for children, young people and maternity services: the mental health and psychological wellbeing of children and young people.* DCSF Publications: Nottingham.

[94] Kurtz, Z: Mental Health Foundation (1996). *Treating children well, a guide to using the evidence base in commissioning and managing services for the mental health of children and young people;* London.

[95] Based on Office for National Statistics (ONS) mid-2008 population estimates, August 2009.

[96] Allgar VL, Mir G, Evans J, Marshall J, Cottrell D, Heywood P, Emerson E. *Estimated prevalence of people with learning disabilities: template for general practice*. Br J Gen Pract. 2008 58(551): 423–428.

[97] Emerson and Hatton (June 2004), *Estimating the current need/demand for supports for people with learning disabilities in England;* Institute for Health Research, Lancaster University.

[98] ibid. Appendix 3.

[99] Based on Office for National Statistics (ONS) mid-2008 population estimates, August

These age-specific rates reflect the increasing identification of children with mild learning disabilities with age.

Table 6 shows that over one in three children and adolescents with a learning disability in the UK (36%) have a diagnosable psychiatric disorder. Children and adolescents with a learning disability are over six times more likely to have a diagnosable psychiatric disorder than their peers who do not have learning disabilities.

This increased risk of learning disabled children and young people having a mental health problem cuts across all types of psychiatric disorders. Children with learning disability are:

- 33 times more likely to have an autistic spectrum disorder
- 8 times more likely to have attention deficit hyperactivity disorder
- 6 times more likely to have a conduct disorder
- 4 times more likely to have an emotional disorder
- 1.7 times more likely to have a depressive disorder

Table 6: Estimated prevalence of mental health problems among children and young people, with and without learning disabilities[100]

Condition	UK (%) with learning disabilities	UK (%) without learning disabilities	Croydon (number) with learning disabilities	Croydon (number) without learning disabilities
Any psychiatric disorder	36%	8%	16855	3746
Any emotional disorder	12%	4%	5618	1873
Any anxiety disorder	11%	3%	5150	1405
Any depressive disorder	1%	<1%	468	468
ADHD/hyperactivity	8%	1%	3746	468
Any conduct disorder	21%	4%	9832	1873
Autistic spectrum disorder	8%	<1%	3746	468
Tic disorder	<1%	<1%	468	468
Eating disorder	<1%	<1%	468	468

Source: Emerson and Hatton (2007). *The mental health of children and adolescents with learning disabilities in Britain,* Institute for Health Research Lancaster University

These figures help to indicate possible levels of need in Croydon and provide a starting point for further investigation into needs and gaps in services to help meet those needs.

Children and young people with attention deficit hyperactivity disorder

Prevalence of attention deficit hyperactivity disorder in the UK is usually estimated at about 5% of the school age population (5 to 16 years),[101] and the male to female ratio in diagnosed prevalence is at least 4 to 1.[102] In Croydon this would lead to an estimate of 2576 children and young people with attention deficit hyperactivity disorder.[103]

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[100] Croydon numbers based on Office for National Statistics (ONS) mid-2008 population estimates, August 2009, for children aged 5 to 15 years.

[101] National Institute for Health & Clinical Excellence. technology appraisal guidance – No. 13. Guidance on the use of methylphenidate (Ritalin, Equasym) for attention-deficit/hyperactivity disorder (ADHD) in childhood. October 2000

[102] Scottish Intercollegiate Guidelines Network, 52 Attention *Deficit and Hyperkinetic Disorder in Young Children: A National Clinical Guideline,* June 2001, http://www.sign.ac.uk/pdf/sign52.pdf.

[103] Based on Office for National Statistics (ONS) mid-2008 population estimates, August 2009

At January 2010 the number of children recorded by general practitioners in Croydon with a diagnosis of attention deficit hyperactivity disorder was 361 (305 males and 56 females).[104] The difference between these figures and the estimated numbers above could be because general practitioners tend to see those children with more severe attention deficit hyperactivity disorder who require medication. Under reporting of the disorder may be a problem as some children with less severe symptoms may remain undiagnosed.

Furthermore, attention deficit hyperactivity disorder is a chronic condition and cases remain open until transferring to adult services or until cases are discharged because medication is no longer needed.

Children and young people with challenging behaviour and learning disabilities

Children and young people with learning disabilities can display challenging behaviour which may put themselves or others at risk, or which may prevent them having access to a mainstream education, a normal home life, or using facilities in the community. Many need specialist children's learning disability, therapy and mental health services, and have a longer term requirement for adult services.

The following information is taken from a report on young people in Croydon aged 14 to 18 years who have a learning disability and have been identified as exhibiting challenging behaviour.[105] Information in the report is extracted from data collected for a larger study of young people with health and social care needs in transition between children's and adult services.[106] The research was conducted within Croydon and studied young people selected as likely to require social care support as adults. This was a social research study and needs assessment, with qualitative as well as quantitative aspects rather than an epidemiological study. Its aim was to estimate future demand for adult services in Croydon and identify the issues which may determine that demand.

Nearly half (76) of the 159 young people in the study exhibited some form of challenging behaviour. The majority of those who exhibited challenging behaviour were male (74%). Most of the young people with challenging behaviour had severe learning difficulties (high) (37%) or autistic spectrum disorders (36%) as their primary need diagnosis.[107]

Behaviour was categorised as physically, verbally or socially challenging, and within each of these categories as moderately or substantially challenging.

Many within the study of young people in transition displayed behaviour that was challenging in more than one way.

- 79% displayed behaviour that was described as socially challenging
- 64% displayed behaviour that was described as physically challenging
- 42% displayed behaviour that was described as verbally challenging
- Moderately challenging behaviour of one type or another was identified in 79 instances; substantially challenging behaviour in 63 instances.[108]

The large majority (78%) of those with challenging behaviour were living at home. The capacity of families to deal with the needs of a young person was categorised as high, moderate or little or no capacity. 18% of families of those with challenging behaviour were seen to have a high capacity to deal with their needs, but 30% had a little or no capacity. However, a low family capacity to deal with challenging behaviour was more common when the level of challenge was categorised as substantial rather than moderate.

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[104] Croydon general practice data, 31 January 2010.

[105] Currer C and Currer A, June 2009, *Report on children and young people who have challenging behaviour.*

[106] Currer C and Currer A, January 2009, *Young people aged 14-18 years in transition and likely to require the support of adult services: a report on their current and future needs. for Croydon service surgery.*

[107] Categorised as per the special educational needs register.

[108] Totals exceed 100% as most young people displayed more than one form of challenging behaviour.

Although the majority of these young people were currently living at home, the likelihood of doing so in future was predicted to reduce significantly with the level of challenge they presented. Thus, 17% of all those with challenging behaviour were seen as having a high likelihood of living at home in the future, however where behaviour was described as substantially challenging, only 0 to 5% had a high likelihood of living at home. Half of all those with challenging behaviour are predicted to require residential care in the future and the balance of care between home, supported living and residential care can be seen to be markedly skewed in favour of residential care where behaviour is described as presenting a substantial challenge of any kind.

The study has identified that challenging behaviour in children and young people with learning disabilities is a major factor in families and schools not being able to sustain them at home or be supported by local provision. This eventually leads to long term, high cost, adult placements that are usually out of borough and at some distance from family.[109]

Children, young people and their families require a comprehensive assessment and a programme of integrated, well informed support. Early contact offers relief to families and carers and has a greater chance of success in ameliorating behaviour. It also enhances the capacity and resolve of parents to sustain the care they offer.

Support needs to be consistent and offer continuity so that differences of approach and information within and across agencies are avoided. A person centred and flexible approach is needed to take account of the diversity of children, young people and their families.

A workshop was held in June 2009 with wide stakeholder representation to examine these issues in more detail and to propose a way forward. A strategy has been developed to help reduce the impact of challenging behaviour on children, young people and their families, and to reduce the impact on all who work with or are affected by it. Implementation of the strategy is currently under discussion. It covers training, processes and resources to support children, young people and families with learning disability and challenging behaviour.

A virtual team approach: meeting the needs of children and young people with learning disabilities, autistic spectrum disorders and attention deficit hyperactivity disorder

NHS Croydon and Croydon council have been working in partnership through the Children's Trust to develop more coordinated services across agencies to meet the needs of children and young people with autistic spectrum disorders, learning disability and attention deficit hyperactivity disorder. Stakeholder steering groups are in place to take a strategic overview and to direct and support these developments.

Improved multi-disciplinary working across agencies is being developed through a virtual team approach, with three teams in place at varying stages of development. This allows staff whose core work involves working with children and families with these conditions to work together in a more joined up way, whilst employment terms and conditions remain unchanged.

The approach involves identifying key core team members who then regularly meet to develop, agree and implement shared criteria, care pathways, joint assessments and intervention plans, together with an operational information sharing protocol. They discuss and agree care plans, allocating and sharing service provision amongst team members as appropriate. The meetings also act as a learning forum to improve understanding of roles and cultures across agencies and disciplines.

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[109] London Borough of Croydon, transitions transformation programme data, 2008-2009.

The benefits of this approach are that services feel more joined up for service users due to improved communication between providers; limited resources are used to better effect by removing potential duplication; children and young people who have urgent needs can be prioritised in an informed way through shared knowledge; and skills and knowledge are increased through closer working. This results in a more informed basis for understanding needs and developing services.

Transitions for young people with disabilities: moving from children's services to adult services

Transition is the period, process and support offered to young people with disabilities as they move from children's services to adult services. There is a challenge here in terms of ensuring that these young people have high quality transition from children's services into adulthood. There is a multi-agency virtual team providing this support because it is recognised as a difficult and stressful time for families and disabled young people as they move towards adulthood and need to navigate changes in service provision, legislative frameworks, education and independence.

Not all those young people who receive support from children's services will need or be eligible for adult services. Using national data it is estimated that between 36 and 60 young people with critical and substantial learning difficulties would be eligible for adult services in Croydon each year.[110] However, a Croydon study of young people aged 14 to 18 years,[111] put alongside local service user data from the past five years[112] indicates that with current thresholds, no more than 40 additional young people a year are likely to become users of adult services in Croydon.

Effective transition for disabled young people requires early planning to ensure that services provide a continuity of support that is focused on individual need. Disabled young people should be fully consulted in accessing their preferred services but difficulties have persisted with transition as services have had differing criteria for access and differing transition points. Arrangements to facilitate the transition from services for young people to those for adults have typically been late starting, fragmented, insufficient and not a consistently good experience for service users. They have also tended to lead to packages of care that can be expensive and have not always maximised independence.

Within Croydon these issues are being addressed by the transition transformation programme, which was initiated nearly two years ago and has made good progress. It focuses on young people and young adults (aged 14 to 25 years) and their families, who are likely to require the services of adult social care when reaching 18 years of age and beyond. These are mostly learning disabled young people but also include some physically disabled and some other young people who may be vulnerable as adults.

The programme's aim is to improve the extent to which these young people, as adults, will be able to live more independently and more locally. A related purpose is to make more cost effective use of resources and to dampen the upward pressure on costs for this aspect of adult services.

Aiming high for disabled children[113] requires better coordination of services for all disabled young people and helps to ensure young people and families can access high quality information at key points. Croydon's inclusion strategy is helping to address the needs of those disabled young people who are in transition but will not require, or be eligible for, adult services.

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[110] Emerson and Hatton: Nov 2008, *Estimating future need for adult and social care services for people with learning disabilities in England;* Centre for Disability Research

[111] Currer C and Currer A, January 2009, *Young people aged 14-18 years in transition and likely to require the support of adult services: a report on their current and future needs.* For Croydon service surgery.

[112] Simon Gifford, February 2009, Learning disability cohort and analysis v4, (Internal document for Croydon Council service surgery).

[113] Department for Education and Skills (May 2007). *Aiming high for disabled children: better support for families,* DES: Runcorn.

The programme is comprehensive and encompasses process changes as well as commissioning to meet gaps in provision. Key elements are:

- Introducing person centred transition reviews and planning.
- Establishing an information technology system dealing specifically with young people in transition.
- Improving information to young people and families.
- Developing and revising policies, procedures and protocols for transition.
- Developing a comprehensive commissioning strategy and plan.
- Involving stakeholders, particularly young people, families and carers.

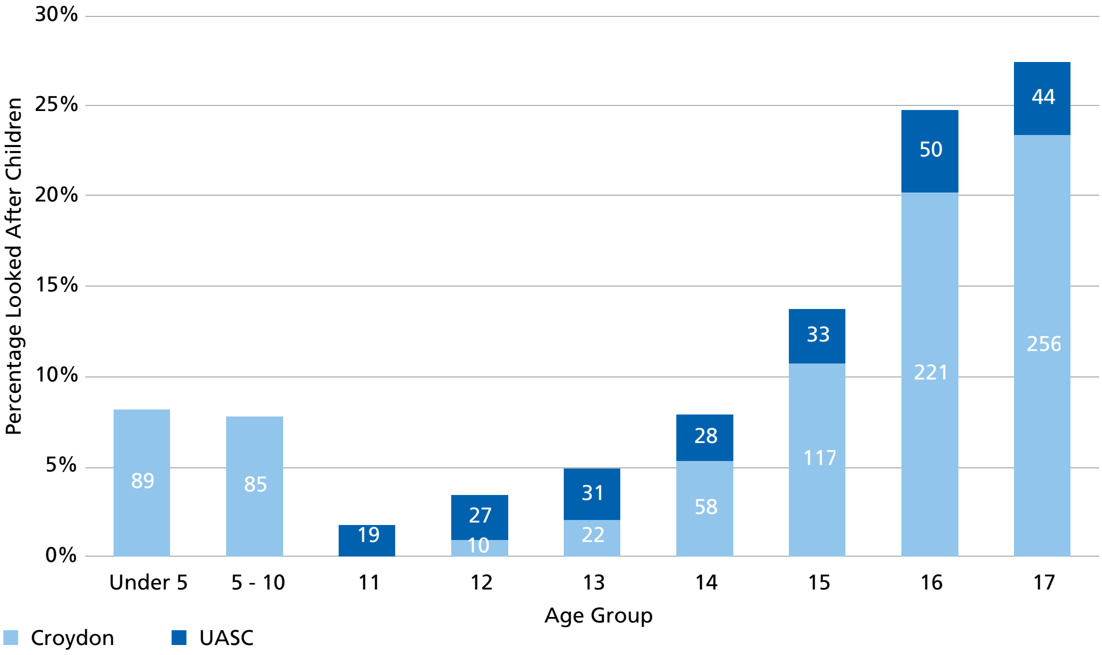
Looked after children, and children with a child protection plan

Looked after children

At July 2009 there were 1095 looked after children in Croydon up to the age of 18.[114] This figure includes those accommodated on a voluntary basis and those subject to court orders. Some looked after children have special educational needs and disability.

Figure 22 shows the distribution of looked after children in Croydon, by age. The chart also shows the proportion of looked after children who are unaccompanied asylum seekers; approximately 63% of all looked after children in Croydon are unaccompanied asylum seeking children.

Figure 22: Distribution of looked after children in Croydon, by age showing unaccompanied asylum seeking children (UASC) and those originating in Croydon, 2009[115]



Source: Looked after children (LAC) analysis: Local authority social care data system, July 2009

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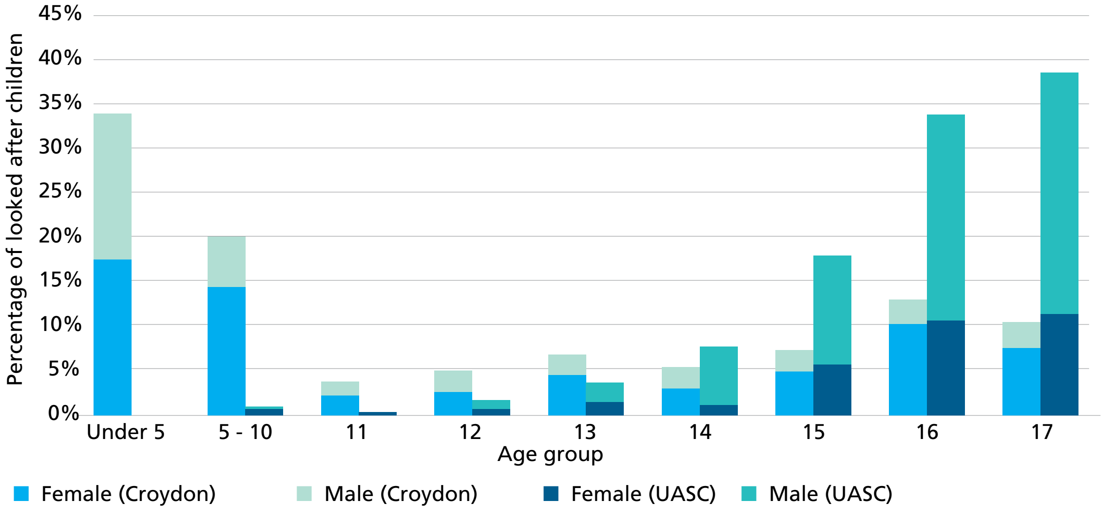
114 Looked After Children (LAC) Analysis: Local Authority Social Care Data System, July 2009.

115 Numbers under 5 have been suppressed due to data sensitivity. Numbers in bars are numbers of looked after children.

There is a considerable gender difference in that 76% (833) of looked after children are male and the remaining 25% (262) are female.[116] Figure 23 shows that this gender difference is exacerbated due to the high number of male unaccompanied asylum seeking children, mainly aged between 14 and 17 years. 70% of male looked after children are unaccompanied asylum seeking children. Conversely, the majority (68%) of female looked after children come from Croydon.

Figure 23: Distribution of looked after children in Croydon, by age and gender showing unaccompanied asylum seeking children and those originating in Croydon, 2009[117]

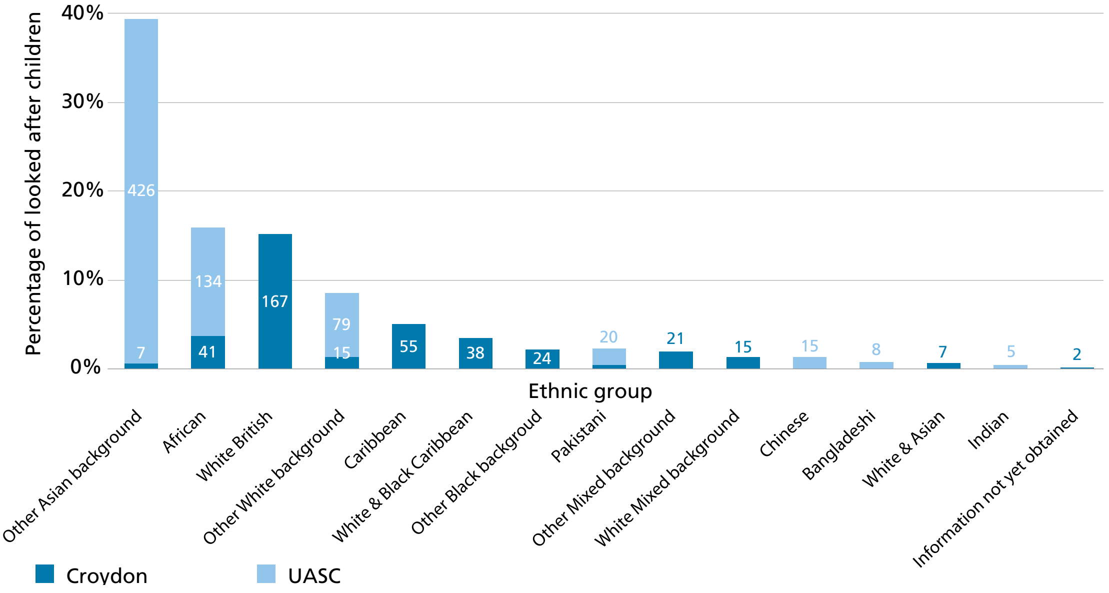


Source: Looked after children (LAC) analysis: Local authority social care data system, July 2009

Figure 24 shows that the highest percentages of looked after children are from other Asian background (38.5%) and from African ethnic groups (16%). This is because of the large numbers of unaccompanied asylum seeking children from these ethnic backgrounds. The other white ethnic group also contains a large proportion of unaccompanied asylum seeking children.

When unaccompanied asylum seeking children are not included in the figures, about 42% of children are from the white British ethnic group.

Figure 24: Distribution of looked after children in Croydon, by ethnicity, 2009[118]



Source: Looked after children (LAC) analysis: Local authority social care data system, July 2009

[116] Looked after children (LAC) analysis: Local authority social care data system, July 2009.

[117] Numbers under 5 have been suppressed due to data sensitivity. .

[118] Numbers under 5 have been suppressed due to data sensitivity. Numbers in or over bars represent number of looked after children.

A significant number of disabled looked after children are placed out of borough in residential provision or in out of borough foster placements. The aim of all services is to prevent accommodation and to enable these numbers to be reduced greater emphasis needs to be placed on early and ongoing family support. For those where remaining at home is not possible, alternative provision within Croydon needs to be developed. This would entail foster placements with adapted accommodation, appropriate equipment and other support services to enable disabled young people to be supported in foster families locally where possible.

Children looked after by local authorities have been identified as children in need in the community and some will have been in need of protection. Many have increased physical and emotional health needs in comparison with children and young people from comparable socio-economic backgrounds. Both health and social care are working in partnership to effectively promote the health and wellbeing of children and young people in the care system. This includes the promotion of health care plans, assessment and monitoring.

Likewise many looked after children's educational achievements are lower than others in their age group. Raising the attainment of a looked after child is a central responsibility of local authorities and their partners. Personal education plans for all looked after children are completed, with additional support for those at risk of not reaching expected standards of attainment.

Children with a child protection plan

A child protection plan sets out actions and responsibilities to reduce the likelihood of a vulnerable child suffering harm.

Children who are subject to a child protection plan are one of the most vulnerable groups in Croydon with significant health, emotional, social and educational needs.

At July 2009, 292 of the 1095 looked after children were subject to a child protection plan,[119] some of whom will also have special educational needs and disabilities. Further analysis is required to identify the numbers of children with a child protection plan who are asylum seeking and those who are from within Croydon.

Key messages from parents, carers and young people

There have been a number of consultation exercises with parents and carers of young people over the last few years. These have sought views on a range of issues and information has been used to help inform strategy and service development. Examples include:

- Open Space event in 2008 to develop the carers' strategy.
- You Matter event Croydon Xpress 2007.
- Child Care Sufficiency survey 2008.
- Positive parenting survey consultation 2007-8; survey of the views and thoughts of parents of disabled children.
- Aiming high disabled children short break consultation 2008.
- Play strategy 2009 consultation.
- Children and young people's network event, May 2009.
- Parents in Partnership consultation, July 2009.
- Transition support programme consultation.

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[119] Looked after children (LAC) analysis: Local authority social care data system, July 2009.

Relevant information arising from some of these consultations is outlined below.

Children and young people's network event, May 2009

A range of statutory and voluntary sector groups involved in Croydon's children and young people's network were asked for their views on:

1. What would improve the lives of children and young people with additional needs and disability?
2. What would improve their parents' lives?

Key issues raised were:

- Greater availability of therapy services.
- Request for more and clearer information about services and support.
- Easier access to information.
- Earlier intervention and greater levels of support from agencies.
- Guidance and assistance including parenting programmes.
- Better integration of services and joined up working.
- Increased after school activities for youngsters with special educational needs and disability.
- More short breaks; including at weekends and after school.
- Transport provision (schools and leisure).
- Clearer pathways between agencies.
- Quicker response time from services.
- Greater use of the common assessment framework.
- Greater range of youth services.
- Positive inclusion.
- Clear pathways and opportunities for young people aged 16 and over.
- Training for staff including disability and special educational needs awareness.
- Focus on all children and their individual needs.
- Less assessment.

Aiming high disabled children short break consultation, autumn 2008

Views of children, young people and their families about current services and gaps in services were obtained to inform the development of the *aiming high* disabled children short break programme. Questionnaires, interviews and attendance at a range of parent support groups and short break activities formed part of the needs analysis of this group.

Responses from the children and young people suggested that they enjoyed the whole range of short breaks including those provided at Calleydown short stay unit, home based care, domiciliary support and schemes. However, they consistently said they liked being with friends and talked about a range of activities that they would like to be involved in.

Young people made the following comments about what they wanted:

- Activities: snooker, basket ball, computer games, drums, music, swimming, trampoline, horse riding, camping, football, outings.
- To be with my friends.
- To feel safe and like the staff.
- Not enough days provided.
- To be the same as any other young person.

It was particularly apparent that the needs of teenagers, in terms of appropriate activities and opportunities to be with their peers, needed to be addressed in the development of the programme. Young people commented that social opportunities were limited; venues and equipment were not always appropriate; and there was a make do culture which disadvantaged many of them. The overall wish from disabled children and young people was to have the same opportunities as other children and young people.

Consultation with parents was by questionnaire distributed through parents' groups, and through meetings with individual parents and parents groups, for example, Croydon Opportunity Group, Rutherfords, National Autistic Society, Parents in Partnership, Heshima Group and the Parents' Lunch Group.

The following gaps were identified in the provision of short breaks:

Children and young people with autistic spectrum disorders

There has been a steep rise in number diagnosed. This is the largest group of disabled children requiring residential placements. At times the service struggles to provide carers or activities that can support the more challenging youngsters.

Children and young people with challenging behaviour connected with various disabilities

Parents commented on insufficient support and pressure on current provision. Unsuitable premises for short break activities exacerbate difficulties and could lead to the exclusion of some disabled youngsters from activities. There are also risks if accommodation is unsuitable, staff training is inadequate or there is a low ratio of staff to children. Parents identified the need to develop outreach support, home based care and a mentoring and befriending service.

Teenagers with disabilities

There is limited provision for this group in the community, particularly if the youngster has a significant disability. Increased after school, holiday and weekend provision within the community is required. Greater partnership working with the Youth Service and extended schools would support this. Inclusive principles need to be embedded across services.

Children and young people with complex health needs

There is a steep rise in numbers of children and young people with complex health needs. Short break provision for this group of children in Croydon is limited and further specialist provision is needed. Specialist training and equipment is required to support them. Protocols with hospices and joint work with NHS Croydon need to be developed to ensure joined up working for children with palliative care needs.

Children and young people with moving and handling needs

Provision within short break care, particularly home based, is limited due to the need for appropriate equipment, accommodation and facilities. There is limited short break residential provision in Croydon for youngsters with a physical disability requiring moving and handling support.

Disabled children who are not eligible for short break services from the children with disabilities service

Some families felt that the needs of children and young people with mild to moderate disabilities with behavioural difficulties, who do not meet the eligibility criteria for services from the children with disabilities service, are not always met by universal or specialist services. Parents of children with attention deficit hyperactivity disorder and some on the autistic spectrum, particularly those with challenging behaviour, requested a greater level of support.

Parents in Partnership consultation, July 2009

A meeting with Parents in Partnership, a network of parents of children with disabilities and special needs, offered the opportunity to raise a range of issues:

- Transport difficulties caused by changes in school transport policy.
- Waiting times and lack of a range of therapies. This influenced parents' choice of school including requests for out of borough placements.
- Information and the use of inappropriate standard letters.
- Outcomes of statements of special needs.
- Impact of disability on siblings in the family and the importance of not overlooking this.
- Importance of services working to support hard to reach families including those from ethnic minority groups.

Further discussion on the range of issues raised above is required. Working in partnership with families will continue, with a greater emphasis on meaningful participation of parents and users in service design, delivery and review. Further opportunities need to be developed to gain young people's views and their participation.

Transition transformation programme consultation

There is ongoing consultation with parents and users around the transition transformation programme. This aims to develop a strategic transitions protocol, local transition pathways, provide information, guidance, and participation and enhance multi-agency work for those in transition. The group consulted includes young people aged 14 and over with learning disabilities who may require support from adult services. Views gathered are assisting in developing the transitions programme and content of the work plan.

Parent representatives have continued to be involved in significant groups and comment on progress and priorities. Young people are represented in the transition transformation reference group. Further work is required to make participation meaningful.

A learning disabilities development day focusing on transition was held in July 2008 with about 200 attendees, of whom about half were parents and young people. They drew attention to the need for:

- Better and timelier information.
- More local college options.
- Employment opportunities and support into employment.
- Travel and transport assistance.
- Better access to leisure.
- Support for young people in their move towards independence.

Parents in Partnership contributed to the self assessment questionnaire sent out by the Department of Children Schools and Families in December 08 under *aiming high for disabled children*. Points arising include:

- Parents and young people in the moderate learning disability group receive very little information and support.
- 'Transition to what?' is the main issue, with a shortage of college and employment options.
- Financial support from statutory sources for groups like Parents in Partnership is fragile and uncertain but their role is key to parents and young people being engaged.
- The third sector is recognised as fulfilling an important function in respect of support, social and leisure activities but this is not reflected in statutory plans.
- Parents and young people do not generally feel that they have an impact on service developments.

Concluding remarks

This assessment highlights the urgent necessity to create capacity within Croydon to meet the needs of children and young people with special educational needs and disability within their local community.

Removing barriers to achievement (2004),[120] addresses national issues for children and young people with special educational needs:

- Too many children wait too long to have their needs met.
- Children who should be taught in mainstream settings are sometimes turned away and too many staff feel ill equipped to meet the wide range of pupil needs in today's classrooms.
- Many special schools feel uncertain of their future role within an inclusive education system.
- Families face unacceptable variations in the level of support available from their school, local authority or local health service.
- The challenges for schools posed by children with severe behaviour, emotional and social difficulties.
- Difficulties in planning specialist services for children with less common special educational needs and rising expenditure on residential special schools.

The findings of this strategy reflect the current challenges to be faced in Croydon, and we are taking these issues forward through our *transforming Croydon schools* programme and our inclusion strategy.

The most recent overview of special educational needs in the London region from the Department of Children Schools and Families reports that a key challenge in the London region is the maintenance of 'a broad range of special educational needs provision' to replace the 'high level of dependency on the use of placements in the independent and non-maintained sector'[121].

The key to moving beyond this special versus mainstream education debate is strategically building capacity across the system to meet a diverse range of needs. This not only involves capital development but enhancing the quality of existing provision thus getting better value for money for Croydon's children, young people and families with these needs.

[120] Department for Education and Skills (2004) *Removing barriers to achievement: the Government's strategy for special educational needs.* Nottingham: DfES Publications.

[121] Department for Children, Schools and Families (2008) *Removing barriers to achievement: the Government's strategy for special educational needs - overview of the London region.*

This involves several key, inter-related, elements:

- better strategic planning.
- better access to specialist teaching and support.
- better training for staff and workforce development.
- stronger collaboration between schools and services.

For disabled children and young people lessons need to be learned from *aiming high for disabled children: better support for families.*[122]

The *aiming high* principles need to be embedded across all services, both universal and specialist provision. These are:

- Empowerment; access to information and transparency, including parent forums.
- Responsive services and timely support, including early intervention.
- Service quality and capacity.

Aiming high was established with the vision that children and young people with disability, including children with complex health needs, life threatening or limiting conditions and challenging behaviour, should have the same opportunities as their non-disabled peers. They should be able to fulfil their potential and enjoy opportunities; they should have equal access to play, leisure, cultural and social activities; they should be able to express their views, make informed choices, participate in decisions that affect their care and lead as ordinary lives as possible.

Croydon is making progress in implementing the national *aiming high* programme for children and young people with disability and their families. There is evidence of some positive impact; however *aiming high* is just one small step to taking things forward for children and young people with disability.

In Croydon, local research, surveys and consultations with service users and parent carers have highlighted similar issues to those identified nationally. A children and young people's plan has been produced by the newly established Children's Trust. This will help to ensure that children and young people with special educational needs and disability will achieve the *every child matters* outcomes.

Croydon Children's Trust is developing an inclusion strategy which will take forward Croydon's vision for all children. A special educational needs strategy will also be developed which will outline how we intend to improve outcomes for children and young people with special educational needs and disability. The development of this new strategic framework provides an opportunity for Croydon's Children's Trust to engage children and young people with special educational needs and disabilities and their families. The aim will be to transform their experiences and outcomes, making a difference that will extend into their adult lives through life long planning.

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[122] Department for Education and Skills (2007) *Aiming High for Disabled Children: better support for families,* Nottingham: DfES Publications.

Appendix 1: national reports and initiatives

There are a number of national initiatives which focus on the needs of children and young people with special educational needs and disability.

Every child matters is the overarching government approach to the wellbeing of children and young people from birth to age 19. It identifies the five outcomes that are most important to children and young people, to:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic wellbeing

These outcomes are universal ambitions for every child and young person, whatever their background or circumstances. Improving outcomes for all children and young people underpins all of the development and work within the children's trust.

The **Bercow review (2008),** reviewed services for children and young people (0 to 19 years) with speech, language and communication needs. It made a range of recommendations and outlined steps to be taken to transform existing provision and experience of services for this group of young people and their families. It highlights the importance of communication and recommends early intervention, a continuum of services and more joint working.

The **Lamb inquiry (2009)** reviewed special educational needs and parental confidence in the system. It identified issues to help inform national developments relating to the special educational needs assessment process. It reported on the quality and clarity of statements and inspection, accountability and school improvement. It outlined recommendations, including two statutory changes: to provide a right of appeal for parents if a local authority decides not to amend a statement after a review; to place a specific duty on Ofsted to report on the quality of the education provided for disabled children and children with special educational needs.

Aiming high disabled children (2007 to 2011) is part of the *every child matters* agenda and sets out further actions that will be taken by local authorities to improve outcomes in health, independence, wellbeing and equality of opportunity for disabled children and their families.

Every disabled child matters is a national campaign by four leading organisations working with disabled children and their families: Contact a Family, Council for Disabled Children, Mencap and the Special Educational Consortium. The aim is to ensure access to the services and support disabled children need to live ordinary lives. To ensure disabled children are a greater priority for local authorities, *every disabled child matters* has launched a local authority and primary care trust charter. The charter commits local authorities to providing a range of services for disabled children and their families, and also to addressing the needs of disabled children in their strategic planning and local area agreements.

Healthy lives, brighter futures (2009), the child health strategy, aims to improve outcomes for all children and young people from pre-birth to 19 years through greater partnerships between local authorities and primary care trusts to support children at key stages of their lives. Information, timely access, links between services and improved services for all groups including those with special educational needs and disability are critical.

Better lives and better care (2008) gives the opportunity to improve outcomes and experiences for children and young people and their families living with life limiting and life threatening conditions. Emphasis is made on the provision of palliative care, community equipment and individual care plans.

Removing barriers to achievement (2004) is the Government's strategy for special educational needs. It set out the Government's vision for giving children with special needs and disabilities the opportunity to succeed. Building on the proposals for the reform of children's services in *every child matters,* it set the agenda for improvement and action at a national and local level. Key elements are early intervention, removing barriers to learning, raising expectations and achievement, and delivering improvements in partnership.

Inquiry into special educational needs (2006) by the Education and Skills Select Committee recommended that the Government improve outcomes for all children with special educational needs and disabilities in England. These included having a child centred approach with regard to each stage of the statementing process; developing a system based on early identification and intervention, where schools are fully resourced and staff fully equipped to meet needs including investing in training; and where there is a broad range of suitable, flexible, high quality provision available.