Westminster's

AUTISTIC SPECTRUM CONDITIONS NEEDS ASSESSMENT

Part of the Joint Strategic Needs Assessment Rolling Programme

NHS Westminster and Westminster City Council

Contents

Executive Summary

Autistic Spectrum Conditions (ASC) are complex lifelong developmental conditions that affect approximately 1% of the population. People with the condition have difficulties in three main areas: social communication, social interaction and social imagination. They also display rigid stereotyped behaviours and can often have sensory difficulties. Approximately 50% of people with an ASC also have a learning disability and many have other co-occurring medical conditions such as epilepsy, depression and anxiety.

People with an ASC and learning disability are usually eligible for support from learning disability services. Those people with an ASC and no learning disability do not meet eligibility criteria for learning disability or mental health services, yet many experience significant difficulties that impede their functioning and independence.

This needs assessment aims to uncover the unmet needs of adults with an ASC in Westminster, with a particular focus on those with an ASC and no learning disability who appear to "fall through the gaps" between learning disability and mental health services.

There have been a number of legislative and policy developments recently that have highlighted the gaps in services for people with an ASC. The *Autism Act 2009* and the upcoming National Strategy for Autism will place new obligations on NHS and local authorities to meet the needs of all people with an ASC.

Westminster has approximately 2060 adults with an ASC, half of whom have no learning disability. The number of adults with an ASC that Westminster has contact with is lower than expected. A survey of Westminster GP practices revealed a high proportion of younger people diagnosed with the condition compared to adults, suggesting identification of people with an ASC is improving over time. There are thought to be a number of undiagnosed adults with an ASC in Westminster.

Evidence suggests if Westminster can identify and support 4% of the ASC population without a learning disability costs will be neutral and supporting more than 4% can result in cost savings to the public purse. The identification, diagnosis and provision of appropriate preventative support for people with an ASC can also prevent the condition deteriorating to the point where expensive intensive support is needed. There are a number of cases in Westminster where this has occurred.

This needs assessment revealed a number of unmet needs, predominantly among those with an ASC and no learning disability. The gaps identified include a low identification rate due to a lack of diagnostic services, misdiagnosis, missed diagnosis, complex routes to diagnosis and low staff awareness of ASCs. Many staff members also have low confidence regarding how to best support people with an ASC. There is a lack of practical preventative support provided to those with an ASC and no learning disability, such as employment schemes, supported education, housing, advocacy, safe guarding and social skills training that can maintain and improve independence, functioning and quality of life. Best practice

interventions are also not available to people with an ASC and no learning disability, including those who have co-occurring mental health problems.

There are a number of information gaps in Westminster, in particular information on the number of young people with an ASC coming through transition. This has implications for the ability of the NHS and local authority to plan and commission appropriate services.

A number of recommendations have been made to improve the way Westminster meets the needs of adults with an ASC and ensure Westminster complies with legislation and national policy. Improving the identification and support of people with an ASC will not only be of benefit to the individual and their family but will also potentially provide cost savings to the public purse.

The recommendations made include the need to clarify and make clear the roles and responsibilities of learning disability and mental health services to work together to assess and meet the needs of people with an ASC through shared protocols and care pathways. Information on people with an ASC needs to improve to ensure better planning and commissioning of services. A number of service developments have also been recommended, such as an in-borough diagnostic service for Westminster, improved access to assessment and preventative services that will enable people with an ASC and their family to live a better quality of life. Lastly, a comprehensive workforce development plan is needed to ensure staff in the NHS and local authority are better able to identify and support adults with an ASC.

1.0 Introduction

This needs assessment is part of a wider rolling programme of needs assessments, the Joint Strategic Needs Assessment (JSNA), undertaken in partnership between Westminster City Council and NHS Westminster. The JSNA is part of the commissioning cycle and ensures the needs of the local population are imbedded into service design and effective commissioning. This needs assessment informs the *Westminster Strategy for Adults Aspergers Syndrome 2010-2013.*

This needs assessment forms an integral part of the investigation into current and future needs of people with an Autistic Spectrum Condition (ASC), with a particular focus on people with an ASC and IQ above 70. This includes people with High Functioning Autism and Aspergers Syndrome.

Persons with Aspergers Syndrome or High Functioning Autism have an IQ above 70 and are considered to be "falling through the gaps" due to traditional eligibility boundaries of services such as learning disability and mental health services, as evidenced in a recent National Audit Office Report (2009). There are thought to be a high number of people with Aspergers Syndrome or High Functioning Autism undiagnosed in the community and, therefore, not accessing services. It is also not known how many people are in fact accessing existing services or whether these services are appropriate for people with Aspergers Syndrome or High Functioning Autism.

In addition it is not known how many people with an ASC on the lower functioning end of the spectrum are in Westminster, how many are in touch with services and whether these services meet their needs. This needs assessment is also concerned with identifying the unmet needs of this group.

Therefore, the aims of this needs assessment are to:

- Determine the number of people with an ASC in Westminster;
- Project the number of people with an ASC in Westminster in the future;
- Describe the health and social care service provision for people with an ASC and identify gaps in services and any unmet needs;
- Determine the number of people with an ASC already in contact with services; and
- Determine whether the current use of services is appropriate and best meeting the needs of persons with an ASC.

1.2 Why are Autistic Spectrum Conditions important for Westminster?

In recent years there have been a number of national government publications released relating to ASCs, many specifically relevant to adults as they are a group thought to have a number of unmet needs. The *Autism Act 2009* (UK Parliament 2009) was proclaimed in November 2009 which also has significant implications for local areas in relation to the work they undertake for adults with an ASC. The most significant of the policy papers include the National Audit Office (2009b) report *"Supporting people with autism through adulthood"*, and the National Autism Strategy due to be released in early 2010. The relatively new developments in policy and legislation place an obligation on local areas, including Westminster, to improve the way it meets the needs of people.

A local paper by Green (unpublished, 2008), a former Clinical Psychologist Consultant employed by Westminster Learning Disability Partnership, examined the current situation in regards to people with ASCs living in Westminster with a special focus on those with Aspergers Syndrome or High Functioning Autism (the group thought to have the most difficulty accessing services). The investigation revealed that there are thought to be a large number of people in Westminster with an ASC that have not been identified and are in need of services, but are not receiving them. The paper recommended that a thorough analysis should be conducted into the unmet needs of this population.

Without identification and appropriate early intervention and support, groups such as those with an ASC can become isolated and vulnerable. Over time this can lead to crisis or breakdown, then requiring intensive support often at high cost to the individual and family as well as financially to the local area.

1.3 Policy Context

As mentioned there are a number of policy documents and the newly introduced *Autism Act 2009* that place obligations on the NHS and local authorities to assess and meet the needs of people with an ASC, often within existing budgets. The most relevant government documents and policies are summarised below:

Better Services for People with Autistic Spectrum Disorder (DoH 2006): This paper clarified existing government policy and how it relates to people with an ASC. The policy documents relevant to people with an ASC that are discussed in the paper include: *Fair Access to Care, Valuing People, National Service Framework for Mental Health, Our Health, Our Care, Our Say: a New Direction for Community Services, Improving the Life Chances of Disabled People and the NSF on Long Term (Neurological) Conditions*. Transition policy documents such as *Growing into Adulthood*… are also relevant to young people making the transition from Children to Adult Services. The crux of the "*Better Services*…" paper involves a clarification that the previously mentioned policies are also relevant to people with an ASC and their needs must not be ignored.

The situation where people with an ASC are falling through the gaps between Mental Health and Learning Disability Services is "unacceptable and contrary to the intentions of government policy" (DH 2006, p. 7). Further to this, the paper clarifies the requirement of local authorities and NHS bodies to support the social inclusion of people with an ASC, make available direct payments and individual budgets to people with an ASC and ensure services for people with an ASC are part of contractual agreements.

Autism Act 2009: The Act requires a National Autism Strategy to be published and associated guidance to be issued to all local authorities and NHS bodies outlining what they are required to do to ensure the needs of people with an ASC are met. A draft national strategy (*A better future…*) has been released for consultation and a final strategy is due for release in early 2010.

Supporting People with Autism through Adulthood (National Audit Office 2009b): The National Audit Office conducted an investigation into how the needs of people with an ASC are currently being met. The findings revealed improvements are urgently needed in strategy and planning, information/data, awareness and training as well as better use of existing resources. The report also argued additional expenditure to support people with an ASC and IQ above 70 would over time be outweighed by benefits to the public purse.

1.4 The focus of this needs assessment

This needs assessment is concerned with all adults with an ASC in Westminster. An overview of children with an ASC, available services and the process and issues related to transition are also considered to inform future service needs for this group.

1.5 Methodology

This needs assessment was lead by the Public Health Team of NHS Westminster and was overseen by the Autistic Spectrum Condition Steering Group. The Steering Group has a multi-disciplinary membership drawn from NHS Westminster, the local authority and the third sector. People with an ASC and their carers were consulted throughout the needs assessment and strategy development to ensure their views are included. Due to the nature of the condition individual interviews with people with an ASC were considered more appropriate as opposed to a group forum.

This needs assessment largely draws on published national and international literature, local data, views of local service providers and interviews with service users and their carers. There are, however, a number of limitations with data which should be considered:

- Services in Westminster are not uniform in their collection of data on the numbers and characteristics of people with an ASC. In particular, most do not differentiate between a person who has Autistic Disorder or Aspergers Syndrome/High Functioning Autism. If data is recorded at all, it often only involves a diagnostic label of "autism".

- A number of people in touch with services were “suspected” to have an ASC but had not been given a diagnosis. These cases have been included in some of the analyses but where they have been included this has been flagged.

- Anecdotally it is thought data recording of diagnosis is not systematic therefore numbers may not reflect the real picture of the number of people with an ASC in touch with services.

- GP surgeries record diagnosis of an ASC inconsistently therefore this data cannot be relied upon, however it does give a useful picture of future trends.

- Diagnosis of an ASC if often secondary to other diagnoses, such as a mental health problem, therefore data scanning can be extremely difficult and data produced cannot be considered completely reliable.

- A certain level of “double counting” of people in touch with Westminster services is assumed where it was not possible to perform data linkage.

- Prevalence estimates based on national prevalence are to be interpreted with caution for a number of reasons:

    - Most prevalence estimates are based on child and adolescent studies, not adults.
    - Only one study has been conducted on ASC prevalence among adults, and this study was of a small scale.
    - Prevalence studies are most often among “white” populations, therefore differences in prevalence among ethnic groups is difficult to determine at this point in time.
    - There are significant variations in the prevalence rates found between studies, predominantly due to changes in diagnostic tools and clinical definitions used over time and between studies.

2.0 Autistic Spectrum Conditions

ASCs are complex lifelong conditions defined in the ICD 10 (WHO 2007) and DSM-IV-TR (American Psychiatric Association 2000) under Pervasive Developmental Disorders. This paper will refer to Pervasive Developmental Disorders as Autistic Spectrum Conditions (ASCs) as the terms are interchangeable.

The condition is characterised by impairments and difficulties in three main areas: social interaction, social communication and social imagination (known as the triad of impairments). People with an ASC also display inflexible, repetitive behaviours and often have hyper or hypo sensitivity to sensory stimulus (e.g. sound, light, touch). The condition can be significantly disabling for many people, even those who have an IQ in the above average range. Often difficulties are hidden due to there being no obvious physical indication of the presence of a disability.

The term “spectrum” is used as there are significant variations between individual cases, including the severity and presentation of the triad of impairments such as differing IQ levels; sensory difficulties and general functional abilities. All people with an ASC, regardless of IQ level, experience difficulties to a greater or lesser extent in relation to the triad of impairments.

The triad of impairments is described in more detail below.

1. Social interaction:

- Problems in acquiring and using social skills.
- Difficulty processing social and emotional information.
- Often unable to initiate social contact so can become very isolated.
- Alternatively, craving social contact but initiating it inappropriately and unable to work out social rules.
- Difficulty forming and sustaining friendships/relationships.

2. Social Communication:

- Delay of language acquisition (or in some cases can be mute). This is not the case seen in those with Aspergers Syndrome, who appear to develop language at a normal rate but may still not use language in a socially appropriate way.
- Difficulties interpreting, understanding and using speech, body language, intonation, mood, gesture, personal space, writing and visual symbols.

3. Social imagination:

- Unable to use social imagination therefore empathise with others and distinguish real from imagined.
- Find it difficult to:
    - initiate actions without prompting;
    - inhibit behaviour;
    - switch their attention; or
    - reflect on learning/experiences.
- Exhibit repetitive behaviours and rituals and have an obsessional interest.

Those people with an ASC and an IQ level of 70 or above are often considered to be on the "higher functioning" end of the autistic spectrum due to their IQ level. However, this is not necessarily the case due to many still experiencing significant difficulties with social interactions, social communication and behaviour that can make them particularly vulnerable. A small but significant number of people with an ASC and IQ above 70 require intensive care and support, as is the case in Westminster. Most of those with an IQ level of 70 or above would have a diagnosis of Aspergers Syndrome or High Functioning Autism. Further explanation of the subgroups of ASCs is given Table 1 below.

Although subgroups exist, their use may not be considered helpful in some cases. For instance, a child diagnosed with "Autistic Disorder" may develop into an adult presenting symptoms closer to Aspergers Syndrome or High Functioning Autism. The condition appears to change over time, as do the abilities of the person with the condition.

Table 1: Autistic Spectrum Conditions

(adapted from ICD-10, Diagnostic Statistical Manual IV and the National Autistic Society website)

Autistic Spectrum Condition	**Description**
Autistic Disorder (also known as Classic Autism or Kanner's Autism)	Autistic Disorder is considered to be at the severe end of the Autistic Spectrum. It is characterised by the presence of the "triad of impairments", which include impairments in: (1) social interaction abilities; (2) communication abilities; (3) presence of repetitive, stereotyped behaviours. Onset is also before the age of 3 years. The presentation of the disorder is different across individuals depending on their developmental level and chronological age.
Aspergers Syndrome (AS)	Aspergers Syndrome is also characterised by the presence of the triad of impairments, however there is no delay in the development of language and IQ is in the average to above average range (IQ≥70). Difficulties in motor skills and coordination are often present.
Pervasive Developmental Disorder- Not Otherwise Specified *(Also referred to as "Atypical Autism-ICD-10)*	This diagnosis is given if the criteria for another autistic disorder is not met (i.e. one of the triad of impairments may not be present or it is difficult to determine whether onset was before age 3).
High Functioning Autism (HFA)	High Functioning Autism is not currently recognised by either the ICD-10 or the DSM-IV, but is nevertheless referred to in the literature. Those with High Functioning Autism also present with the triad of impairments and language delay in childhood, but are found to have IQ levels in the normal range (IQ≥70). Adults with HFA present similarly to those with Aspergers Syndrome.

2.1 The difference between Aspergers Syndrome and High Functioning Autism

There is often confusion in the literature, among professionals and the public regarding the difference between Aspergers Syndrome and High Functioning Autism. Adults with these conditions present in the main very similar and there is debate whether a difference actually exists. People with a diagnosis of Aspergers Syndrome or High Functioning Autism have the "triad of impairments" and both groups have average or above average intelligence (IQ≥70). Gillberg, Rassmusen and Ehlers (1998) identified primary areas where conflict exists regarding the difference between the two conditions. They suggest differences exist in the delay of language (there is no delay in those with an Aspergers Syndrome diagnosis) and in the presence of motor difficulties that appear more frequently in those with Aspergers Syndrome. They also suggest there are minor differences in cognitive functioning and the age of onset. Generally children are more likely to get a High Functioning Autism diagnosis whereas an adult would get an Aspergers Syndrome diagnosis.

It appears of little use to differentiate between the two when they present so similarly. High Functioning Autism is not recognised as a definitive condition in the ICD-10 or DSM-IV-TR. For the purpose of this paper Aspergers Syndrome or High Functioning Autism are considered together as their presentation in adults is so similar and the services they require would also be similar.

2.2 Aetiology

Following the recognition of ASCs, for many years it was thought parents (in particular mothers) were responsible for causing the condition in their child (Kanner 1943). This idea has since been rejected. The aetiology of ASCs is now considered multi-factorial, with the most likely explanation being an interaction between genetic and environmental factors. Current evidence appears to confirm a strong genetic link, whereas studies on environmental factors are not yet able to confirm specific environmental causes.

2.3 Diagnosis

The diagnostic criteria and tools used to diagnose ASCs have developed considerably since the introduction of the term "autism" in the 1940's (Kanner 1943). The notion of an "autistic spectrum" was introduced when it was recognised a range of conditions existing along a continuum, with varying degrees of severity. The commonality between the conditions was the existence of the triad of impairments (Wing and Gould 1979).

ASCs are diagnosed based on a qualitative analysis against a set of behavioural criteria. The ICD-10 and the DSM-IV-TR are generally in agreement regarding the criteria used to diagnose an ASC, which include:

- Early emergence of the condition (before 3 years of age)
- Qualitative impairments in social interaction
- Qualitative impairments in communication (and imagination)
- Restricted and repetitive interests in activities

The diagnostic tools most readily used to diagnose an ASC include:
- Diagnostic Interview for Social and Communicative Disorders "DISCO" (Wing 2002)
- Autism Diagnostic Interview-Revised (Lord et al. 1994)
- Autism Diagnostic Observation Schedule-Generic (Lord et al 2000)
- Aspergers Syndrome Diagnostic Interview (Gillberg 2001)

2.3.1 Issues with diagnosis

The lack of awareness of ASCs in the community and by professionals; variable presentation of ASCs between individuals and across time; inherent difficulties diagnosing a condition in someone who has communication difficulties; the reliance on early childhood information; risk of misdiagnosis and the high cost of purchasing a diagnosis all combine to make access to a reliable diagnosis extremely difficult. These issues are discussed in further detail below.

Each behavioural criteria used to diagnose an ASC may present differently in different individuals. In regards to the behavioural criteria of impairment in social interaction, an individual may present with inappropriate 'over friendly' behaviour whereas another may appear aloof and indifferent to others. In the case of communication, an individual may present with complete muteness at one end of the spectrum, to another who appears pedantic and literal in their use of language at the other (MRC 2001).

To further add to the complexity of diagnosis, ASCs appear to change over time from child to adulthood, even in the same person. A child may lack social imagination, which is evident by their lack of ability to 'pretend play', whereas in adulthood a lack of social imagination may show as a lack of interest in fiction and a fascination with facts (e.g. memorising insignificant dates) (MRC 2001).

So called "less severe" forms of ASCs such as Aspergers Syndrome or High Functioning Autism may be missed if diagnosis is carried out by only one professional without sufficient time or input from sources such as parents, family, school and others in contact with the person (Ghaziuddin 2005). Difficulties can be subtle and difficult to pick up without thorough investigation by experienced clinicians.

Misdiagnosis and very late diagnosis are also significant problems faced by people on the higher functioning end of the autistic spectrum (i.e. those with Aspergers Syndrome or High Functioning Autism). People on the higher functioning end of the spectrum are diagnosed on average several years later than people on the lower functioning end of the spectrum

(Gillberg 1989). Late or misdiagnosis are a problem not only for the individual and their family but also because the most effective interventions and management strategies are those that start at an early age (Howlin 1998).

Persons with an ASC may be misdiagnosed with schizophrenia, attention deficit hyperactivity disorder, obsessive compulsive disorders, affective disorders and a number of other psychiatric conditions. Accordingly, interventions and treatments based on a misdiagnosis are ineffective and in some cases could result in a deterioration of the ASC (Fitzgerald & Corvin 2001). It would seem diagnosis based on qualitative analysis and clinical observation is highly vulnerable to misinterpretation. Therefore, it is recommended that only those with high levels of experience in diagnosing ASCs should have this responsibility in cases where there is confusion about a diagnosis.

Diagnosis is likely to be more difficult in adults compared to children for a number of reasons. It is likely that children are more readily identified and referred for diagnosis due to their frequent contact with health professionals and teachers during early years. The low awareness of ASCs in the past may have resulted in many adults who have Aspergers Syndrome or High Functioning Autism not being identified in childhood, therefore they may not realise they have a diagnosable condition. The need for early childhood (prior to age three) developmental information is needed by many diagnostic tools, further complicating or preventing diagnosis if family/parents are not around to provide this information.

Lastly, diagnosis is expensive – this is mainly due to the need to involve staff with specialist skills. For example, The Maudsley Centre, providing diagnostic services for complicated ASC cases, charges over £1700 per case for a multi-disciplinary diagnosis which takes a day to complete.

All of the above mentioned issues need to be kept in mind when designing services for the Westminster population.

3.0 Adults with an ASC in Westminster

3.1 Prevalence

Epidemiological studies looking at prevalence rates have been conducted on ASCs since the mid 1960's. Prevalence studies have concentrated on children and adolescents and rates have varied considerably between studies. The principle reason for the difference in prevalence rates across studies is the different methodologies used and the widening of the spectrum. Diagnostic tools for identifying cases of ASC have developed and changed over time, greatly affecting the number of people identified with the condition. Smaller studies also tend to find higher prevalence rates than larger studies.

Fombonne (2009) has performed an analysis looking at prevalence rates of all ASCs across 53 epidemiological studies conducted between 1966 and 2008. Fombonne's analysis revealed the prevalence for all ASCs to be at least 63.7 per 10,000 population. This was made up of estimates across the various sub-groups of ASCs (Autistic Disorder: 20.6 per 10,000; Pervasive Developmental Disorder-Not Otherwise Specified: 37.1 per 10,000; Aspergers Syndrome 6 per 10,000). These estimates are considered conservative.

The first study looking at the prevalence of ASCs in adults was conducted recently by the NHS Information Centre (2009). This study found prevalence to be around 1% in adults, a rate comparable to that found in children (NHS Information Centre 2009). However, this study was based on a very small sample so this estimation must be interpreted with caution. Nevertheless, the National Autistic Society uses a prevalence rate of 1 in 100 (1%) people to estimate the number of people with a condition somewhere along the autistic spectrum. Anecdotally the National Autistic Society reports other boroughs in London use this rate to determine their estimated prevalence of people with an ASC.

The rate of 1% is likely to be an overestimate, but may be beneficial to use due to the fact that even if someone does not have a diagnosis of an ASC, they may present with autistic like symptoms therefore may still be in need of some support. Parents and immediate family members of a person with an ASC have been shown to display "autistic traits", therefore it could be assumed the rate of 1% also allows for those people without a specific diagnosis of an ASC. For these reasons, the ASC Steering Group has decided to use the rate of 1% to estimate the Westminster ASC population.

Based on a prevalence of 1%, an estimated 2,360 persons in Westminster are likely to have an ASC.

In addition to the overall prevalence of ASCs it is important to consider the number of people with an ASC and IQ level of 70 or above because this is the group that are considered to be "falling through the gaps" between Learning Disability and Mental Health services. The National Autistic Society estimates that 50% of people with an ASC have an IQ of 70 or above (NAS 2009).

Based on an overall prevalence of 0.5%[1], an estimated 1,180 persons in Westminster are likely to have an ASC and have an IQ of 70 or above.

The total number of people 15 years[2] and over with an ASC and ASC with IQ of 70 or above in Westminster is shown in Table 2 below. Figure 1 shows a breakdown according to age.

Table 2: Total expected number of people with an Autistic Spectrum Condition in Westminster

	all ages	15 years +
ASC population with IQ≥70	1180	1030
Number of persons with an ASC	2360	2060

Source: ONS mid-year 2008 population estimate[3]

It is important to note that Westminster has a unique population makeup. There are a large number of ethnic and culturally diverse groups, whose experience of disability and interaction with services may be different. Westminster also has a large number of single person households and a large proportion of the population are of working age (aged 20-65). Some studies show higher rates in immigrant families (Gillberg 1987 and Gillberg et al. 1995), though studies are not considered robust and other studies have not found such an association (Yeargin-Allsopp et al 2003). If following further research ethnicity is found to have an impact, this would be significant for Westminster given the increasing ethnic diversity of the population (Westminster has the highest population of people born outside the UK: 52% for Westminster and 9% for England). A closer look at ethnicity and its potential impact on the identification and support of people with an ASC is given in section 5.9.

3.2.1 General Practice data

[1] Based on the National Autistic Society (2009) estimate of 50% of people with an ASC also having a co-occurring learning disability (IQ below 70)

[2] Age 15+years is used as opposed to 18+years due to the age categories given in National Data sets (ONS & GLA). The number of people in Westminster between the ages of 15-17 is minimal therefore there is minimal difference between the prevalence of AS in the 15+years compared to 18+years.

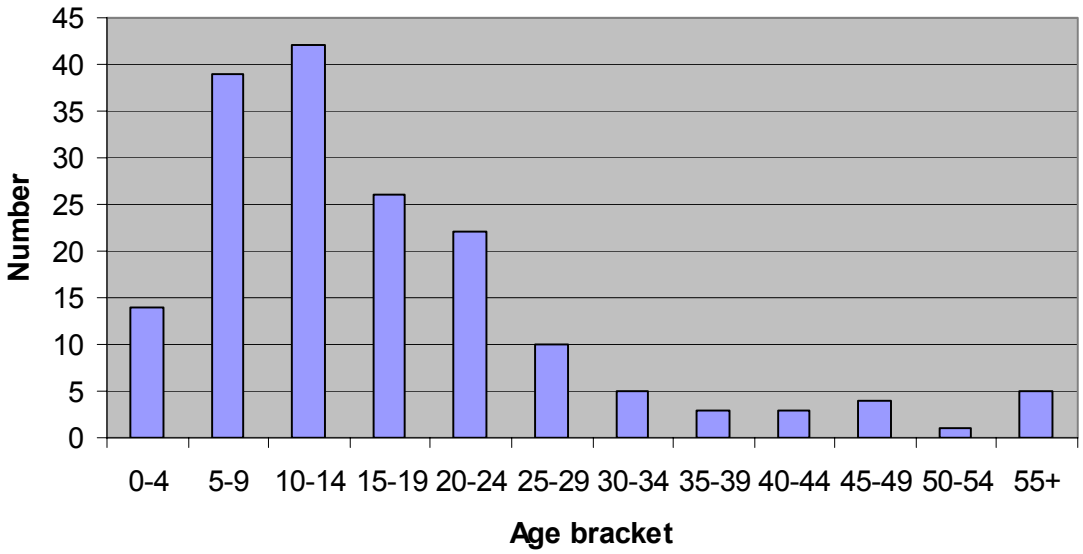
[3] Methods employed to estimate and project population changes are based on the national census of the population. The census is a decennial survey of all people and households in the United Kingdom and provides the most accurate population count available. However, as the census is carried out every ten years, in non-census years, population counts must be estimated as must future population projections.

GP practices in Westminster were asked to provide information on the number and characteristics of their patients registered as having a diagnosis of an ASC. A very good response rate was obtained (69%) however numbers obtained are considered an underestimate as it is unknown whether those GP surgeries that did not respond did so because they had no patients, or simply they did not provide the information.

Figure 1 below shows a breakdown of the number and age profile of patients with an ASC registered with a GP practice in Westminster. The data recording of GP practices is highly inconsistent therefore the reliability of these numbers is questionable. However, this represents one of the better data sources available on the numbers of people with an ASC in Westminster. Due to data being unreliable it is not possible to confidently break the numbers down into those with an ASC and IQ over or under 70.

As can be seen from the table a high proportion of those identified are in the under 18 age group. This is inconsistent with the older age profile of Westminster residents as we would expect there to be higher numbers identified in older age groups. This suggests identification and diagnosis is much better in younger age groups than in adults. This will have implications for the number of children coming through transition from Children to Adult Services who will be expecting an assessment of their needs and access to appropriate support.

Figure 1: Number of patients with an ASC registered with a Westminster GP practice (based on 69% GP response rate)



Source: Survey of GP practices in Westminster, 2009

3.2 Incidence

Most epidemiological studies of ASCs have only concentrated on prevalence estimates, not incidence. The small number of incidence studies conducted has revealed an increasing trend (Powell et al 2000, Smeeth et al 2004).

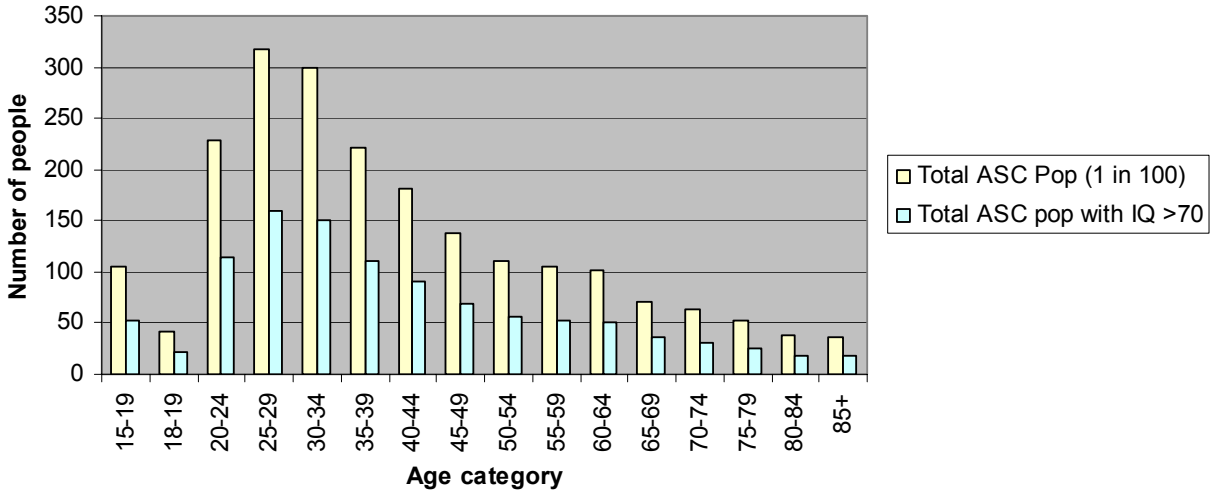
Powell's (2000) incidence study looked at ASC diagnosis across two areas of the West Midlands between 1991 and 1996. Using records from four Child Development Centres, Powell described an increasing incidence of ACS: 18% per year for Autistic Disorder and 55% per year for all other ASCs. It is likely the increasing incidence is due to the increased awareness and better identification of ASC in the community.

Therefore, from such studies it is impossible to say whether there has been a real increase in the incidence of ASCs or whether the increase is a result of increased awareness and diagnosis of ASCs.

3.3 Age Profile

The prevalence of ASCs is said to be equivalent across age groups. As Westminster has a unique population with a large number of people in the 25 to 59 year age group we can see from Figure 2 that we expect to have a large number of people with an ASC in these age groups. This has implications for the importance and cost effectiveness of employment programs that aim to facilitate those in this age group into paid employment. Despite the expected prevalence being equal across the age groups it is not expected that the number of people identified and diagnosed is equivalent. We would expect to see higher numbers to be identified in the younger age groups where contact with health professionals and other professionals are much higher.

Figure 2: Westminster's estimated ASC population, by age



Source: ONS mid-year population estimates

3.4 Gender

The ratio of males to females is higher across all ASCs. According to DSM-IV-TR (APA 2000) the ratio of males to females is approximately four or five to one in those with Aspergers Syndrome/High Functioning Autism (IQ≥70). For Autistic Disorder it is slightly less at four to one. Similarly the NHS Information Centre's recent study (2009) found prevalence rates of 1.8% in men and 0.2% in females. Again it must be stressed this study was of a small scale so findings must be interpreted with caution. The DSM-IV-TR ratios have been applied to the predicted ASC Westminster population – these suggest that of the 2063 (approximate) adults with an ASC, 1685 are male and 378 are female.

Table 3: Number of people with an ASC by gender (NOTE: numbers are rounded)

	Males 15 years+	**Females 15 years+**	**ASC Total**
ASC (IQ≥70)	860	172	1032
ASC (IQ<70)	825	206	1032
ASC total	1685	378	2063

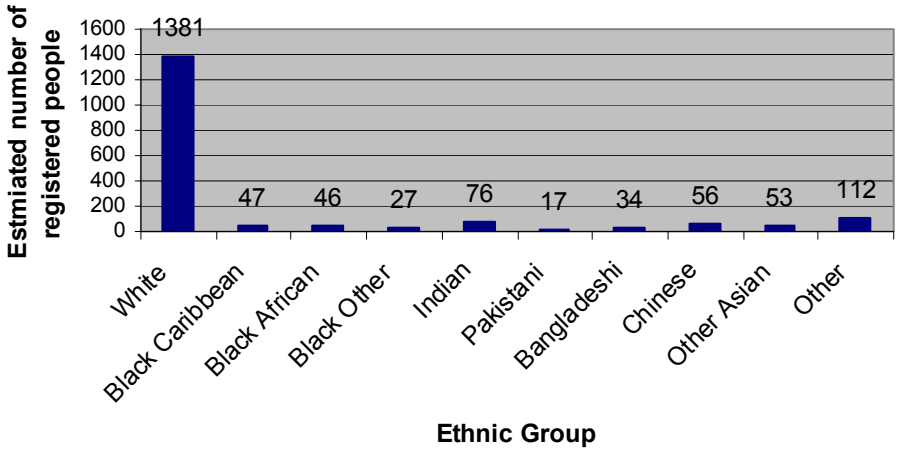
Source: based on ONS 2008 mid-year population estimate

3.5 Ethnicity

The majority of research into ASCs has concentrated on white population groups. The evidence base regarding ethnicity and ASCs is minimal. Fombonne's (2005) review on the characteristics of ASC study samples revealed variable rates of ASCs for different ethnic groups, however the studies have methodological flaws, statistical insignificance and/or very small sample sizes. One UK survey by Powell et al (2000) found comparable rates of ASCs across ethnic groups. It is not possible, with current available research, to confidently suggest whether any real difference in rates of ASCs exist among different ethnic groups. Further research is required in this area.

An estimated breakdown of the ASC population according to their ethnic group is shown in Figure 3, according to GLA projection figures, which are considered to be an underestimate.

Figure 3: Westminster's predicted ASC population, by ethnicity



Source: GLA Ethnicity projections

The likelihood of identification and access to diagnosis may be different among different ethnic groups. Westminster has an extremely diverse ethnic makeup therefore this is highly significant to consider when planning services. Many may not have had access to diagnosis in their country of origin or ASCs may not be widely known about. This may result in adults from minority ethnic groups requiring diagnosis later in life and efforts may be needed to ensure ethnic minority groups are aware of the condition and the assistance that is available to them. Further discussion of the cultural constructs of disability and its relevance to ASCs can be found in section 5.9.

3.6 Disability

The disabling features of Aspergers Syndrome or High Functioning Autism may not fit into a learning disability or mental health "category" but are nonetheless considered significant in many cases. Disabling features of the conditions are centred on social and behavioural difficulties which can cause equivalent levels of disability in terms of an individual's ability to function independently. Difficulties can often be hidden resulting in people being assessed as more able than they in fact are.

For this reason it may be considered the presence of Aspergers Syndrome or High Functioning Autism results in an inequity when considering their level of need compared to the level of support they are eligible for from Adult Social Services.

3.7 Deprivation/Socio-economic class

Other than very early studies with significant sampling bias, there have been no reliable studies published that suggest there is any difference in ASC prevalence or diagnostic rates between social-classes or deprivation levels. Powell's UK study (2000) of pre-school children diagnosed with an ASC between 1991 and 1996 found no difference in rates despite differences in the deprivation levels of the two areas studied. We would therefore expect proportions of people with an ASC to be equivalent across the various local areas of Westminster.

Despite there being no evidence of a difference in prevalence between social classes and deprivation levels it is relatively safe to assume a level of social drift is likely to occur in this group. Due to low employment levels among people with an ASC and the fact that many require the support of family members (which could result in the family member/carer being unable to work) may result in many people drifting into a worse socio-economic position over time.

3.8 Location

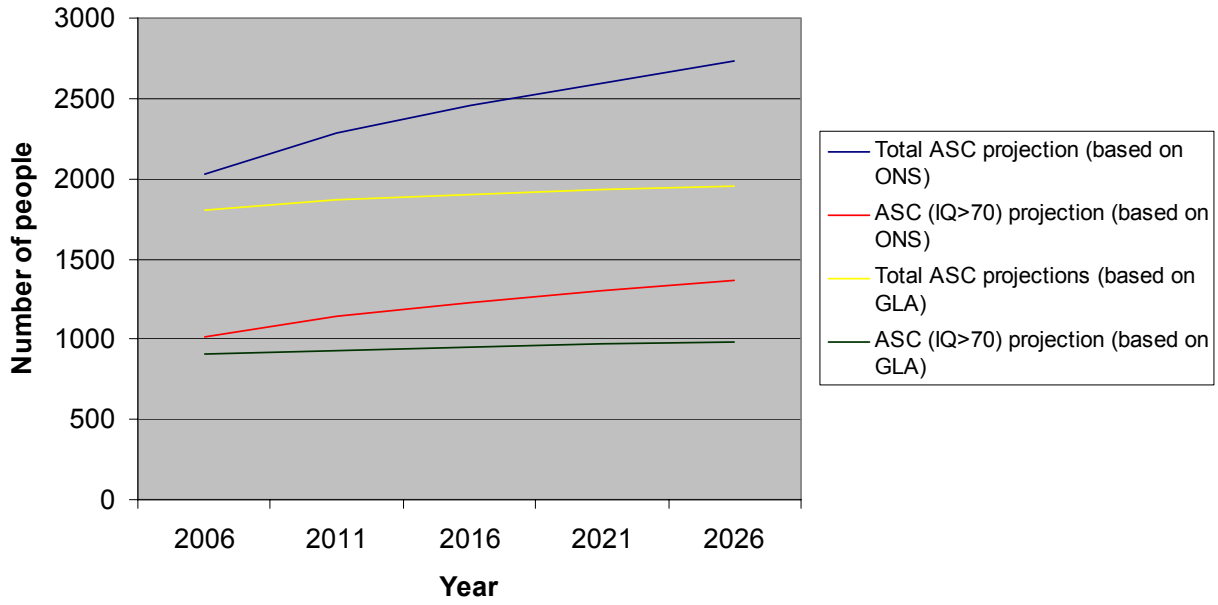
We would expect there to be equivalent proportions of the population with an ASC across Westminster wards due to the evidence suggesting levels of deprivation is not associated with prevalence. However, we may in fact expect differences related to areas due to social drift resulting in people living in areas of higher deprivation. The only information available that gives an indication of the location of people with an ASC in Westminster is through plotting the location of those in touch with Westminster Learning Disability Partnership. The vast majority are those with an ASC and learning disability.

A copy of the map cannot be shown for confidentiality reasons due to low numbers. As expected the majority of people with an ASC in touch with services live in the residential areas of the North West and South, however lower numbers than expected were located in the South. Six people live out of borough. There was slight concentration of people in the deprived wards of Queens Park and Church Street.

3.9 Future trends

The number of cases of ASCs identified has been increasing significantly over recent years. As mentioned in section 3.1 the causes of the increase have been attributed to better case ascertainment, changes in diagnostic processes, increased awareness in the community and so on. Although a change in causal factors cannot be ruled out, the aforementioned factors are likely to play a large part in the apparent increase of diagnoses and will continue to play a part in the future. Based on current prevalence levels of ASCs (1%) the number of people with an ASC in Westminster in the future can be expected to increase along with the expected increase in population. The estimated increase is shown in Figure 3 below.

Figure 4: Projected number of persons with ASC in Westminster based on population growth alone, 2006[4]-2026



Source: based on GLA and ONS projected population levels.

Projecting by how much the Westminster population will grow (and, therefore, projecting by how much the number of people with ASC will increase) is problematic.

Currently the Greater London Authority (GLA) and the Office of National Statistics (ONS) produce population projections for Westminster based on data derived from the 2001 Census. Overall, the ONS based estimates are thought to overestimate the projected increase in the size of the Westminster population, showing unrealistic population growth; this is largely because their methods do not take into account the onward movement of international migrants from Westminster.

GLA based population projections are thought to be more realistic as they take into account future housing capacity in Westminster and also make different assumptions regarding where migrants settle.

Generally GLA population estimates and projections are considered more accurate for planning purposes and service development, however, ONS population estimates are thought to be more useful for describing the current population and making regional and national comparisons. Given the uncertainty around how the population of Westminster will

[4] 2006 is used as opposed to 2008 due to predictions of population being provided in five year intervals from 2006 - 2026

change in the future, this needs assessment provides estimations based on both ONS and GLA population projections.

If further widening of the spectrum of ASCs occurs in the future, (as has been happening over the past few decades), then the prevalence of ASCs is likely to increase beyond what is expected based on population growth alone. However, given that the estimated prevalence of 1% is considered an overestimate, the increase in prevalence may be accounted for by using this estimate.

It is unlikely that there will be a significant increase in prevalence - the most significant difference will be seen in the increasing numbers of people identified and seeking diagnosis, assessment and in turn needing/expecting support and services. In addition, increased life expectancy means people are living longer and will therefore require support in later life.

As mentioned previously studies suggest there is no difference in prevalence between ethnic groups. When considering population projections based on ethnicity we would therefore expect prevalence changes to be equivalent between Westminster residents from different ethnic groups. The largest ethnic group of people in Westminster are of a white background therefore the largest increase is expected in this group, followed by the “other” ethnic group and those of Indian and Chinese background. This does have relevance however for the delivery of services due to the varying experiences of disability across ethnic groups.

4.0 Co-occurring conditions

A number of other conditions occur at a higher rate in people with an ASC compared to the general population. learning disabilities and difficulties, epilepsy, attention deficit hyperactivity disorder, mental health problems and other less common genetic conditions such as fragile X syndrome, cerebral palsy, phenylketonuria (PKU), neurofibromatosis, Downs-syndrome and other rare conditions all occur at higher rates than expected in the general population. The majority of these co-occurring conditions are rare; the most common are discussed below.

It is of relevance to know this information in order to effectively manage all conditions in the most effective way as well as identify people who may be undiagnosed.

4.1 Learning Disabilities and difficulties

It is estimated that 7.5% of people with a learning disability also have an ASC (Cooper 2007). The number of people with a learning disability over the age of 15 in Westminster was estimated to be 4,000 (Westminster Learning Disabilities JSNA 2009). Applying the estimation of 7.5% to this predicted number would mean 300 of those with a learning disability are also likely to have an ASC.

Estimations of the number of people with an ASC and co-occurring learning disability have been conducted, with varying results. It is reported that 30% of people with an ASC have normal to above average intelligence (IQ≥70), 30% have between mild-moderate learning disability and the remaining 40% have serious to profound learning disability (Fombonne 2005). Explanation of the different levels of learning disability can be found in the Learning Disability JSNA at http://westminstercitypartnership.org.uk/default.aspx.

The National Autistic Society suggests that approximately 50% of people with an ASC have normal to above average intelligence (IQ≥70) groups and the other 50% have below average intelligence (IQ<70) (NAS 2009). The difference is likely to be attributed to the NAS including all people with autistic like traits in their estimations, whereas epidemiological studied tend to be stricter in their criteria for inclusion in a study.

Applying the National Autistic Society prevalence estimates to the Westminster population, it is estimated that the number of people with an ASC and learning disability over 15 years of age is 1030.

4.2 Epilepsy

A number of studies have examined the association between ASCs and epilepsy, with a lower IQ being associated with a higher risk of having epilepsy (Tuchman & Rapin 2002;

Canitano 2007). A recent meta-analysis found that 21.5% of people with an ASC and a learning disability also had epilepsy, whereas 8% of those with an ASC and no learning disability had epilepsy. In addition females with an ASC were found to be at higher risk of having epilepsy than males with an ASC (Amiet 2008).

The lowest prevalence rate (4%) of epilepsy is said to be found in those with Aspergers Syndrome (Cederlund 2004) whereas the highest prevalence (77%) is found in those with childhood disintegrative disorder, a form of pervasive developmental disorder (Mourisden 1999).

It is important this medical condition is managed in this already vulnerable group. In addition there is potential for undiagnosed people with AS to be identified and referred for diagnosis through epilepsy services. Training of staff managing epilepsy would seem appropriate to ensure undiagnosed cases of AS can be referred for diagnosis and support.

4.3 Mental Health Problems

Evidence suggests that persons with an ASC are much more likely to have mental health problems than the general population, in particular depression and anxiety. Estimates of the prevalence of common mental health problems amongst persons with ASC vary from 16 to 35%, which is in comparison to the general population prevalence estimate of 16.4%, evidenced in the Westminster Mental Health JSNA (Bebbington et al 1997, Brugha et al 2001).

In a large scale survey of parents of adults with Aspergers Syndrome it was reported that 30% of those with Aspergers Syndrome had experienced a mental health problem at some point in time, over half experiencing depression (Barnard et al 2001). The presence of an ASC may potentially mask the appearance of a mental health problem due to the reduced ability of the person to convey feelings and emotions, therefore rates may in fact be an underestimate.

Based on Westminster's estimated prevalence of Aspergers Syndrome (ASC and IQ ≥70) and the abovementioned reported rate of 30% experiencing a mental health problem, we might expect at least 309 adults with an ASC to have a co-occurring mental health problem such as depression or anxiety.

The expression of autistic traits may be misinterpreted as a mental health problem. This has been found in a number of ASC cases in touch with Westminster Community Mental Health Teams, where a person has been previously misdiagnosed with a mental health problem for a number of years before obtaining the correct ASC diagnosis. This obviously has significant implications including the possibility of incorrect intervention/treatment provision and cost of care packages which may not be entirely necessary had the correct diagnosis and support been given at an earlier stage. The individual and family would also likely experience frustration and distress from an incorrect diagnosis.

Not all of those with an ASC experiencing a mental health problem will require specialist mental health services. The less severe, more common mental health problems such as depression and anxiety would most often require low intensity support that can be provided through primary care, such as a modified version of Cognitive Behavioural Therapy, which is shown to be effective in this population for the treatment of common mental health problems (Attwood 2003, Hare 2004, Anderson & Morris 2006). The traditional form of Cognitive Behavioural Therapy is not appropriate for those with an ASC due to their unique cognitive style and inability to use social imagination.

It is thought the majority of less severe mental health problems could be prevented if individuals are provided with timely support to access employment, educational opportunities, social skills training and social groups. Without the appropriate low intensity support mental health problems could escalate resulting in need for intensive high cost crisis intervention. This comes at a high social and emotional cost to the individual and financially can cost up to £300 per day (Curtis 2008).

Ensuring those with an ASC have access to primary care mental health services is important, as is ensuring preventative support such as employment, education, social skills training and social groups are made available. Lastly it is imperative staff in all mental health service are up skilled in how to identify and manage cases of ASC to facilitate access to diagnosis and appropriate intervention.

4.4 Attention Deficit Hyperactivity Disorder (ADHD)

Evidence suggests persons with an ASC can be misdiagnosed with ADHD in childhood due to the similarities in presentation of the two conditions (Ghaziuddin 2005). In addition, co-occurring ADHD and ASC is reported to be very high: up to 43% (Hofvander et al. 2009). The number of prevalence studies looking at co-occurring ADHD and ASC are minimal therefore this rate should be interpreted with caution. It may in fact confirm the theory of a high rate of misdiagnosis. Again, as above, this is a potential route for identifying undiagnosed or misdiagnosed cases of AS therefore staff in ADHD services should receive specialist training on ASCs.

4.5 Other less common co-morbid conditions

ASCs have been found to co-occur with a number of other genetic conditions, further supporting the strong genetic aetiological explanation for the condition. The definitions of these conditions can be found in the Glossary section. The most common co-occurring genetic conditions are described below. There is no evidence of any such cases in Westminster at present.

Fragile X Syndrome: This condition is the most common cause of inherited mental handicap with an estimated prevalence of 1 in every 1000 males and 1 case of generally milder mental handicap in every 200 females. In males it is characterized by moderate to

severe mental handicap, long thin faces with prominent jaws, large protuberant ears and autistic features. (WHO 1996). Fragile X syndrome is estimated to occur in 2.1% of ASC cases (Kielinen et al. 2004).

Phenylketonuria (PKU): this disorder is characterised by an increase in phenylalanine in the blood as the body is not able to produce the enzyme to metabolise it. If PKU is not treated, phenylalanine, which is acquired through a person's diet, can build up to harmful levels in the body, causing intellectual disability and other serious health problems. It has been associated with the expression of autistic traits if left untreated.

Tuberous sclerosis: Tuberous sclerosis is a condition where tuber like growths on the brain calcify with age and become hard. Abnormal tuberous sclerosis growths can affect almost any other organ of the body (including the skin, eyes, heart, kidneys and lungs) but they may cause little in the way of problems. The condition is said to occur in 1 in 7,000 of the population, though many are unaware they have the condition as it does not cause problems in all people. Approximately 25% of people with tuberous sclerosis are autistic and another 25% show aspects of autistic spectrum disorder, including higher functioning autism or Aspergers Syndrome (Tuberous Sclerosis Association 2001). Estimates of prevalence in those with an ASC ranges from 0-4% and as high as 8-14% in those with an ASC and seizure disorder (e.g. epilepsy) (Volkmar et al. 2005, Wong, 2006, Smalley, 1998).

Neurofibromatosis: Is a genetic condition that can cause mild learning difficulties, or at the more serious end can cause hearing loss, deafness and mobility problems. (Neurofibromatosis Association UK 2009). It has been associated with autistic traits.

5.0 Issues affecting people with an ASC

5.1 Diagnosis

It is predicted that the number of adults living with an ASC but who do not have a diagnosis is high, which is supported by the disparity between the number of people identified as having an ASC compared to the estimated prevalence of ASC in Westminster. It is also confirmed by the low number of people receiving diagnosis funded by Westminster mental health services and learning disability services, both of whom have funded less than 5 new diagnoses per year since 2006. Westminster's neighbouring boroughs, such as Camden and Islington fund at least 15 out of borough diagnoses per year. Consultation with Westminster residents with an ASC also confirmed access to diagnosis is extremely difficult.

Timely diagnosis is important for a number of reasons. Delayed diagnosis can have detrimental effects on the family and individual and can also result in a higher likelihood of misdiagnosis with a mental health problem (NAS 2009). Characteristics of an ASC can be mistaken for a mental health problem, or in some reported cases can be misdiagnosed as attention deficit hyperactivity disorder (Ghaziuddin 2005). This can result in expensive ineffective mental health intervention being provided when it is not needed. Appropriate intervention for the ASC could prevent high cost unnecessary treatment for a condition the person does not have.

It is understandable that the individual (and their family) would want a diagnosis to understand why they are the way they are and what strategies or interventions could improve their quality of life as well as open up access to financial assistance. Being able to access appropriate ASC specific support services with staff that understand the condition would also be beneficial.

Gould (unpublished, 2010) also suggests diagnosis is important as many undiagnosed people with an ASC are inadvertently involved in the Criminal Justice System that may have been avoided had they had a correct diagnosis and support earlier.

5.2 Employment

Employment levels among people with an ASC are very low. According to Barnard et al's (2001) study for the National Autistic Society, the rate of employment among those on the lower functioning end of the spectrum is as low as 2%, those in the higher functioning end of the spectrum have an full time employment rate of approximately 12%, 6% for part time employment. If applied to the Westminster ASC population of working age (18-64 years) we might expect at best 349 people to be in some form of employment, out of a possible 1746 people with an ASC.

The barriers to employment are thought to be linked to the social difficulties experienced by people with an ASC who by the mere nature of their condition struggle to participate in work environments that are often highly social settings. Lack of understanding of ASCs from employers and colleagues has also been suggested as a barrier experienced by people with an ASC. The expected skills needed in a work place, such as time management and organisation are also not natural abilities of many people with an ASC, which would also impact on ability to maintain employment.

From interviewing a number of Westminster residents with an ASC the issue of employment came out as a key priority. Most of those interviewed were currently unemployed and claiming disability benefits. Most reported they would like to work either part time or full time but required help to do so.

5.3 Education

Evidence suggests people with an ASC can find certain aspects of education difficult such as coping with the social or physical environment and managing time (Breaky 2006). In addition, lack of understanding and awareness of university or college staff in regards to ASCs and the difficulties students may face can also result in further barriers and potential drop-out. Further education, including university, college and vocational courses can improve employability and future outcomes. Education, both formal and informal such as leisure courses, can also improve quality of life and decrease social isolation.

Through the interviews conducted with Westminster residents with an ASC the need for support when undertaking further or higher education was evident. One poignant comment from one interviewee summed up the difficulties faced: “I find coping with life difficult enough without studying”. Those wanting to study commented they could only do so with support and understanding from classmates and teachers.

5.4 Housing

According to the National Autistic Society (2008b) 40% of adults with an ASC live at home with their parents. Through interviews with Westminster residents with an ASC it was clear that access to housing was an issue for both the individual and their family. Although some of the interviewees lived independently, loneliness and isolation were impacting on their lives considerably. In one case an interviewee had lost a significant amount of weight since moving into his own apartment, due to not wanting to eat alone. The issue of safety was also raised in one interview where the interviewee had been followed home and subsequently robbed and sexually abused.

Although it was evident that the interviewees wanted independence they also required a significant amount of assistance and support to do so, such as help with paying bills, cooking and cleaning. This is supported by the National Autistic Society “I exist” report (NAS 2008b) which showed most people with an ASC need some form of daily support, some more intensive than others. Much of this is thought to currently be provided by

families and carers, however if the drive for independence is to be realised people with an ASC will require some level of practical support and/or training.

It is important to encourage and support independent living if that is the wish of the individual, however, the appropriate support and personal protection will need to be in place, even for those on the higher functioning end of the autistic spectrum.

5.5 Social inclusion

People with an ASC experience high levels of social isolation and exclusion (NAS 2008). The characteristics associated with an ASC, such as impairments in social interaction, social imagination and social communication mean developing friendships and social networks can be extremely difficult. This area is seen as a high priority in the National Autism Strategy consultation paper and was also confirmed through the interviews conducted with people with an ASC in Westminster. Issues of loneliness, isolation, lack of friendships and social networks were all consistent themes in discussions.

5.6 Advocacy

Access to advocacy services is considered extremely important for people with an ASC (NAS 2003, Aman 2005). People with an ASC and no learning disability still have a high need for advocacy to promote their rights and independence as well as facilitate access to housing and employment. This area of work should be a priority due to the potential positive impact on independence and the prevention of already vulnerable adults becoming more at risk of negative outcomes.

The nature of the condition including impaired ability to communicate can mean a person may require help to express their needs and promote their rights. Advocacy may be needed at different points in time such as during transition from Children to Adult services, when a person is seeking to access housing, employment or other social and health services.

5.7 Safe-guarding

According to the National Autistic Society (NAS 2008b), 56% of adults reported they had been bullied or harassed as adults. The inherent nature of the ASC means a person can come across as “odd” and potentially be a target for abuse and bullying. As mentioned in the section on housing, one of the interviewees consulted had experienced sexual abuse and theft after being followed home one day. This is obviously of extreme concern. In addition, whilst attending a Westminster Learning Disability Partnership meeting, another case of bullying was raised by a staff member, in which a person with an ASC was being regularly targeted and bullied, to the extent where police may have to be called.

5.8 Criminal Justice

A review of published studies looking at criminality and its association with ASCs reveals the majority refer to case studies of individuals and the prevalence studies conducted have produced equivocal results (Allen 2007). Relatively recent community studies (Woodbury-Smith et al 2006) have revealed rates of offending are in fact lower than the general population. The varied findings of published studies suggest it is an area requiring further investigation using more robust study design. Currently there are no people with a recorded ASC diagnosis in touch with Westminster Forensic Services.

There are a number of characteristics of ASCs that potentially put people with this condition at higher risk of being the victim of crime or offending, as well as being highly vulnerable if they come into contact with the criminal justice system. Features of the condition, such as the inability to understand social norms; increased likelihood of being socially misunderstood; obsessive interests; apparent lack of empathy; impaired communication and literal interpretation of language are all factors that theoretically could put a person with an ASC at higher risk of coming to the attention of police and increasing their vulnerability when in touch with the criminal justice system. This has implications for services such as police, forensic services and the courts. The National Autistic Society has recognised this as a significant issue and has made a number of recommendations for police and the criminal justice system when dealing with a potential offender with an ASC.

Police services in Westminster do not currently receive training specifically on ASCs and the impact this condition may have on a person's interaction with the criminal justice system. Police services that were contacted for this needs assessment suggested ASCs would be picked up as a mental health condition and police doctors would be made aware of the case if warranted. There are also specially trained police interviewers who are said to possess the skills necessary to interview a person with a mental health condition, which has been extended to cover those with an ASC. It would appear police services are confident in their abilities to identify and manage people with an ASC, however further investigation and work may be warranted if ASCs are found to be significantly associated with being a victim of crime or criminality.

5.9 Cultural Constructs of Disability

Considering Westminster has an extremely diverse ethnic makeup, it is essential to understand and keep in mind the potential impact this has on the identification, diagnosis and support of people with an ASC. Although the available evidence does not suggest a difference in prevalence of ASCs between ethnic groups, the experience of this condition is likely to vary considerably between ethnic groups. Much of the research available on the role culture plays in the identification, diagnosis and experience of ASC has been published in the USA. Lessons learnt from these studies are still relevant to the UK as the general "multi-cultural" makeup of the two countries is somewhat comparable.

Identification and diagnosis of an ASC in some ethnic groups may be delayed for various reasons. Possible reasons for this may be that developmental problems signalling a possible ASC may not be considered problematic in some cultures, such as the avoidance of eye contact or hyper-active behaviour. Evidence also suggests developmental milestones used to assess an ASC are culturally specific therefore delayed development may not be recognised. In addition potential stigma surrounding disability or a reluctance to "label" a child could also play a role in preventing early diagnosis (Dyches et al. 2004).

In addition to the potential delay of diagnosis, once a diagnosis is made other issues may impact access to support services. Previous experience with authority, knowledge of rights, reluctance to accept help outside the family and the cultural acceptability of services provided may all impact on the readiness for families to access support. Lastly, the perceived causes of the condition can be influenced by different cultural beliefs, which in turn can affect treatment choices (Dyches et al. 2004).

The above mentioned issues are not exhaustive but indicate the importance of considering the role culture plays in the diagnosis and support provided for people with an ASC. Existing and new services must keep this in mind and efforts to raise awareness and train staff should also keep these issues at the forefront.

5.10 Outcomes for people with an ASC

There have been a number of studies looking at the outcomes for children born with an ASC. In the majority of studies adults diagnosed as children with an ASC experience predominantly negative outcomes in relation to independence, relationships, employment and housing. There is general agreement that outcome is significantly associated with IQ level and early language development, however external factors such as schooling, improved transition from child to adult services, supported employment schemes and housing are also said to be important (Howlin 2004a).

A small number of studies have followed people diagnosed with Aspergers or High Functioning Autism. Although people with Aspergers Syndrome and High Functioning Autism have IQ levels in the normal to above normal range (IQ≥70), most studies have reported negative outcomes for a large number of those followed up in adulthood. Issues with employment, independence and lack of friendships were again evident.

5.11 Suicide

Although limited studies have looked at suicide rates in people with an ASC, the descriptive studies conducted have suggested risk of suicide is greater among those with an ASC, in particular Asperger Syndrome (Howlin 2004b). This is not surprising considering the significant association between depression and ASCs. It would seem efforts should be put into preventative work to decrease the factors associated with depression in people with an

ASC to prevent and better manage depression, which would in turn decrease the risk of suicide attempt.

This is further supported by the recent Suicide Needs Assessment available at: http://westminstercitypartnership.org.uk/default.aspx. In this needs assessment it is reported the risk of suicide is greatly increased in those with a mental health problem.

5.12 Mortality

A small number of studies have compared mortality among those with ASCs and the general population (Shavelle et al. 2001; Mouridsen et al. 2008), suggesting the mortality rate of people with an ASC is higher than the general population. The studies have shown an increased standard mortality ratio[5] (SMR) for people with an ASC compared to the general population, however caution should be taken when interpreting results due to the small sample sizes of the studies.

In the Shavelle study the Standard Mortality Ratio (SMR) was 2.4, indicating a mortality rate more than twice as high as expected compared to the general population. Similarly Mouridsen et al's Danish study (2008) calculated an SMR of 1.9. Interestingly in their study Mouridsen found the overall SMR higher for females (SMR=4.01) than males (SMR=1.57), an association also found in Shavelle's study. IQ levels were not found to be statistically significant with respect to mortality risk in Mouridsen's study, but were found to be significant in Shavelle's study.

Epilepsy, infectious diseases and accidents were implicated in the majority of deaths in the Mouridsen study, however due to the small sample size it was not possible to compare cause-specific death rates to that expected in the general population. Mortality due to Epilepsy is known to be two to three times higher than in the general population, particularly in younger people (Annegers & Coan 1999). In Shavelle's study those with no or mild ID died from seizures, nervous system dysfunction, drowning and suffocation at a higher rate than would be expected in the general population.

It is important to understand the causes of death and SMR for people with an ASC so appropriate management and preventative strategies can be put in place. Clearly attention should be given to identifying, monitoring and managing Epilepsy in people with an ASC as well as ensuring sufficient supervision is provided to prevent infectious disease and accidents in this vulnerable group. The inability of some people at the severe end of the Autistic Spectrum to effectively communicate may impede their ability to convey pain or discomfort. This should also be kept in mind by staff and families when monitoring general health and well being.

[5] Standard Mortality Ratio is a measure used to compare the observed number of deaths compared to the expected number of deaths in a population group. An SMR greater than one indicates the observed deaths exceeds the number of deaths expected.

6.0 Parents, siblings and carers

ASCs can have impacts on the families and carers which need to be understood so better support can be provided to carers and families, which in turn can prevent a breakdown in family support. Evidence suggests parents of children with an ASC have a higher than average risk of experiencing poor mental and physical health, in particular if the care needs of their child with an ASC is not met (Hare 2004). The established genetic connection also means a small number of siblings and parents also show autistic like traits (Ghaziuddin 2005). Barnard et al (2001) also suggests the families of a person with an ASC experience adverse impacts, in particular if diagnosis is delayed.

Family members and carers of a person with an ASC are likely to require support in their own right, to care for the person with an ASC but also to care for themselves. The needs of carers have been the subject of a recent needs assessment available at: http://westminstercitypartnership.org.uk/default.aspx.

Westminster Learning Disability Partnership provided information on the number of people with an ASC that were known to have a carer. According to their records 25 out of 72 people with a confirmed or suspected diagnosis of an ASC had a carer providing significant amounts of care and were therefore eligible for a carer's assessment. Carers Network Westminster may provide carer assessments but does not record an ASC as a diagnosis so cannot provide the number of carers supporting people with this condition. It is likely there are more carers than the number identified by Westminster Learning Disability Partnership, however the exact number is not known.

As has already been established, most people with an ASC and IQ of 70 or above are not eligible for a service from Adult Social Services, therefore carers of those ineligible for services would also not be receiving an assessment of their needs and subsequent support. Even if they are not eligible for a formal assessment of their needs (due to not meeting the statutory definition of a "carer"), it is imperative carers of people with an ASC are offered appropriate support and information to mitigate against the negative impacts of caring such as increased stress, poor health and potential breakdown in care for the person with an ASC.

7.0 Staff awareness of Autistic Spectrum Conditions

7.1 Primary Care

Primary care services, in particular General Practitioners, are the gatekeepers to the rest of the health and social care system for people with an ASC. ASCs are not a medical condition therefore medical management of an ASC alone is not required. However, if a person has a medical condition in addition to their ASC, such as epilepsy or a common mental health problem such as depression, they may require further support from their GP or primary care.

Currently people with an ASC and IQ≥70 are not eligible for Adult Social Services therefore the role their GP may play in managing their condition could be more significant. According to research recently conducted by the National Audit Office (2008), 80% of GPs felt they required more training to identify and manage people with an ASC.

Westminster does not currently have a GP training programme related to ASCs, therefore this is an area that requires development.

7.2 Health and Social Care Staff

A number of meetings were held with staff from NHS Westminster and the local authority. It became evident from the consultations that the level of awareness of ASCs is variable across services. Staff from Westminster Learning Disability Partnership appear more confident in the identification and management of ASCs compared to staff from Mental Health Community Mental Health Teams. From consultation it was apparent many Community Mental Health Team staff are not confident in their skills or experience to deliver effective care to people with an ASC in touch with their service.

Westminster Learning Disability Partnership staff are thought to be more confident due to the fact that there are a high number of people with an ASC on the lower functioning end of the spectrum already in touch with Westminster Learning Disability Partnership services. Another factor that appears relevant is the presence of a small number of staff members in the Westminster Learning Disability Partnership who have a particular interest in the condition and have therefore taken a lead role. Anecdotally the Westminster Learning Disability Partnership Clinical Psychologist and Consultant Psychiatrist have offered yearly ASC training for staff from Westminster Learning Disability Partnership but have seen relatively low attendance.

The low level of identification and diagnosis of ASCs in Westminster, together with the number of misdiagnoses, suggest that the level of awareness and understanding of ASCs is quite low amongst most staff in health and adult social care settings. The unique nature

of the condition, and often hidden difficulties experienced by people with an ASC, mean all health and social care staff need to be more competent in identifying people with a potential ASC and referring them to services where they can access diagnosis and appropriate support. In addition, mainstream services need to be equipped with the knowledge to better serve this group, due to many not being eligible for specialist support.

8.0 Services in Westminster

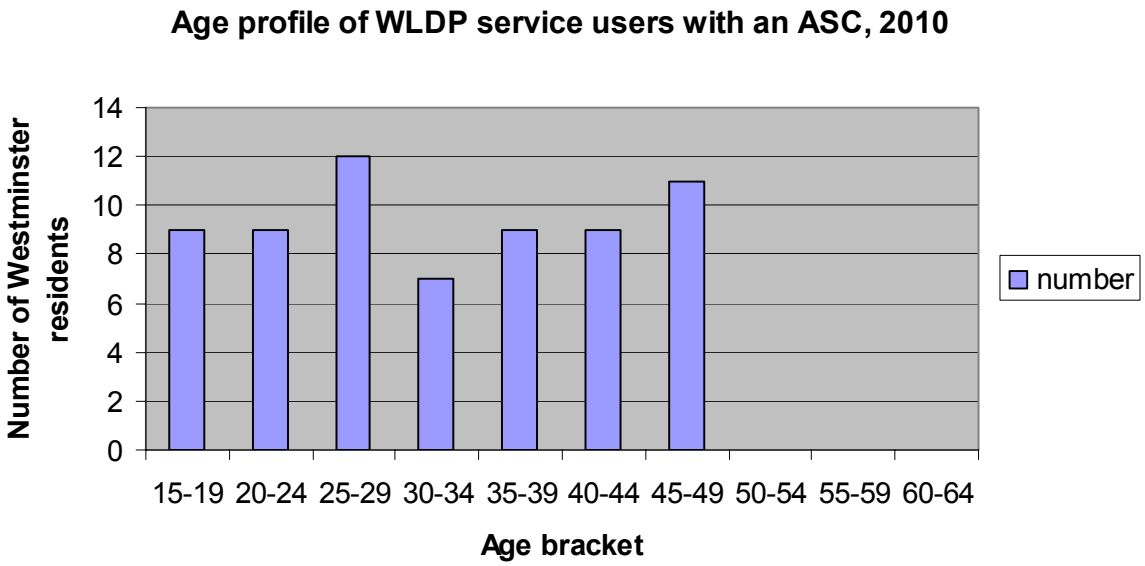
8.1 Westminster Learning Disability Partnership (WLDP)

Westminster Learning Disability Partnership provide services to people with a learning disability (IQ<70). This includes a number of people with an ASC and learning disability. WLDP were asked to provide the numbers and characteristics of the population of people with an ASC and learning disability that they are in contact with. In past years IQ level was not used to determine eligibility for services, therefore a small number (under 5) of people with an ASC and an IQ≥70 are provided with WLDP services. Currently people with an IQ≥70 are not eligible for WLDP services, which means those with High Functioning Autism and Aspergers Syndrome are not eligible for services.

Learning disability services are in contact with 48 people who have a confirmed diagnosis of an ASC. A further 24 people are "suspected" to have an ASC but have not received a confirmed diagnosis. The vast majority of people with an ASC receiving services from WLDP have an IQ below 70, which is an eligibility criterion for the service. This compares to the estimated 1030 people with an ASC and co-occurring learning disability in Westminster, suggesting low identification and under-diagnosis.

There are less than 5 people in the 50-54, 55-59 and 60-64 years age group (numbers less than 5 are not stated for confidentiality reasons). We would expect a higher number in the 30-34 age bracket due to there being a higher number of expected people with an ASC in this age group. We also have a higher than expected number of females in touch with WLDP (33% compared to expected 20%). In relation to ethnicity, many of the numbers are below 5 therefore data cannot be presented. Overall the expected ethnic breakdown is as we would estimate, however the numbers from Asian ethnic groups are lower than expected.

Figure 5: Westminster residents with a confirmed or suspected ASC diagnosis in touch with Westminster Learning Disability Partnership, by age



8.1.2 Community Access: Westminster

Community Access Westminster is part of the Westminster Learning Disability Partnership and includes a number of "day services" that provide support to people with an ASC. The services aim to integrate people with an ASC into the community as much as possible. Community Access is made up of a number of services which have been very briefly described below.

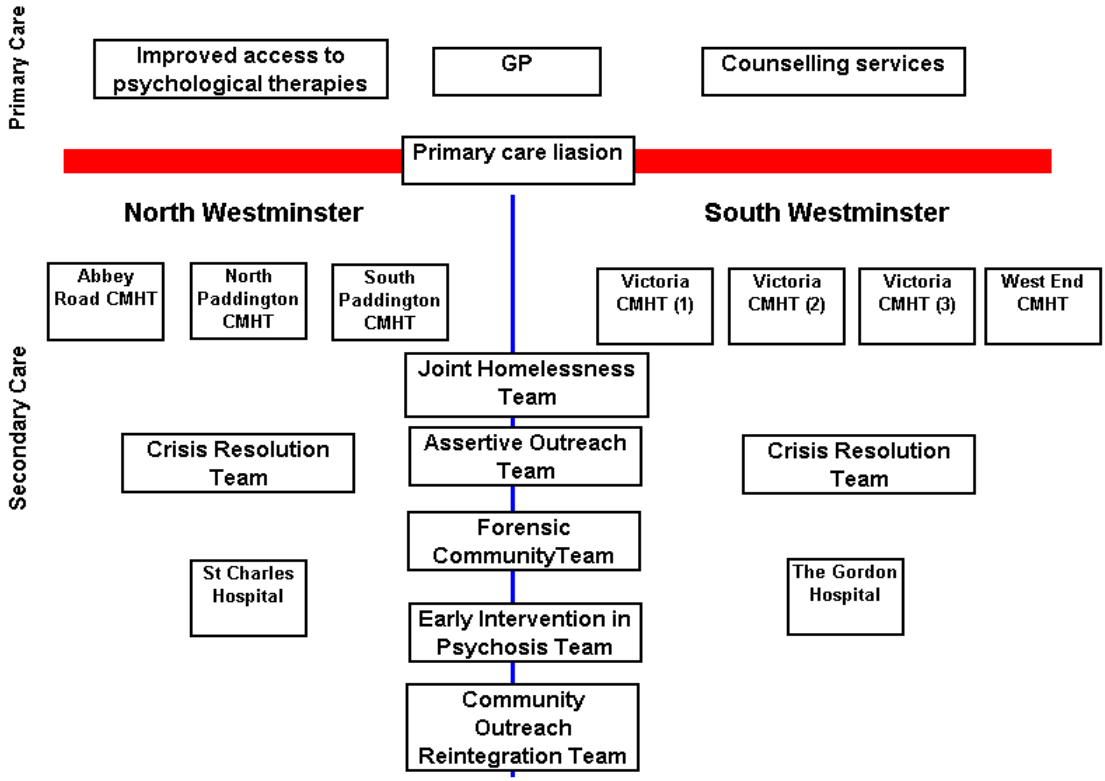
- *131 Droop Street:* This service supports people who have profound and complex learning and physical disabilities often with associated underlying health problems.
- *Buildings and Community Service:* This service supports people with highly complex problems to participate in the community as much as their coping mechanisms and abilities allow them to participate.
- *Flexible Response Service:* This service was developed as a result of a number of people identified who were unable to participate in current day service provision due to their challenging behaviour and or family concerns.

- *Community Support Team:* This service is a community based service therefore people are supported directly to and from their homes and are encouraged to be independent and empowered to advocate for themselves.
- *219 Lisson Grove:* This service actively promotes a person centred approach, working to empower and provide flexibility and choice to people who have difficulty in communicating verbally.
- *Greenhouse:* This community based leisure service provides person centred activities and support to older people with learning disabilities.

8.2 Mental Health Services– Central North West London (CNWL)

The spectrum and severity of conditions that encompass mental health problems is both broad and complex. Accordingly, the services that deliver care to and manage individuals with mental health problems are numerous and the pathways into and between these services are sometimes difficult to navigate. An overview of primary and secondary mental health services is shown below.

Figure 6: Mental health services in Westminster



Community Mental Health Teams (CMHT) are part of CNWL, the main provider of mental health services in Westminster. CMHTs provide community services to people with a severe and enduring mental health problem, such as a Psychotic Disorder. Only those with

a severe enduring mental illness are considered eligible and the threshold for access to these services is set relatively high. Unless they have a mental illness that warrants a secondary mental health service, a person with an ASC will not normally be able to access secondary mental health services.

Community Mental Health Teams have supported 12 people with an ASC between 2000-2009. The majority of individuals have a recorded diagnosis of Aspergers Syndrome (9 out of 12) and a co-occurring common mental health condition (depression, anxiety, obsessive compulsive disorder, personality disorder). All were male and of white British or white "other" ethnicity.

Each Community Mental Health Team was requested to provide further information on the clients with an ASC they have on their caseload. From the responses received, it was evident most of the clients had received an original misdiagnoses, most commonly schizophrenia or personality disorder and had only been diagnosed correctly with an ASC at a relatively late age. A number had not actually received a diagnosis but were suspected to have an ASC. Many of the clients had expensive care packages and in some cases were in residential housing.

Many staff reported a very low level of confidence in supporting and providing intervention to their clients with an ASC and were keen to receive training. However, as pointed out by one respondent, the number of clients with an ASC they come across is small so there would be a risk newly acquired skills would be lost if not regularly put into use. It was suggested staff should have access to specialist input to support them in providing intervention and care to people with an ASC.

Although Aspergers Syndrome is not a mental health condition, anecdotally these service users have all had extremely severe behavioural and functional difficulties that have warranted intervention and Community Mental Health Teams were the only service able to provide care to this group. It is not known how appropriate the care provided to this group has been. It appears this group have ended up in this service because there was nowhere else for them to go. This is obviously not an ideal situation and warrants further attention to ensure this group are receiving appropriate care and intervention for their ASC.

The number of people with an ASC admitted to Central North West London in-patient facilities is very low (under 5) since 2000.

As mentioned, the vast majority of people with an ASC would not require, nor would be eligible for, secondary mental health services, such as that supplied by Westminster's Community Mental Health Teams. The most common mental health problems experienced by people with an ASC could be managed by primary care. It is not known how many people with an ASC have accessed primary mental health services. Once the new Improved Access to Psychological Therapies services are up and running, data recording and monitoring of the number of people with an ASC accessing this service will be easier to obtain.

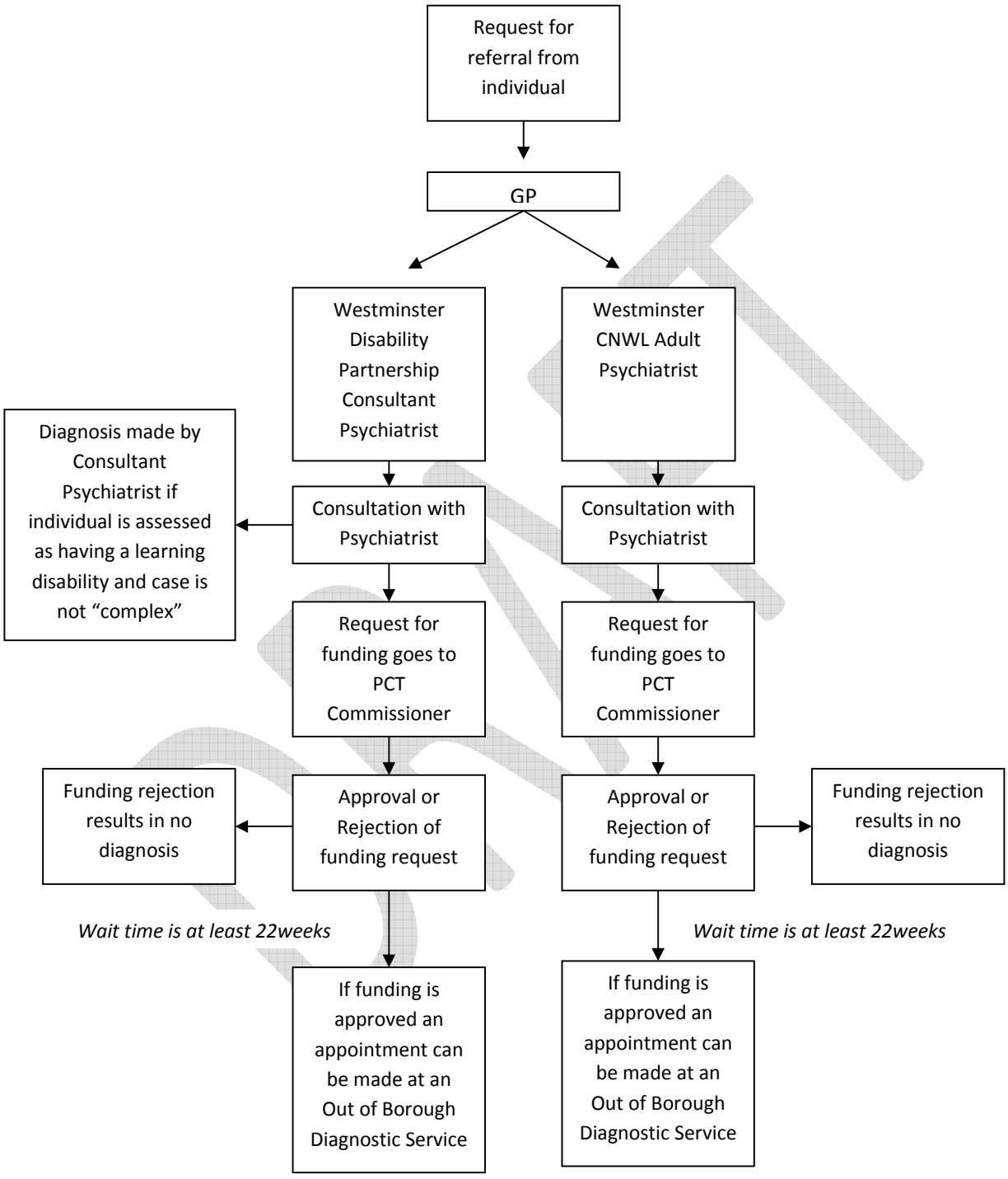
8.3 Primary Care Services

The primary care services relevant to people with an ASC consists primarily of General Practitioners and primary mental health services. ASCs are not medical conditions therefore GPs are not likely to be accessed unless a person is seeking referral for diagnosis or to manage co-occurring medical conditions.

8.4 Diagnostic services

The Maudsley Centre for Behavioural Disorders and the Lorna Wing Centre (part of the National Autistic Association) provide an out of borough diagnostic service for people suspected to have an ASC, including people living in Westminster. A request for diagnosis comes from GPs in the first instance and is then passed to psychiatry (either in Mental Health Services or Westminster Learning Disability Partnership). The request for diagnosis then goes to the Westminster PCT commissioner for funding approval, which is (anecdotally) said to happen without delay.

Figure 7: Current pathway to a diagnosis of an ASC



The centres usually take referrals for complex cases however waiting times are said to be very high (up to 22 weeks for the Maudsley Centre). In order for funding to be approved referrals must first go through the Consultant Psychiatrist of Westminster Learning Disability Partnership or Mental Health Services, greatly increasing waiting time and resource use. Diagnoses are approved on a cost per case system by the PCT. Westminster does not have a block contract with either centre so applications for funding are assessed on a case by case basis. Since 2006 less than five diagnoses were funded by Westminster Learning Disability Partnership and approximately six have been funded by mental health services over this time.

The Westminster Learning Disability Partnership Consultant Psychiatrist has made approximately 12 diagnoses over this period of time, however these were all for cases where it was evident the person also had an IQ of below 70 therefore would be considered eligible for Westminster Learning Disability Partnership services. Those with an ASC and IQ above 70 are usually not eligible to access a diagnosis due to being ineligible for a service.

Access to diagnostic services appears to be difficult and waiting times unacceptably long. The process a person needs to go through to obtain a diagnosis is complicated, lengthy and in the end costly to the PCT through having to purchase services out of borough. This is inconsistent with best practice.

8.5 Assessments

Currently Westminster Learning Disability Partnership conduct Fair Access to Care (FAC) Assessments for people with an ASC and learning disability (IQ<70). A small number of FAC Assessments have been conducted by secondary mental health services where the person has an ASC and IQ≥70 but is experiencing severe difficulties, which is reportedly to be most often due to a breakdown of carer support leading to the person requiring social service support. As the current eligibility criteria stands, those with an ASC and IQ≥70 are not eligible for a FAC Assessment of their needs, this goes against FAC guidelines which state a persons needs should be assessed regardless of their diagnosis or IQ level. In addition, it is unclear whether those that perform a FAC Assessment for this group are trained in the needs of people with an ASC. This may result in a person being assessed as more able than they in fact are due to the often hidden difficulties experienced by this group.

8.6 Employment support

Westminster Learning Disability Partnership has a contract with Westminster Employment to provide employment support to people with an ASC and learning disability. This means people with ASC and no learning disability (IQ≥70) are not eligible to access this service. Westminster Employment are also contracted to provide employment support for people with a learning disability coming through Job Centre Plus, therefore people with ASC may

come into contact with the service through this avenue. The Routes to Employment Programme is open to people who are under Community Mental Health Team care management, therefore the small number of people with Aspergers Syndrome eligible for this service may receive employment support through Routes to Employment.

People with an ASC may also come into contact with Job Centre Plus Disability Advisers. People with ASC and no learning disability can often come across as more capable than they in fact are through their learnt coping abilities. Currently Job Centre Plus Westminster provides support to under five people with an ASC and no learning disability. The Adviser assesses the individual's employment support needs, helps them decide what they would like to do, supports them with their CV and to prepare for applications and interviews. The advisers also consult with potential employers about how they can make reasonable adjustments to employ a disabled person. Referral routes to Disability Advisers range from self referral, job centres, GPs and Westminster Employment. Anecdotally, the main barrier Disability Advisers face is the lack of knowledge of employers about ASCs.

Training for Job Centre Plus Disability Advisers receive training on ASCs. Currently ASCs are included in training for new Disability Advisers but many existing Advisers may not have received training.

8.7 Safe guarding services

The safe-guarding team in Westminster have no record of cases of people with an ASC accessing safe-guarding support. Anecdotally, from attending a Westminster Learning Disability Business Meeting, a case was discussed where a person with an ASC in touch with Westminster Learning Disability Partnership was under threat in the community through bullying. This case was to be taken to the Safeguarding team. It appears there is a need to be aware of the threats to vulnerable people with an ASC who are at risk and may require referral to the safe-guarding team in the earliest possible stage to prevent escalation.

8.8 Advocacy Services

Westminster provides most of its advocacy services through "The Advocacy Project". Within this service is a Westminster Learning Disability Partnership specific project "Our Choice" which promotes the rights of people with a learning disability. This service is open to people with an ASC and learning disability, however specific diagnoses are not kept by the project manager of "Our Choice". Anecdotally it is thought less than five people with an ASC and learning disability have been in touch with "Our Choice". It is imperative people with an ASC and learning disability are engaged and offered a voice in this project. The methods needed to engage with these people may be different to traditional engagement models due to the communication and sensory difficulties experienced by people with an ASC. This should be kept in mind when attempting to engage and include people with an ASC in advocacy services.

In relation to those with an ASC and no learning disability (i.e. IQ≥70) there appears to be no advocacy service currently available to meet needs. The Advocacy Project are aware of this gap in service provision and report five people in the past year have not been provided a service due to their ineligibility for services. People with an ASC and no learning disability also have a high need for advocacy to promote their rights and independence as well as facilitate access to housing and employment. This area of work should be a priority due to the potential positive impact on independence and the prevention of already vulnerable adults becoming more at risk of negative outcomes.

8.9 Westminster Housing

Westminster's Supporting People Team provides supported housing to a small number of people with an ASC. Five people with a confirmed ASC diagnosis are currently in mental health supported housing. Westminster Learning Disability Partnership provides housing to 9 people with an ASC and learning disability. The Westminster Learning Disability Partnership service is a "shared living" environment run by Yarrow. Anecdotally this service does not appear to be meeting the needs of this complex group with very high needs due to the sensory difficulties experienced by those within the service. The service is due to be re-modelled to suit the needs of people with an ASC by 2012.

The eligibility for supported housing for those with an ASC and no learning disability is unclear-they are not a priority group per se. The importance of access to housing for this group is clear due to such a high number still living with their parents (at least 40% according to the National Autistic Society), however with low levels of employment and lack of practical daily living support this is made extremely difficult.

8.10 Further and Higher Education

The exact number of Westminster residents with an ASC in further education or higher education and the rate of drop-outs are not currently recorded. National data is also not recorded so cannot be applied to the Westminster population. In relation to universities, students can opt to declare whether they have a disability and the nature of that disability. National data suggests the number of people with an ASC accepted to a university course has increased from 139 to 706 (equivalent to a 408 % increase) between 2003 and 2008 (UCAS unpublished). This cannot be broken down into Westminster residents specifically.

Universities are obligated to provide support to students with a disability and students may be eligible to receive Student Disability Allowance which can be used to purchase a personal support assistant or mentor. National data suggests over half the students with an ASC in the UK receive a Student Disability Allowance. Westminster University report they see a very small number (under 5) of people with an ASC per year and these people are supported by Disability Advisers. However, many staff in the university report they are not confident knowing how to best support these students and further work in this area would

be welcomed. It is imperative services are aware this is available to potential students and help is given to students to access this benefit.

Westminster Adult Education Service and City of Westminster College have provided data on the number of people with an ASC coming through their vocational and leisure courses, if the student chose to declare their disability. Numbers are said to be an underestimate as many students may not wish to declare their disability.

8.11 Westminster Adult Education Service (WAES)

The Westminster Adult Education Service runs a separate service provision for adults with a learning disability, which serves those with an ASC and a learning disability. Courses can be vocational (such as Computer Courses) or for leisure. It is reported many of the students in the specialist provision have multiple complex problems and can have multiple conditions. In 2008 less than five people with an ASC and learning disability attended a course at WAES through the special programme. Again under five people with an ASC and no learning disability attended the special programme, but it was felt this was not appropriate to their needs. The service also reported, during 2008, less than five people with an ASC and no learning disability accessed a mainstream course. Those attending the mainstream course were said to need assistance and support to facilitate their learning in the course.

The WAES can access funding for a specialist support worker to assist a person with a disability (which includes Aspergers Syndrome) if that person requires assistance and is undertaking a skill development course. The funding for the support worker is not available for courses deemed for “leisure” interests.

City of Westminster College
City of Westminster College provides a number of further education courses to people with an ASC. There are specialist support workers to assist students with a disability, including an ASC. There is also a discrete provision service for people with a learning disability which also takes people with an ASC and learning disability.

In 2008 seven people with an ASC attended the college, this does not include those who did not declare their disability, therefore is thought this is an underestimate. Anecdotally the college believes a small number of students have an ASC but do not have a diagnosis.

8.12 Social Inclusion

In Westminster “The Key Club”, located at Paddington Arts Centre, appears to be one of only two support groups available to people with an ASC (only for those on high functioning end of the spectrum and aged 16-26 years). No Westminster residents with an ASC are currently attending the group. The service also reported they are currently running at close to full capacity. The National Autistic Society runs a social group based in Paddington, but

is not exclusively for Westminster residents. The Ladbroke Grove National Autistic Society also provides a social group for people with an ASC but only to those eligible for Social Services, which means those without a learning disability are not eligible.

Evidence also exists supporting the introduction of social skills training for people with an ASC (Howlin 1999). Although research in this area is minimal, the outcomes seen from this intervention appear positive. There is currently no social skills group offered in Westminster.

9.0 Transition and an overview of Children's Services

Meetings were held with key "Transition Team" members as well as those representing the main services that come into contact with children with an ASC in an attempt to determine the number of children with an ASC in Westminster, changes in diagnostic trends, transition planning and future needs. Through conducting this piece of work focussing on adults with an ASC, it became evident that an assessment of unmet need would be useful in relation to children with an ASC. Evidence is emerging around the effectiveness of Intensive Early Intervention for children with an ASC and staff from the Children's Services involved in consultations were also keen to have the unmet needs of children with an ASC looked at in more detail. However, the scope of this paper did not allow for this to occur.

The "Transition Team" oversees the transition of children from Children to Adult Services. Planning for transition is supposed to start at age 14. The Team has representatives from Children and Adult Services. Decisions are made on which Adult Social Service Team is best placed to support children who are receiving support from Children Services. In cases where the team are unsure whether a person is eligible for an Adult Service they will be referred for further investigation into their needs.

In the case of children with an ASC, those with an ASC and learning disability are referred to Westminster Learning Disability Partnership. Currently, if a child is known to have an ASC and IQ≥70 they are not eligible to access any Adult Services and therefore cease receiving services once they reach 18 years of age.

9.1 Numbers in transition

A number of barriers prevented the data from being provided, including data confidentiality and sharing concerns and the lack of a central database of containing data on all children with a disability in Westminster.

A prevalence of 1% was applied to the population of children in Westminster order to estimate the number of children expected to have an ASC. An estimated 3960 (based on ONS population) children in Westminster have an ASC, 50% of whom are likely to also have a learning disability.

It is important to note the age profile in Westminster means there are a low number of children under 18 years, however data collected from GP practices (shown in Figure 1) in Westminster shows there are a much higher proportion of children identified with an ASC compared to adults. This suggests that services are either more aware of ASC in children as opposed to adults – likely reflect increasing awareness over recent years.

9.2 Westminster Children with Disabilities Team

The Children with Disabilities Team are a multi-disciplinary team providing services to children with a long term disability in Westminster, including those with an ASC and Aspergers Syndrome. Services provided include:

- Family support work
- Welfare benefits advice
- Transition support
- Occupational therapy
- Behavioural support
- Short term breaks
- Funded play provision/ activities for children/ young people
- Direct Payments

In order to access the Children with Disabilities Service an assessment first needs to be conducted by the Children and Families Assessment Team, who can then refer to the Children with Disabilities if the needs of the child and/or family are such that they require ongoing support and care.

9.3 Children with a Disability Register

The Register of Children with Disabilities under the Children Act 1989, is administered within the Children with Disabilities team and is now amalgamated with the Registers of RBKC and Hammersmith and Fulham under the auspices of Westminster PCT. The register is voluntary and therefore not considered representative of children with a diagnosed disability in Westminster. The Children with Disabilities Service suggested the best data on the number of children with an ASC in touch with their service is through the Children with Disabilities register. According to this database 78 children are registered as having an ASC in Westminster.

9.4 Child Development Service

The Child Development Service provides diagnosis, assessment of need and treatment interventions to children (0-19years) with a suspected disability, including ASCs. Treatment for ASCs is provided to children under five, however capacity to provide intervention for children over five years of age is limited therefore children over five are often referred to the Child and Adolescent Mental Health Service for treatment. The majority of referrals to the service are made by GPs; other referrals come from Child and Adolescent Health professionals.

9.5 Child and Adolescent Mental Health Service

The Child and Adolescent Mental Health Service provide an assessment, diagnosis and treatment service for children with complex needs, including those with an ASC. As mentioned above many children over five, in particular those with co-morbid mental health problems are referred to the service for intervention and assistance with diagnosis of an ASC in complex cases. Treatment models include family therapy, marital therapy for parents, individual psychotherapy, art therapy, behavioural/cognitive therapy and a medical/psychiatric model of therapy. Referrals are made by Child and Adolescent Health professionals, including GPs, paediatricians, social services and education.

9.6 Connexions

The overarching local authority service "Connexions" provides a support service to young adults aged 13-19 years old (up to 25 years of age if they have a learning disability/difficulty) who require assistance in accessing further education, training or employment. The Learning Disability and Difficulty personal advisers in Connexions provides intensive support to enable vulnerable young adults with a statement of special educational need to access further education, training or employment. A universal mainstream "Connexions" service exists for those young people aged up to 19 without a Special Education Need Statement.

A number of gaps in service provision have been identified by Connexions. Due to limited resource capacity Connexions LDD advisers can only provide intensive support to children with a Statement. It was acknowledged, for various reasons, not all children with a special need receive a Statement therefore many who require intensive assistance fall through the gaps and do not receive the support they require. It is thought many young adults with Aspergers Syndrome or High Functioning Autism fall into this group, however it is difficult to quantify this number. It was thought some children with Aspergers Syndrome or High Functioning Autism may be part of the "School Action/School Action Plus" group or may end up in the Pupil Referral Unit[1].

The provision of support to those with Aspergers Syndrome or High Functioning Autism was considered a gap that requires filling through better identification of this group, increased service provision /resources through the mainstream Connexions service, improved access to Statements and more awareness in schools of how to identify and support children with Aspergers Syndrome or High Functioning Autism. Supported placements for students with special needs (not necessarily just those with a "Statement") at colleges such as City of Westminster College was also considered lacking, however a

limited number of supported places for children 16-19 years have recently become available at College Park.

10.0 Services for parents, carers and siblings in Westminster

Carers Network Westminster provide information, advice and support to carers in Westminster regardless of whether they are caring for someone who is eligible for social services. Carers caring for a person with an ASC are not recorded separately therefore it was not possible to determine the number of carers in touch with CNW that are caring for a person with this condition. Consequently it was also not possible to find out the number who had received a carer's assessment.

Adult services were also requested to provide information on the number of carer assessments carried out for people caring for a person with an ASC. All of those service users with a carer who are in touch with Westminster Learning Disability Partnership had received a carer's assessment as discussed previously. In an attempt to uncover information Community Mental Health Team's and Westminster Learning Disability Partnership were asked to provide an indication of the number of carers and carer assessments they were aware of through their service. Only a small number of carers were identified, and an even smaller number had received a carer's assessment (under 5).

11.0 Consultation with people with an ASC and their carers

As part of this needs assessment, and to inform the *Joint Commissioning Strategy for Adults with Aspergers Syndrome 2010-2013,* a number of interviews were conducted with people with an ASC and their carers to find out their perceived unmet needs and views on services. Westminster Learning Disability Partnership and mental health staff were asked to nominate service users they felt would be happy to be interviewed. In addition a number of third sector services such as Aspergers Foundation and the Ladbroke Day Service were asked to nominate any appropriate Westminster residents with an ASC who would be willing to be interviewed, however no interviewees were nominated by these services. Although only a small number of interviews were conducted, key themes resounded throughout.

The interviews centred on a number of themes including diagnosis, employment, social inclusion, housing, education, general health and well being and personal views on the need for services and support.

All interviewees were male, and were of white British/white European or Middle Eastern ethnic background. Some of the interviewees were in receipt of adult social services, whilst some were not. The age range of interviewees was between 23 years and 47 years. All respondents received their diagnosis of an ASC at a late age and one had not received a definitive diagnosis at all. All stated it was difficult to obtain a diagnosis, for reasons centring on the lack of awareness of professionals resulting in their condition not being picked up. All interviewees had at least one co-occurring condition, which included epilepsy, tourettes syndrome, depression, anxiety or asthma.

Those interviewed were predominantly unemployed but reported wanting to be employed, at least in a part time capacity. All were on some form of disability allowance. Some had previously held employment which was facilitated through supported employment schemes such as Westminster Employment. The employment support the interviewees felt they needed ranged from “knowing Westminster Employment is there to help [me] if needed” to individualised support, such as travel training and job trials. One interviewee commented he had applied for almost 400 jobs but had not been successful, which was said to be eroding his confidence and making him feel depressed. This particular respondent had previously had a job stacking shelves but was not promoted or given more responsibilities after a year of employment so quit the position. He has since been seeking a job at a higher level and has yet to find an employer willing to take him on.

The educational attainment of the respondents varied from incomplete secondary school to completion of further education. Two respondents were keen to undertake further education but stated they required support to do so. One respondent was undertaking a university degree.

In relation to housing status, most respondents lived independently, with support such as help with practical chores, paying bills and so on (from family members, or, in one case,

social care). One lived at home with his mother, but his mother wanted him to become more independent through having his own house attached to her own.

All of the interviewees reported that they were extremely socially isolated, most having no friends or social network. All were keen to be more socially included but found it difficult to initiate or maintain friendships. The social communication difficulties experienced by all interviewees were evident.

The disparity between what services interviewees received was significant. Due to being in touch with Westminster Learning Disability Partnership before the IQ eligibility criteria was introduced one interviewee with Aspergers Syndrome was receiving a number of support hours and regular psychology input that appeared to be supporting his independence. Conversely, another interviewee with Aspergers Syndrome came into contact with the service after the introduction of the IQ eligibility criteria and therefore was not eligible for a service, despite having a high need for support and practical assistance with everyday tasks such as travel, cooking and showering. The disparity in support received between those who were in touch with Westminster Learning Disability Partnership before the IQ eligibility cut-off and those who weren't was highly significant. A clear inequity is evident between the groups.

Family members who provide care for people with AS were actively involved in the interviews and a small number of interviews were conducted with carers separately. It was clearly evident from the interviews that carers were experiencing high levels of stress and pressure through having to provide a high level of support to their family member. Most reported a poor level of general health. It was thought if a better level of support was provided to their family member there would subsequently be less pressure and stress on the carer. This is further supported by the Carers Joint Strategic Needs Assessment available at: http://westminstercitypartnership.org.uk/default.aspx.

12.0 Summary of unmet needs

This section provides a summary of the unmet needs of people with an ASC in Westminster. The conclusions made have come about through the analysis of what is shown to be good practice compared to what is currently being provided or made available to Westminster residents with an ASC. In addition, the information gleaned from interviews with service users and non-service users and their carers is also taken into consideration. A number of good practice examples are apparent in the services supporting people with an ASC and learning disability (IQ<70), however the group with an ASC and no learning disability (i.e. IQ≥70) currently have a number of unmet needs.

With appropriate support many adults with ASC have the potential to live in the community relatively independently and contribute to their community in positive ways. The National Audit Office (2009) also suggests that if 4% of the ASC population (with IQ≥70) can be supported costs will be neutral. If more than 4% of individuals are supported then the wider public purse may see cost savings.

Without appropriate support, people with an ASC are at increased risk of experiencing negative outcomes including social isolation, mental health problems, low employment and dependency on family or social care support, putting strain not only on the individual but also families and carers. The abilities and disabilities of each person with an ASC are very different, and regardless of IQ level, most will need a certain level of support and services to maximise their independence and quality of life. It is difficult to apply a "blanket" solution to all people with an ASC therefore services need to be individualised, person centred and preventative wherever possible.

There is a dearth of evidence on effective "treatments/interventions" for adults with an ASC. The condition is not a medical problem but rather a lifelong developmental condition and therefore "treatments" are usually of the social and behavioural nature where the aim is to modify behaviour and improve everyday functioning and independence. There is an ever growing body of evidence for what works for children with an ASC to improve their development, including Early Intensive Behavioural Intervention (EIBI) which is showing some positive impacts on children (Research Autism 2009). However, longer term studies have not yet been completed to show results in adulthood and a potential reduction in support needs in later life for those receiving EIBI as children.

Cognitive Behavioural Therapy and Applied Behavioural Analysis are two interventions that have shown positive effects for adults with an ASC (Research Autism 2009). Cognitive Behavioural Therapy can be used to improve social skills as well as treat co-morbid common mental health problems such as depression in people with an ASC, providing it is adapted to the cognitive style of people with the condition (Attwood 2003).

Other than this limited number of interventions/treatments the most benefit to people with ASC is likely to be achieved through social support such as employment and education support, housing, social groups/social skills training to reduce isolation and access to early

accurate diagnosis. This is further supported by the evidence gathered from consultation with service users and their carers. Improvement of social support systems are likely to reduce the likelihood of a person experiencing common mental health problems however appropriate intervention for those experiencing mental health problems is also vital for this vulnerable group.

Those on the low functioning end of the autistic spectrum are eligible for Westminster Learning Disability Partnership services and staff in these services are (anecdotally) skilled in providing intervention for this group, including social integration opportunities. The services for this group are thought to be best practice due to their individualised models and flexible ways of working. Services are based in the community as much as possible and services such as the Flexible Response Service have been shown to improve quality of life and social inclusion for those with extremely challenging behaviours, many of whom have an ASC and have previously been excluded from services.

There are a small number of people with an ASC and IQ≥70 in touch with secondary mental health services due to the fact that they have extremely high needs that impede their everyday functioning and independence. These individuals have also ended up in mental health services due to no other service being available or appropriate. Through further investigation into these cases it appears the teams managing the cases are not confident in their skills to effectively manage and provide treatment to these people therefore it appears evidence based intervention is not being provided.

The unmet needs identified through this needs assessment are summarised in themes below.

12.1 Identification and diagnosis

The number of people with a diagnosis of ASC identified and in touch with Westminster services is much lower than prevalence estimates suggest the Westminster ASC population to be. The reasons for the low number of people diagnosed in Westminster are numerous and include:

- The prevalence estimate being an overestimate;
- Misdiagnosis or missed diagnosis;
- Ineligibility for a diagnosis;
- Lack of awareness amongst health and social care staff;
- Lack of awareness amongst the individual and their family;
- Some may be in contact with the criminal justice system;
- Some may have committed suicide or died from accidental injury/infection/seizures;
- The lack of need for services by some people with an ASC;
- The ineligibility of most people with an ASC and IQ≥70 to receive any services;
- People with an ASC purchasing private support; and

- Families not wanting to access local authority services due to the appropriateness of services or for cultural reasons.

The number of diagnoses being provided in Westminster is very low, however this is not considered reflective of the need. For example, Islington PCT have commissioned over 15-20 diagnoses per year for the past few years compared with Westminster's average of five. A lack of access to diagnosis is apparent in Westminster. This is further supported by the level of misdiagnosis and very late diagnosis as evident amongst clients in touch with secondary mental health services and those who were interviewed.

It is important for a person to have access to diagnostic services, however this currently comes at a high price if purchased out of borough. The referral route to diagnosis in Westminster is also complex and difficult to navigate. Although access to services should not be based on a diagnostic label, but rather on an assessment of need, diagnosis can assist an individual and their family to understand their condition and in turn be able to access appropriate support services to improve their quality of life.

12.2 Assessment of need

An assessment of the needs of a person with an ASC is needed in order to ensure needs are comprehensively assessed and the appropriate support is delivered. Current national social care policy is based on the 'social model of disability' which emphasises the eligibility and allocation of services should be based on individual needs as opposed to a diagnosis or IQ level.

Currently people with an ASC and IQ above 70 are not eligible for a FAC assessment, unless their needs are considered very high. In some cases they are screened out before receiving a screening assessment due to their diagnosis or IQ level. In order to determine the unmet needs of people with an ASC, a screening assessment is needed at the very least. If following the assessment the individual is found to not be eligible for a service they should still have access to appropriate preventative services and signposting that will maximise their independence and prevent the need for high cost services in the future.

Professionals appear to have poor knowledge and awareness of ASCs therefore the abilities of a person with an ASC may be assessed as higher than they in fact are due to the hidden difficulties often faced by this group.

12.3 Supported employment

The provision of employment support is not currently meeting the needs of people with an ASC and IQ≥70 and it is not clear how well this service is meeting the needs of those on the lower functioning end of the autistic spectrum. The number of people with an ASC supported to achieve employment is low. This could be somewhat explained by a lack of employer awareness of ASCs or the lull in the job market due to current economic times.

However, the fact that current employment programs do not offer support to people with an ASC and IQ≥70 is a clear gap in service.

There is evidence to support the need for individual employment schemes that can enable people with an ASC to access employment (Keel *et al.*, 1997 and Smith *et al.* 1995). The available evidence suggests that these schemes can result in not only higher employment but also greater job satisfaction, higher employer satisfaction, improved quality of life, better mental and physical health and reduced carer burden (Robertson and Emerson 2006, Howlin 2004). The recent National Audit Office (2009b) report estimates that if local employment services supported 4% or more of adults with high functioning autism in their local area that they could become cost-neutral (as well as resulting in additional earnings for individuals and reduced expenses for individuals). Howlin's (2004a) research on outcomes for adults with an ASC also showed employment success rates can be significantly improved and maintained long term by access to specialist employment services.

The most effective employment scheme in London appears to be the National Autistic Society's PROSPECTS employment service, which has been evaluated as a high cost but extremely effective service (Howlin, Alcock & Burkin 2005). Individualised placement support and mentoring is provided to people with an ASC and assessment of strengths and abilities is undertaken to ensure the person is placed in the most appropriate job according to their abilities.

12.4 Supported Further and Higher Education

Support for further and higher education is needed by people with an ASC as they are known to struggle with the demands of study, such as organisational and time management skills. The adult education services in Westminster do come into contact with people with an ASC and some provision is made for those with an ASC and learning disability. However, those with an ASC and no learning disability appear to not "fit" into either the learning disability or mainstream courses due to their unique need for support and mentorship. To ensure that those with an ASC and no learning disability have equitable access to educational courses provision of support and mentorship should be provided through adult education services. Furthermore, ensuring those with an ASC who want to attend university or college are aware of the Student Disability Allowance (that can be used to purchase support/mentors) and how they can access this will also further improve the access to education for this group.

Facilitating students with an ASC to access the Student Disability Allowance, as well as ensuring teachers/lecturers are aware of the difficulties experienced are effective ways to ensure people with an ASC are given the best opportunity to succeed in further or higher education.

12.5 Advocacy

Advocacy for people with an ASC and learning disability is available through "The Advocacy Project", however the engagement the Westminster Project has with people with an ASC is minimal. There is a gap in advocacy for people with an ASC and no learning disability as they are currently not eligible to access advocacy through "The Advocacy Project".

The methods needed to engage with people with an ASC is very different due to their social and communication difficulties. Group consultation is not always effective with this group and in most cases one-on-one consultation may be more appropriate, depending on the abilities of the person involved.

The NAS have released a DVD that discusses the most appropriate ways of consulting and involving people with an ASC. Consideration needs to be given to the individual's sensory difficulties and social communication problems as well as their preferred way of communicating, which in some cases may not be in a group. Individual advocates need to understand the uniqueness of the condition and be skilled in working with people with an ASC.

12.6 Housing

Positive outcomes are associated with independent living therefore it would seem appropriate that improving access to housing for people with an ASC in Westminster would lead to more positive outcomes and potential prevention of a breakdown in family support. The number of people with an ASC and learning disability who are in supported housing is low and the appropriateness of the housing arrangements has been the topic of development work in recent times. Ensuring the sensory needs of people with an ASC is taken into account is extremely important for successful independent living, as is the provision of practical support with daily tasks.

The supported living opportunities available to people with an ASC and IQ above 70 is a clear gap. Despite having an IQ above 70, many still need practical help with daily tasks such as cleaning, cooking, paying bills and so on. Again, as abovementioned the sensory difficulties experienced by people with an ASC should also be considered.

12.7 Social integration

Social isolation is a major problem identified for people with an ASC and social interventions such as social groups and social skills training appear to have the potential to reduce isolation. It would be beneficial for people with an ASC to have access to social groups and social skills training in order to improve their integration into the community, as would improved access to leisure facilities. Westminster residents with an ASC have access to a small number of social groups, mainly those in the younger adult age group or

those who are already able to access Adult Services. Local evidence suggests no Westminster residents with an ASC and no learning disability are accessing social groups in the area. There are currently no social skills training opportunities available in Westminster for people with an ASC. Ensuring all people with an ASC, including those ineligible for Adult Services, can access social groups and social skills training to improve social integration is imperative.

12.8 Safe guarding

As mentioned those with an ASC appear to be at high risk of experiencing bullying and can be at risk of being the target or involved in criminal activity. The Safe Guarding Team have indicated they do not have contact with anyone with an ASC, however from consultations it appears this is an area that requires further development by the Team. It is highly likely that cases would not be overt therefore active identification of people at risk would be needed.

12.9 Staff awareness/specialist knowledge

Apart from an ASC course run by the Westminster Learning Disability Partnership Clinical Psychologist and Consultant Psychiatrist there is currently no workforce development programme in place to increase the awareness and knowledge of mainstream and specialist staff in regards to ASCs. The unique nature of the condition, low identification and diagnosis rates in Westminster combined with a level of misdiagnosis all signal an urgent need for staff to be trained in ASCs. The ineligibility of many people with an ASC to access services means mainstream services need to be up-skilled in how to support people with an ASC to ensure they have equitable access to the same opportunities as others in the community.

Community Mental Health Teams, who provide care management for a number of people with a confirmed or suspected ASC diagnosis, are in the main not confident and skilled to provide care and intervention to this group. However due to the extremely complex nature of the condition of many of these service users, Community Mental Health Teams have been considered the most appropriate team to provide care management and intervention. If Community Mental Health Team staff can be provided with appropriate awareness, and in some cases specialist training, they will be better skilled and equipped to manage and intervene with those with an ASC that they care manage as well as refer those with suspected ASC for a formal diagnosis.

National information suggests GPs are not confident and skilled to identify undiagnosed people with an ASC or provide effective support to people already diagnosed (NAO 2008). Due to many adults with an ASC not being eligible for social service it seems imperative that GPs are better equipped to provide support and care to those who would otherwise not receive any support. The additional risk people with an ASC have to experiencing mental health problems and other medical conditions like Epilepsy further supports the need for GPs to have a greater level of knowledge and awareness of ASCs.

12.10 Mental Health Intervention

As previously mentioned people with an ASC are at high risk of experiencing mental health problems, in particular depression and anxiety. These mental health problems are best managed in primary care mental health facilities. A modified version of CBT has been shown to be effective for this group. This is currently not available to people with an ASC in Westminster.

The prevention of mental health problems could be achieved through appropriate social supports, however those that do experience a mental health problem should have timely access to appropriate therapies.

12.11 Family/Carer support

The families and carers of people with an ASC are at risk of poor health and stress if not provided with appropriate support. Although many family members would not be considered a "carer" under the statutory definition, many are still providing significant amounts of support to their family member. This was supported through the consultations conducted for this needs assessment.

Timely access to diagnosis for the person with an ASC is shown to be beneficial to the family and carer, as well as the individual. Ensuring access to diagnosis, as well as individualised information and support to the carer/family member is important.

12.12 Transition

Through consultation with the Transition Team the gaps for those with an ASC going through transition were made clear. Those with an ASC and learning disability will be referred to Westminster Learning Disability Partnership for Adult Services. Those with an ASC and no learning disability are currently not referred to any Adult Social Care Team or other support service as there is currently not one available. Connexions sees many of those ineligible for Social Care but the Personal Advisers who specialise in supporting those with a learning disability or difficulty are already at capacity supporting those with a Statement of Special Educational Need.

Planning for those coming through transition is made difficult due to the lack of data available on children with a disability. Those coming through transition that will not be eligible for an adult service still need to be supported and provided with a plan for how they can be best supported after turning 18, such as through supported education and employment opportunities and social groups/social skills training.

13.0 Professionals and staff opinion on unmet need

Meetings were held with a number of staff and stakeholders to inform this needs assessment. During these meetings staff were able to provide their own opinion on what the unmet needs of people with an ASC are. In addition, staff views were gathered during the consultation for Westminster's response to the National Strategy Consultation document: *"A Better Future…"*. The ASC Steering Group met periodically to provide input into the needs assessment and further opportunity for the inclusion of information from staff is given through the release of this draft needs assessment for comment. An overview of the key themes and information gathered is included in this section.

A recurring theme arising in most meetings was the concern of staff at the lack of appropriate services for people with an ASC and IQ≥70. This group were considered to "fall through the gaps" between LD and MH services. Despite people with an ASC and IQ≥70 being considering "higher functioning", many staff felt this was a misconception as a high level of support is still needed for many in this group. Preventative support was seen as the way forward for those more able, as was the need to provide easier access to diagnosis. The roles and responsibilities of services in relation to who should meet the needs of the higher functioning group was difficult to establish. Many staff felt they were not experienced or confident to effectively support this unique population group.

Another recurring theme in discussions was a general concern about the disparity between services children with an ASC can access and what adults with an ASC can access. Staff likened this to "falling off the cliff" once a person reaches 18 years of age, if they do not "fit neatly" into an Adult Service. Transition of children to adult services can result in a child who was previously provided with services subsequently becoming ineligible for services when they turn 18. Through findings in reports such as this, the Public Health Team of the PCT are undertaking a joint strategic needs assessment on transition which can be referred to for further information.

Senior staff support the current work happening in relation to ASCs, yet are concerned during times of tightening budgets, that funding new service developments will be extremely difficult. It was recognised that people with an ASC are not a homogenous group and have extremely diverse needs and abilities, therefore support planning must be individual with some needing an extremely high level of support whereas others may need minimal or no support.

The personalisation agenda was seen as relevant to those with an ASC, but special consideration was needed to ensure those with less capabilities are supported appropriately in order to benefit. Staff were particularly concerned about those with extremely high support needs and how these needs were going to be taken into account in the new Resource Allocation System.

It was considered important that people with an ASC are included in the community as much as possible, but still with the recognition that some people with an ASC have extreme

difficulty being in social situations and allowances need to be made for these people to ensure they do not miss out.

Recommended initiatives or services for people with an ASC that were suggested by staff include:

- Improve ongoing data collection through an electronic health and social care recording system and consider how data can influence current practice.
- Establish an ASC Special Interest Group, possibly in association with other boroughs.
- Establish and commission a local ASC Team, possibly across boroughs.
- Commission specialist health and social care services, possibly in alignment with other boroughs in CNWL.
- Provide preventative services, such as flexible respite, improved service delivery through GPs and intervention to reduce mental health problems.
- Evaluate current diagnostic and assessment arrangements.
- Develop an agreed clear pathway for assessment, referral, ongoing support, crisis care provision and commissioning.
- Ensure transparent management and pooling of budgets.
- Greater integrated and partnership working.
- Transparent, robust yet flexible contracts that are locally agreed to prevent disputes between services.
- Regular reviews of processes.
- Consider the development of an Aspergers and Autism Alert Card.
- Ensure a GP appointment system that accommodates for people with an ASC through allowing them to walk straight to the consulting room rather than waiting in the reception area.
- Provide additional specialist housing and supported housing.
- Increase advocacy services.
- Training in Person Centred Planning should include specific elements on ASCs.
- Staff should be trained in ASCs including frontline health, housing, education, Job Centre Plus, homeless teams, nursery teachers and so on.
- Professionals should be more confident in the early identification, diagnosis and engagement of people with an ASC in the assessment process.
- Parents should be listened to more.
- General awareness campaigns should target the wider community including bus and taxi drivers, underground staff, library staff, faith groups and others.

14.0 Services in other boroughs and evidence of best practice

A number of other boroughs have previously, or are currently, investigating the number of people in their borough with an ASC, however most are focussing on those on the higher functioning end of the spectrum due to the fact that people with an ASC and LD are eligible and therefore receive services from LD services. A limited number of other boroughs have developed specific services for the group of people with an ASC and no Learning Disability (i.e. IQ≥70), which includes those with High Functioning Autism and Aspergers Syndrome.

Newham, Cumbria, Surrey and the Royal Borough of Windsor and Maidenhead have all carried out needs analysis using various methods, many basing numbers on national prevalence rates or locally collected data. Steering groups have been set up in these and other boroughs such as Leicestershire and Rutland, Wokingham, Dudley, Somerset, Kent and Greater Manchester which are tasked with overseeing the needs analysis and service development work in each area.

Royal Borough of Kensington and Chelsea (RBKC) have a dedicated Service Development Officer who is responsible for initiatives such as awareness raising and workforce development with mainstream and frontline workers. Developments are overseen by a Steering Group consisting of Children and Adult Services representatives from Mental Health, Learning Disabilities, employment, education, housing, libraries, frontline customer service, leisure and a National Autistic Society Liaison Worker. RBKC has not undertaken a needs assessment on people with an ASC as it is thought they have only a small number of people with this condition in the borough.

In regards to service provision, the small number of boroughs that have developed services specifically for people on the higher functioning end of the spectrum have used a variety of different service models. This is a new area of work for most boroughs. All of the services described below are relatively new therefore have not been evaluated. It is therefore difficult to determine the effectiveness of the services. However, the individual support or service they provide, such as diagnosis, social groups, employment support and so on, have been shown to be effective and produce positive outcomes for people with an ASC, so it can be safely assumed the services are of benefit to the ASC community they serve. This is supported by the work done by the National Audit Office (2009), which argues providing support to people with an ASC can over time be cost-neutral.

The services in other boroughs are outlined briefly below:

Kingston

The Royal Borough of Kingston-upon-Thames has a dedicated Aspergers Service that works closely with the LD and MH teams as well as Kingston Workstart, the local employment service for people with a disability. The service offers the following:

- two work related training programmes
- one-to-one appointments

- A carers support group
- A monthly social group
- Confidence and social skills training
- Drop in facilities and social activities

Liverpool

Liverpool has an NHS funded specialist Aspergers Team consisting of 8 core members and a range of other professionals that are on call for advice and further support. Through the team people with AS can access social and healthcare support. The team plays a coordinating role and offers the following services:

- Diagnostic services, including post diagnostic support
- Assessment
- Intervention
- Awareness raising and training to other agencies

Gloucestershire

The Gloucestershire Autism Centre is a jointly funded Council and NAS service, which is overseen by a dedicated partnership board. A joint commissioner has been employed to set up autism specific services. The Autism Centre is relatively new but offers the following:

- Awareness raising and training for staff in contact with people with an ASC
- A web page for the Centre on the NAS website
- Identification of ASC champions at all levels
- Consultations with people with ASC to ensure service developments meet their needs.

Medway

The Medway Project is a pilot project delivered by the charity MCCH. The project aims to engage with vulnerable adults including those with a mental health problem, a learning disability or an ASC, as well as people delivering and commissioning services. The project aims to make services easier to access by offering individual support, person centred plans, mentoring, advocacy and access to individual budgets. The pilot project will share what has worked well and use lessons learnt to inform future service development. Services offered through the project so far include:

- Travel training
- Access to education and voluntary work
- Socialising opportunities
- Training to professionals

Work is also underway to develop a buddying programme to help adults succeed in further education and a local artist initiative to work with people with an ASC to increase their confidence.

Northamptonshire

Northamptonshire has a health funded team whose focus is on transition. The team provides:

- Diagnostic services

- Short term post diagnostic support
- One-to-one support based on individual need (e.g. counselling, advocacy)

Newham

Newham's joint funded Asperger Service coordinates services for adults with AS or HFA and has an open referral system. Currently the service provides:

- Diagnosis
- Help accessing leisure and social opportunities, employment, education, housing, benefits advice, mental health services and other relevant services when needed
- A monthly social group
- Monthly carers support group
- Training and outreach to other services

This service is considered extremely effective service therefore other boroughs such as City of London, Hackney and Tower Hamlets are said to be modelling their own services on Newham's.

At present 45 people with AS/HFA are being supported by the service. Eight of those being supported are also receiving services from Mental Health, although anecdotally 60-70% of those in contact with the service have a mental health problem but do not meet Mental Health eligibility criteria. Another 30% are reported to have attempted suicide.

National Autistic Society

The National Autistic Society provide a number of services for people with an ASC, including employment and educational support, practical assistance with daily tasks, social groups/be-friending as well as training to improve social functioning and independent living. Information and advice is also provided to carers and family members. Other than the PROSPECTS service discussed in section 12.3 the interventions have not undergone evaluation, however many of them have been developed by people with an ASC to meet their needs.

15.0 Information gaps in Westminster

There are large gaps in information and data on the numbers and characteristics of Westminster residents with an ASC which has implications for the ability to plan targeted services. The majority of services that were approached to provide data stated they do not routinely record a diagnosis of an ASC, or distinguish between those with high or low functioning (i.e. IQ above or below 70). In some cases ASC is a secondary diagnosis, making searching for data difficult. This was a particular problem in relation to accessing the numbers of children coming through transition with an ASC. This obviously has implications for the ability of Adult Services to plan for future needs.

The data collected from Westminster GP practices provided a useful picture of the age profile of people with an ASC in Westminster, suggesting the numbers of already diagnosed people with an ASC will increase significantly in future years. However, GPs recording of data is inconsistent and often ambiguous therefore cannot be reliably separated into those with an IQ below or above 70 (i.e. those that have a learning disability and those that do not).

It is imperative all services, including secondary Mental Health and Learning Disability Services and Children's Services record and keep up to date information on those with an ASC and distinguish between the higher and lower functioning group as services to meet the needs of the two groups differ. Having more reliable information means future planning and monitoring the needs of this population will be easier and result in better planning and monitoring of services.

Consideration should be given to the merits of holding one central database of all those with an ASC in Westminster due to their unique place between services (i.e. they do not "neatly" fit into existing categories such as mental health or learning disability). The responsibility for the maintenance of this central register would have to be made clear until such time as a more appropriate method of data recording is put in place.

Children with a Disability Services must also maintain an up-to-date database of children with an ASC (with and without a Special Education Needs Statement/School Action/School Action Plus) so transition planning can be improved and Adult Services can plan for future need of those transferring from Children Services.

At present national prevalence rates are used to estimate the number of people in Westminster with an ASC. The prevalence studies available on ASCs tend to produce variable results therefore more prevalence studies are needed to produce a more robust reliable prevalence figure. Further studies on differences in prevalence amongst ethnic groups would also be beneficial to inform planning in Westminster due to our extremely diverse ethnic makeup.

In addition to the data information gaps, the evidence base on effective treatments for adults with an ASC is somewhat scarce. Although positive results have been shown in

relation to CBT, social skills training, the majority of evidence and treatment trials have occurred in children populations so cannot easily be transferred to adult populations.

16.0 Conclusion

This need assessment has revealed the unmet needs of those with an ASC, in particular those with an ASC and IQ≥70. It is evident from the review of best practice compared to the services and support provided in Westminster that there are a number of gaps and unmet needs that require urgent attention by the NHS and local authority. With the upcoming National Autism Strategy and accompanying Autism Bill there will be further pressure to ensure the needs of people with an ASC are met. The tightening of budgets makes achieving this more challenging, however no less important.

There are a number of pockets of good practices occurring in Westminster that could be attributed to the skill and interest in ASCs of a small number of staff. The expansion of this interest and skill is needed, as is the expansion/adaptation of mainstream and particular specialist services to meet the needs of this unique population group. As time progresses and ASCs become more widely known about and recognised, the pressure on local authorities and the NHS will only increase. This will be made even more evident as increasing numbers of children are identified, diagnosed and progress to Adult Services. Westminster is in good stead to proactively respond to these challenges through implementing the recommendations made within this report as well as the local *Adult Aspergers Strategy 2010-2013.*

17.0 Recommendations

It is recommended that a refresh of this needs assessment is conducted in three years time to update the data and assess unmet needs as well as to evaluate the following (but not limited to):

- Improvement in data recording and accuracy/reliability of local data
- Improvement in pathway to access diagnosis, assessment and support
- Joint working between Mental Health and Learning Disability Services
- Increase in number of people with ASC and IQ≥70 (i.e. those with Aspergers Syndrome) being supported by the local authority and PCT
- Improvement in service user and carer self reported experiences
- Evaluation of new Aspergers Service Model
- Benchmarking against other local authorities

17.1 Roles and Responsibilities

- The Autistic Spectrum Condition Steering Group should continue to meet periodically (propose 6/8 weekly) to oversee the implementation of the rolling needs assessment recommendations and *Adults Aspergers Strategy 2010-2013*, service development, commissioning and monitoring of ASC services. The Steering Group should continue to have commissioning staff from Mental Health and Learning Disability Services as well as a Public Health Team representative. The group may be time limited until such time as the work programme is imbedded into normal service delivery.

- The ASC Steering Group should oversee the development of a clear care pathway and protocol for all adults on the Autistic Spectrum, including those on the higher functioning end of the spectrum. The joint care protocol should clearly set out the roles and responsibilities of mental health and learning disability services, including identifying which teams are responsible for carrying out FAC assessments and Person Centred Support Planning for all Westminster adults on the Autistic Spectrum. The staff responsible for conducting FAC assessments and support planning should receive specialist training relating to Autistic Spectrum Conditions (more in Workforce Development recommendation section).

- Identification of a specific team, with specialist input from mental health and learning disability services, that have responsibility for service coordination for those on the high functioning end of the autistic spectrum (i.e. IQ>70). The team should be able to provide a central point of access to information, advice and signposting as well as facilitating access to diagnosis, post-diagnostic support, FAC Assessment, Person Centred Support Planning, preventative support and best practice interventions when needed. If an individual is found to not be eligible for adult services, the team should provide signposting to appropriate mainstream services that are trained in

supporting adults with an ASC. The team should also work closely with the Workforce Development Departments of Adult Social Services/NHS to ensure workforce development initiatives outlined below are implemented.

17.2 Information

- Improvement of the data recorded on Westminster residents (children and adults) with an Autistic Spectrum Condition by all relevant local authority services. Data should be broken down into those with Autistic Disorder, Aspergers Syndrome, and other ASC sub-groups as relevant. Demographic characteristics should also be included. Data systems should be set up in a way to facilitate data searches to inform monitoring, commissioning and future planning of services.

- Development work should be carried out to ensure GP practices are recording diagnosis accurately and consistently.

- The Specialist Team (outlined in Recommendation 3.) should take responsibility for monitoring and collating data on all people with an ASC in Westminster.

17.3 Preventative Support & Interventions

- Ensure the existing "Advocacy Project" is actively engaging with all adults with an Autistic Spectrum Condition, including those on the higher end of the spectrum, through appropriate engagement methods. This may involve one to one interviews/meetings to ensure views are taken into consideration.

- Ensure individual advocacy is available to all adults with an Autistic Spectrum Condition, including those on the higher end of the spectrum. Those providing advocacy need to be trained in the most effective ways of communicating and engaging with people with an ASC.

- Existing employment support services, such as that available through Westminster Employment, must ensure they are facilitating access to employment opportunities for all adults on the Autistic Spectrum. These services should ensure the unique abilities and specialised skills of those with an ASC are realised and maximised to increase the likelihood of employment. This would also include ensuring employers are made aware of the particular skills, abilities and the particular difficulties faced by those with an ASC.

- Mainstream employment services, such as Job Centre Plus Disability Advisers and Connexions staff, should ensure they have undertaken training in Autistic Spectrum Conditions, including higher functioning autism.

- Continue to commission individualised, flexible person centred support for adults with lower functioning ASC to ensure they can maximise their involvement in the community, such as through the support provided by Community Access Westminster.

- Ensure adults with an ASC on the higher functioning end of the spectrum are able to access social groups that take into account their individual abilities, interests and coping mechanisms.

- Provide social skills training for people with an ASC to improve their social skills and employability as well as increase the likelihood of them developing friends and social networks.

- Increase the further/higher education support provided in Westminster, this may be through promoting the Student Disability Allowance and ensuring those with an ASC who access mainstream course are provided with a mentor/support worker.

- Ensure leisure services are accessible to people with an ASC taking into account their sensory difficulties and social abilities.

- Facilitate improved access to treatment for common mental health conditions, such as Cognitive Behavioural Therapy (CBT) for depression through the Improved Access to Psychological Therapy services. Psychologists will need to be specially trained in how to best provide CBT to those with an ASC.

- Improve access to practical skills training and independent living skills training (e.g. transport) to increase the skills, abilities and independence of people with an ASC. This may be through introduction of skill training in early adolescence.

- Increase access to practical support with daily living tasks to improve independence.

- Increase access to appropriate housing for people with an ASC. For those with particular sensory difficulties these should be taken into consideration. All effort should be made to keep people in borough.

- Improve the early identification of family members and carers and refer them for support and information as early as possible.

17.4 Workforce Development

- ASC awareness training should be provided to mainstream service staff, such as Employment, Housing, Adult Education, Sport and Leisure, Safe-guarding, Police, Criminal Justice. In some cases specific staff in mainstream services such as Connexions, Advocacy services should be supported to undertake specialised training in the support of people on the Autistic Spectrum. Where possible specific

staff members should be earmarked to provide a specialist targeted service for this group.

- Ensure the new primary care Improved Access to Psychological Therapies (IAPT) service includes Psychologists/counsellors specially trained in Autistic Spectrum Conditions to ensure Cognitive Behavioural Therapy is available and relevant to this group.

- Support earmarked mental health and learning disability staff that will be providing FAC Assessment and Person Centred Support Planning/Care Management to attend specialist training on Autistic Spectrum Conditions. These staff should be linked into and supported by the Specialist Team discussed in recommendations above.

- To improve early diagnosis wider awareness training should be provided to services in touch with undiagnosed groups, such as those providing services to people with epilepsy, attention deficit hyperactivity disorder, mental health services, GPs and other relevant health professionals.

17.5 Transition

- Improve the transition planning for young people with an ASC on the higher functioning end of the spectrum. This will involve improved recording of all children with an ASC (broken down into those with Aspergers Syndrome and other ASC sub-groups) in a central location, preferably the Children with Disability Register.

- Earmarked Connexions mainstream/LDD staff to be trained in how to support young people with an ASC, including those without a learning disability.

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19.0 Glossary

Carer: The Department of Health definition of a carer is 'a person who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, disabled or has mental health or substance misuse problems'.

Cognitive Behavioural Therapy: Psychological therapeutic approach that aims to alter emotions, behaviours and cognitions through problem solving. It is an approach used to treat a wide variety of psychiatric problems, including depression and anxiety. It is supported by strong empirical evidence.

Common Mental Health Problems: Are mental health problems that occur more frequently in the community than other mental health problems (such as Psychotic and Personality Disorders). They are also known as Neurotic Disorders and include depression, anxiety, phobias, obsessive compulsive disorder and panic disorder.

Epilepsy: Epilepsy is a chronic disorder characterized by recurrent seizures, which may vary from a brief lapse of attention or muscle jerks, to severe and prolonged convulsions. The seizures are caused by sudden, usually brief, excessive electrical discharges in a group of brain cells. In most cases, epilepsy can be successfully treated with anti-epileptic drugs. (WHO 2009)

Fragile X Syndrome: This condition is the most common cause of inherited mental handicap with an estimated prevalence of 1 in every 1000 males and 1 case of generally milder mental handicap in every 200 females. In males it is characterized by moderate to severe mental handicap, long thin faces with prominent jaws, large protuberant ears, macroorchidism and autistic features. (WHO 1996).

Learning Disability: Westminster's definition of a learning disability is that the person has an IQ under 70.

Phenylketonuria: Phenylketonuria (commonly known as PKU) is an inherited disorder that increases the levels of a substance called phenylalanine in the blood. Phenylalanine is a building block of proteins that is obtained through the diet. If PKU is not treated, phenylalanine can build up to harmful levels in the body, causing intellectual disability and other serious health problems.

Tuberous sclerosis: Tuberous sclerosis is a condition where tuber like growths on the brain calcify with age and become hard or sclerotic. Abnormal TS growths can affect almost any other organ of the body (including the skin, eyes, heart, kidneys and lungs) but they may cause little in the way of problems. The condition is said to occur in 1 in 7,000 of the population, though many are unaware they have the condition as it does not cause problems in all people. Approximately 25% of people with TS are autistic and another 25%

show aspects of autistic spectrum disorder, including higher functioning autism or Aspergers Syndrome. (Tuberous Sclerosis Association 2001)

Neurofibromatosis: Is a genetic condition that can cause mild learning difficulties, or at the more serious end can cause hearing loss, deafness and mobility problems. (Neurofibromatosis Association UK 2009)

Appendix A: Steering Group membership

Tessa Lindfield	Acting Director Public Health, NHS Westminster
Mary Dalton	Head of Commissioning, Westminster Learning Disability Partnership
Sarah Rushton	Head of Commissioning, Mental Health Services
Toni Williams	Public Health Programme Manager, NHS Westminster
Bethan Searle	JSNA Programme Manager, NHS Westminster
Anna Nicholson	Regional Officer, National Autistic Society
Beatrice Buisseret	CEO, Asperger Foundation
Dr Ingrid Bohnen	Consultant Psychiatrist, Westminster Learning Disability Partnership
Steve Carnaby	Clinical Psychologist, Westminster Learning Disability Partnership
Janet Lang	Service Manager, Westminster Learning Disability Partnership
Michael Fielder	Consultant Psychiatrist, Adult Services
Kate Singleton	Head of Children with a Disability, Fostering and Adoption
Lorna Hayes	Carers Network Westminster
Shona Duncan	Manager, Children with a Disability Service
Vikki Wilkinson	Manager, Connexions
Barbara Holme	Director of Adult Education, Westminster City Council
Davina Leeds	Deputy Head of Substance Misuse
Chris Hume	Project Manager, Asperger Syndrome Strategy (contractor)
Sara Rouwenhorst	Public Health Programme Manager (contractor)

Appendix B: Data collected

Data	How/Where was it obtained?
Epidemiological data e.g. expected prevalence, incidence, mortality etc and identification of main issues	• Review of international and national studies • ONS/GLA current population estimates and population projections • National Autistic Society Publications
Information on Westminster residents with an ASC	• Survey of Westminster GPs • Westminster Learning Disability Partnership – audit review of files to reveal identified and unidentified cases of ASC • Central and North West London (CNWL) in patient and outpatient data • Semi-structured survey of CNWL CMHT Managers on unidentified ASC cases
Review of service provision	• Interviews/phone/email correspondence with service managers/leads from the following services/teams: o Westminster Adult Education Service o Westminster City College o The Advocacy Project o Westminster Employment Service o Job Centre Plus o Ladbroke Grove Day Service o Paddington Arts Key Club o Safe-guarding Team o Transition Team o Connexions o Children with a Disability Service o Child and Adolescent Mental Health Service o Child Development Service o Special Educational Needs – Lead Officer o Health Visitors o Older People Team

	o Leaving Care Team o Forensic Services o Police o Supporting People Team (housing) o South London and Maudsley Behavioural Genetics Unit o Lorna Wing Centre (National Autistic Society) o Carers Network Westminster o Asperger Foundation o National Autistic Society o Cross-borough Autism Steering Group
Service user/care perspective	• Semi-structured interviews
Transition Data	• Meeting with Managers of Child and Adolescent Mental Health Service/Child Development Service/Children with a Disability Service/Connexions • Children with a Disability Register