



Wokingham District Mencap
The Coach House (Unit 4)
Woods Farm
Easthampstead Road
Wokingham
RG40 3AE
Tel: 0118 979 8539

Email: admin@wokinghammencap.org
www.wokinghammencap.org

A STRATEGY FOR ADULTS WITH AN AUTISM SPECTRUM DISORDER LIVING IN WOKINGHAM BOROUGH

FINAL REPORT MAY 2009

COMMISSIONED BY



Wokingham
Learning Disability
Partnership Board

Author: Robert Pasterfield, Autism Project Worker, Wokingham District Mencap
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1. EXECUTIVE SUMMARY

This report has been commissioned by Wokingham's Learning Disability Partnership Board and funded by Wokingham Borough Council (WBC) Learning Disabilities Services (part of Community Care) who acknowledge that local services for adults on the autism spectrum are inadequate or inappropriate compared to identified need. Key objectives for future service provision include better outcomes for adults with an Autism Spectrum Disorder (ASD) and reduced spend against current profile. The report has also been written with current policies and guidance – primarily Valuing People Now, Putting People First and the Government's Independent Living Strategy – in mind

Autism is a developmental disability that cannot be cured, although early and appropriate intervention can help people fulfil their potential and, for the more able, lead relatively independent lives. It is characterised by an inability to think flexibly, coupled with disabling social and communication impairments. These characteristics can create tremendous anxieties that drive the behaviour of people with autism. Asperger Syndrome is a condition within the autism spectrum commonly used to describe people with autism who have no recognised learning disability (IQ below 70).

Autism is of particular relevance to Wokingham with an incidence amongst children aged 5 to 16 of 1.3% - **30% higher than the national average of 1 in 100**. Children with autism become adults with autism and estimates of the number of adults with autism in Wokingham vary from 498 to 1445, although not all will require services.

To identify the needs of this group 144 questionnaires were posted to people with autism living in the WBC area. 48 responded and in addition to their survey results 13 were formally interviewed. Separate to the survey, a further 33 Wokingham people were formally interviewed and dozens more consulted at 57 meetings and events attended over the past 12 months. Those consulted were a representative cross-section of Wokingham adults with an ASD, their parents and carers and local service providers from 25 different organisations including WBC departments. Evidence gathering was Borough-specific but areas of best practice were researched and recognised experts in the field of autism consulted.

The key findings were:

1. **A widespread lack of understanding of autism** amongst people who provide services, including WBC employees.

2. **Needs for the less able are generally met:** People who are severely autistic will almost certainly have a learning disability and fall under the Fair Access to Care Services (FACS) eligibility criteria. While their autism means their needs are very special, most of their needs are being met (albeit not always perfectly).

3. Needs for the more able are generally unmet: There is a lack of understanding that a person on the autism spectrum who has no recognised learning disability or current mental health diagnosis is still disabled by their autism and therefore in need of support. As a result people at the more able end of the spectrum - usually with a High Functioning Autism (HFA) or Asperger Syndrome (A.S.) diagnosis – are not always provided with services or have their needs met. This is in spite of their vulnerability to mental health problems and other severe difficulties.

4. Preventative services could save money: At least 10 Wokingham people with HFA or A.S. were found to be in the criminal justice system while several more had mental health problems and other difficulties. There is strong evidence to suggest that early intervention and preventative services for those at the more able end of the spectrum would reduce criminal behaviour, mental health problems and dependence on benefits; while increasing employment, independent living and inclusion. Such measures could therefore save money, as has been evidenced by Hertfordshire County Council, Windsor & Maidenhead, Newham and other local authorities. Indeed Hertfordshire's £153,000 investment in staff training resulted in savings in care costs of £491,000 during 2007/8.

5. Numbers requiring services will double: Numbers entering adult services each year between 2008 and 2013 will be more than double the numbers who entered adult services each year between 1998 and 2007. In spite of this, Wokingham's Disabled Children's Team estimate that over 50% of 11 to 16 year olds with an autism diagnosis will not be considered eligible for adult services under FACS 'critical' eligibility criteria.

6. Inadequate housing provision and poor quality care home staff: 47% of Wokingham people with ASD who live in care homes are placed out of county and it is therefore clear that the Borough has a lack of suitable accommodation - ideally housing which offers independent living combined with communal facilities - for people on the autism spectrum. Additionally there is evidence of poor practice in local residential care homes and this points to the problems of lack of staff continuity, lack of staff with specialist autism knowledge and skills, high absence rates and poor rates of pay.

7. Non-existent adult education facilities in Wokingham Borough for people with an ASD.

8. Gaps in employment, health, social care and support services: Shortcomings in provision of employment support, health and social care services are also detailed in this report. Furthermore, demand exceeds supply for low-level support such as advocacy, befriending, counselling and social activities.

9. Other Local Authorities are developing autism services: In the past 5 years a number of local authorities have started to invest in more comprehensive, better quality specialist services for adults on the autism spectrum, and particularly services for those not assessed as 'critical' under FACS eligibility criteria.

Note: For further insight on key findings, Appendix 2 can be referred to at this point

The key recommendations are:

1. **A specialist ASD Team:** As a developmental disability, autism does not conveniently fit into the four main adult care ‘boxes’ of learning disability, mental health, physical disability and older people. The central recommendation of this report is to create a separate team to recognise (i) the high and increasing numbers in need of services, (ii) the special nature of autism and the expertise and complexity involved in providing good services, (iii) the need to support those whose needs are not being met, (iv) the need to train and advise other service providers, (v) the necessity for an audit of people with autism in the Borough and (vi) the resources required to offer choice, control and personalised services.

2. **Improved availability of prevention services** to those with an ASD who are not assessed as critical under FACS eligibility criteria. This would (i) improve the quality of life for more able adults on the autism spectrum, (ii) avoid expensive crisis management costs and (iii) exploit the money saving opportunities listed under key finding number 4.

3. **An ASD Training Programme** to increase professional understanding and autism insight in education, employment, health, housing and other community services.

4. **Improved housing provision and accommodation support:** A wider range and choice of housing, together with better quality care and support staff so as to ensure the structure and routine, consistency of approach and clear verbal communication needed by residents with autism.

5. **Improved Education Facilities:** The introduction of Further Education courses and facilities specifically for young adults with an ASD, plus the opening of an autism unit complete with outreach service alongside a mainstream secondary school to help (among other objectives) smooth transition for 14 to 18 year olds.

6. **Improved Employment Support and Health services:** Better support at work and into work provided by agencies that work together and complement each other. Specific recommendations for the NHS are also detailed in the main body of the report

7. **Improved partnership working with the voluntary sector** to pro-actively provide low-level services such as advocacy, befriending, counselling and social opportunities

Note: It should be recognised that the autism spectrum is very wide and therefore supports cannot be universally applied

2. INTRODUCTION & GLOSSARY

In early 2006 Wokingham Learning Disability Partnership Board's Autism Sub-Group identified a long-standing needs gap with regard to local services for adults on the autism spectrum. It was felt that too often, in the absence of local services, arrangements were being made for care and support out of area (often some distance away and at considerable expense) and at other times local arrangements were inadequate or inappropriate with regard to identified need.

Furthermore a whole host of national reports, including research undertaken by Government departments, local authorities (particularly Surrey, and Windsor & Maidenhead) and the National Autistic Society, were repeatedly showing that significant needs were not being met and that while services for children were becoming more widely available, adult services across the UK were generally inadequate

Within this context the Autism Sub-Group secured Council funding to support a 30 month project to identify needs and start developing local services. In turn, Wokingham & District Mencap were commissioned by Wokingham's Learning Disabilities Services to manage the project and write the Borough Autism Strategy.

The project started in autumn 2006 and this final report – approved by the Autism Sub-Group - is based on work done since the current Autism Project Worker's appointment on 18th March 2008. Its publication incorporates amendments requested during the comprehensive consultation process.

GLOSSARY (Abbreviations)

A.S. (Asperger Syndrome)
ASD (Autism Spectrum Disorder)
APPGA (All Party Parliamentary Group on Autism)
BAS (Berkshire Autistic Society)
BCA (Berkshire College of Agriculture)
BILD (British Institute of Learning Disabilities)
CCA (Community Care Assessment)
CAMHS (Child and Adolescent Mental Health Service)
CMHT (Community Mental Health Team)
CSIP (Care Services Improvement Partnership)
CTPLD (Community Team for People with Learning Disabilities)
DCT (Disabled Children's Team)
FACS (Fair Access to Care Services)
HFA (High Functioning Autism)
LDD (Learning Disability and Difficulty)
LDPB (Learning Disability Partnership Board)
NAS (National Autistic Society)
NHS (National Health Service)
ONS (Office for National Statistics)
PCT (Primary Care Trust)
PCP (Person Centred Plans – or Planning)
RBWM (Royal Borough of Windsor & Maidenhead)
Service Providers (Employees of WBC, organisations they contract with, other Government and statutory organisations such as health, plus third sector and voluntary organisations)
WBC (Wokingham Borough Council)
WBESS ('new' Wokingham Borough Employment Support Service)
WESS ('old' Wokingham Employment Support Service)

3. OBJECTIVES OF THE PROJECT

The main purpose of the project was to identify and analyse the needs and aspirations of adults (18+) with autism in Wokingham and produce a Borough Autism Strategy designed to provide adequate and appropriate local arrangements.

Its purpose was also to research models of best practice, engage local stakeholders, co-ordinate services (such as health and social care) and provide a long term vision as well as short and medium term plans.

Key outcomes desired by Wokingham Learning Disabilities Services include:

- Better outcomes for adults with an ASD (primarily more independent lives, better access to services and greater social inclusion)
- More local provision and greater expertise amongst service providers **(see note below or see Glossary)**
- Better transition planning
- Fewer preventable out of area placements
- Reduced spend against current profile

As the project was commissioned and financed by Learning Disabilities Services (a division of Wokingham Borough Council Community Care Services) the client group focus was originally defined as those with autism and a learning disability who meet critical eligibility criteria only. It was agreed however that research into a wider group (i.e. all adults on the autism spectrum including those without a learning disability and/or not meeting critical eligibility criteria) with any pertinent observations and recommendations would be helpful.

Important: For the purposes of this report ‘**service providers**’ is used in the widest sense. It therefore includes all people who provide a service, i.e. employees of WBC, organisations they contract with, other Government and statutory organisations such as education, employment and health, plus third sector and voluntary organisations.

4. BACKGROUND

What is Autism?

Autism is a lifelong disability and is sometimes referred to as an Autism Spectrum Disorder or an ASD. It is neither a learning disability, nor a mental health problem but a developmental disability that can stifle a person's ability to (i) communicate appropriately, (ii) think flexibly and (iii) develop social relationships. These three characteristics are known as the "triad of impairments" and lead to people with autism thinking and feeling differently. These differences can create tremendous anxiety and these anxieties can drive their behaviour.

The word spectrum is used because the condition affects people with autism in very different ways, with some able to live relatively 'unsupported' lives and others requiring a lifetime of specialist support. Some people with autism may not speak, or will have limited language skills, while others have good language skills but find it hard to understand. Some will have different degrees of learning disability, while others will be of average intelligence or even graduate from university. Other related characteristics include a love of routines, special interests or obsessions and (a sometimes disabling) sensory sensitivity. Evidence suggests the condition is genetic.

"Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything. A large part of my life is spent trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear"
(Therese Joliffe – a person with autism – NAS 1992)

What is Asperger Syndrome?

Asperger Syndrome is a condition within the autism spectrum and is the term most commonly used to describe people with autism who have no additional learning disability. It has been described as a mild disability – perhaps because one often cannot tell that someone has the condition - but people with A.S. are potentially amongst the most vulnerable and socially excluded in our society. Without support they can go through life unable to hold down a job, unable to live independently, unable to form relationships or make friends and vulnerable to exploitation and mental health problems, particularly anxiety, depression and suicide.

What is a learning disability?

A learning disability is not an illness. It is a permanent condition which affects a person's ability to learn and cope with day to day life. Diagnosis during childhood is primarily based on an impairment of cognitive functioning (generally IQ < 70) but also an impairment of adaptive functioning.

There are many different kinds of learning disability and these are often categorised as mild, moderate or severe (or in schools as moderate, severe and profound & multiple). Across the range of learning disability, individuals may require varying degrees of support from one to one 24-hour support to little or none at all.

The Foundation for People with Learning Disabilities estimate that around 2% of the UK population are affected by learning disabilities (which can include autism)

Prevalence:

The best current estimate of the prevalence rate of autism in children is around 1 in 100 from a study by Gillian Baird and colleagues published in ‘The Lancet’ in July 2006. This prevalence rate of 1% is confirmed by The Office of National Statistics for children aged 5 to 16 and if this is extrapolated across the whole population it equates to around 600,000 people with autism in the UK.

Although estimates of people with ASD and a learning difficulty vary considerably, the Ehlers & Gillberg (1993) studies have been quoted by the National Autistic Society as indicating prevalence at IQ > 70; 71 per 10,000 and IQ < 70; 20 per 10,000. Figures from these studies have been selected for use in this report and (as supplied by the NAS and Berkshire Autistic Society and used by other local authorities e.g. Nottinghamshire) indicate the following prevalence of Autism Spectrum Disorder in Wokingham Borough (2001 Census population 150,229):

	<u>IQ above 70</u>	<u>IQ below 70</u>	<u>Total</u>
Population aged 0 – 19	278	78	356
Population aged 20+	<u>789</u>	<u>222</u>	<u>1011</u>
Total	1067	300	1367

The Care Services Improvement Partnership has also estimated the number of Wokingham adults with ASD (by age group and through to 2025) as shown below:

<u>WBC people predicted to have ASD</u>	<u>2008</u>	<u>2010</u>	<u>2015</u>	<u>2020</u>	<u>2025</u>
Aged 18 – 24	73	75	75	71	73
Aged 25 – 34	98	100	109	113	110
Aged 35 – 44	126	122	114	116	125
Aged 45 – 54	111	115	120	114	107
Aged 55 – 64	<u>92</u>	<u>91</u>	<u>87</u>	<u>95</u>	<u>100</u>
Total population 18 - 64	498	502	503	508	514

CSIP estimates are based on a national prevalence rate of 5 per 1,000 from a 2001 report and all current evidence suggests these estimates should be doubled.

It should also be noted that Wokingham Autism Partnership (an advisory body that brings together health, education and social care professionals with parents and voluntary groups to consider the local needs of young people with autism) has identified a prevalence in WBC children that is 1.3% - or 30% above the national average - and they quote this figure in their 2008 report. A higher local prevalence could be a consequence of children born to parents who work in the disproportionately high number of computer jobs in the Borough – autistic traits have been associated with logical and mathematical minds. (Extrapolation of a 1.3% prevalence rate would indicate 1445 WBC adults with autism)

The numbers identified in this project fall way below any of the statistics above, but this was expected as the ASD client group is very difficult to reach. Reasons for this include their communication difficulties, a lack of adult diagnoses and because many people with ASD just ‘grin and bear it’ – often living in the family home, their life experience having taught them to have low expectations in terms of support outside the family.

Perhaps more significant is that WBC only provide services to those assessed as ‘critical’ and no mechanism exists between local partners to determine the numbers of people with ASD within the Borough’s boundaries.

Current Policies and Guidance:

These revolve around choice, control and personalisation and the report has been written with the following in mind:

The Independent Living Strategy which aims to provide greater access to supports (education, employment, health, housing etc.), greater choice and self-determination over how these supports are provided and greater participation in family and community life.

Putting People First which aims to transform adult social care by providing a personalised system that includes personal budgets and enables people to live their lives with independence, well-being and dignity.

Valuing People Now which reflects on progress made with the principles of the learning disability agenda (rights, independence, choice and inclusion) and responds to feedback from people with a learning disability and their families so that the next three years' priorities can be set. It also finally transfers responsibility for commissioning remaining social care services from the NHS to local government.

5. METHODOLOGY & MAIN AREAS OF FOCUS

Methodology

The first task was to identify, collate and scan-read reports of similar projects and other related publications as this would highlight (i) main areas of focus, (ii) early survey/interview questions and (iii) likely data requirements. The list of publications is shown in Appendix 1.

Once completed, local groups and contacts were identified and the following schedule of work compiled:

- A person-centred needs assessment through questionnaires and face to face interviews with Wokingham adults on the autism spectrum, their parents/carers, service providers and autism experts
- Attendance at local social groups for people on the spectrum and regular meetings with local stakeholders and voluntary groups to gain additional feedback and data
- The mapping of current service provision including analysis of data supplied by Wokingham service providers
- Conducting a gap analysis between need and provision
- Researching areas of best practice, and planning how to meet desired outcomes and other project objectives. (To include more detailed study of the reports shown in Appendix 1)
- Reaching conclusions, making recommendations, compiling Action Plans and completing the Project Report

Main areas of focus

From the reports that were studied prior to obtaining Wokingham specific data the following areas were highlighted:

1. Awareness: There needs to be increased awareness, knowledge and understanding of autism, particularly amongst service providers, so that when people with autism seek help their needs are properly understood. Support measures without relevant staff training and consequent insight into the autistic mind are a potential waste of time and money.

2. Education: More Further Education colleges and universities (particularly those offering courses to mature students) need to understand autism in order to create a suitable learning environment. They need to appreciate that many mature students with autism had little support when they were at school and that specialised courses such as communication skills, social skills and independent living skills training should be made available.

3. Employment: The recent 'I Exist' survey by the NAS found that only 15% of able adults with autism were in full-time employment and 66% do not work at all, yet support into employment has been seen to transform peoples' lives and give them a huge boost to self esteem. Some people with an ASD also have what are sometimes termed 'passions' or 'obsessions' and it would seem a waste of talent if these could not be utilised in a work environment.

4. Health: Adult diagnoses are notoriously difficult to obtain and without diagnosis, access to services is more difficult. Health providers must also understand adults with autism, including their vulnerability to mental illness, the sensory issues that may prevent them from accessing public places (including surgeries and hospitals) and the communication difficulties that have to be understood in order to identify their needs and how to meet them. Communications within health and between health and local authorities have also raised concerns in some localities (so communications between Berkshire Healthcare Trust, Berkshire West PCT and WBC will be looked at).

5. Housing (and Accommodation Support): The 'I Exist' NAS survey found that nearly half of all adults with autism are still living at home with parents due to their inability to live independently without support in areas such as cooking and paying the bills. The question for many parents is 'What happens after we are gone?' A range of housing options with appropriate levels of support across the range of needs has been suggested.

6. Leisure/Social: People with autism often lead lonely lives. In the NAS survey only 28% of adults surveyed had access to social groups for people with an ASD. This is contrary to the 'Valuing People' objective of fulfilling lives.

7. Social Care: The key to receiving services is to obtain a Community Care Assessment leading to a Care Plan which defines the services and support needed. Yet some Local Authorities still appear reluctant to provide a CCA to someone who is not classified as having a learning disability (primarily defined as an IQ of less than 70) or as having a mental health diagnosis. This applies to the majority of adults on the spectrum and is in conflict with Government policy as stated in the Department of Health White Paper 'Better Services for People with an Autistic Spectrum Disorder'. For those adults who do receive services, **Person Centred Plans** are essential to providing choice and control over their lives while meeting their service needs, including **day care**.

8. Support: People with an ASD do not communicate in the same way as the 'non-ASD' population and have difficulties with listening and with processing information. Because adults with ASD are prone to misunderstandings and incorrect interpretation of what is said an **advocacy** service is needed in a wide variety of situations. Extra support is also required during times of **transition** – particularly the years between childhood and adulthood. In addition many adults with an ASD live at home with their parents and the parents/**carers** may also need support – parents report that it can be exhausting looking after someone who has special needs, 24 hours a day, 7 days a week.

9. Other: Welfare benefits, legal and criminal justice issues are included as areas of focus under this heading.

6. IDENTIFYING NEEDS – SURVEY AND INTERVIEW RESULTS PLUS OTHER FEEDBACK

Introduction:

Evidence of need was gained from (i) a Postal Questionnaire, (ii) formal face to face interviews with people with an ASD, their parents or carers, plus service providers within Wokingham Borough and (iii) dozens of informal meetings (at various social groups) with people with an ASD, together with conversations with parents, carers and service providers at numerous events, forums and meetings. There has been no editing so **all** relevant feedback and comments are listed in Appendix 2, but apart from representations made by the Berkshire Autistic Society, feedback from people outside the Borough has not been included in this section. To protect contributors, individual comments are anonymous but acknowledgements are shown in Appendix 3.

Postal Questionnaire / Survey Results:

The Questionnaire was sent by Wokingham's CTPLD to all known adults with both a learning disability and autism. This totalled 115 people of whom 40 (35%) responded. In addition the Berkshire Autistic Society circulated a further 29 questionnaires to the Wokingham adults on their database. Of these, only 8 (28%) replied but it is likely that some BAS members were also known to the CTPLD. Respondents were primarily service users whose needs have been assessed as 'critical' and the main statistical findings from the 48 respondents are as below:

Respondents:

- Ages ranged from 17 to 60 with an average age of 31
- 8 (17%) described their support needs as mild, 18 (38%) as moderate and 21 (45%) as severe (plus 1 don't know).
- 19 (40%) had other relevant health issues or diagnoses of which epilepsy was predominant
- 11 (23%) completed the form themselves and 37 (77%) were completed by a parent or carer. (This is important to bear in mind when analysing answers to questions such as 'Do you feel people understand you?' and 'Do you like where you live?')
- 29 (60%) did not wish to be interviewed further. 19 (40%) were prepared to provide additional face to face feedback either themselves or via their parent/carer but unfortunately not all provided contact details.

Awareness:

- 20 (42%) felt people understood them, 11 (23%) felt some people understood them some of the time, 12 (25%) felt people did not understand them and 5 (10%) left the question unanswered.

Education & Training:

- 26 (54%) had done (or were doing) further education courses since leaving school, 19 (40%) had not done courses and 3 (6%) stated they were too young (2 seventeen and 1 nineteen year olds).
- Of the 26 who had experience of further education 23 liked the course, 2 were unsure and 1 did not give an answer.
- Of the 19 who had not done any courses since leaving school, 2 said they wanted to, 1 was not sure, 8 did not want to and 8 did not respond.

- 42 (88%) needed help with activities like cooking and cleaning but only 30 (71%) had received training. (Training may not be relevant to those needing 24 hour care however).
- 39 (81%) needed help with managing time but only 20 (51%) had received training or support for this.

Employment:

- 4 (8%) worked full time, 8 (17%) worked part time and 36 (75%) did not work at all.
- 11 of the 12 in employment said they liked their job, 1 did not answer.
- Of the 36 (75%) who did not work, 7 considered themselves too young (all aged between 17 and 23), 25 considered themselves unable to work and 4 described themselves as unemployed.
- Of the 4 who were unemployed, 2 had never worked but would like to, and 2 had worked at some time in their lives but were unsure if they wished to obtain work in the future.
- Of these 4, none knew how working would affect their benefits and 2 did not know where to get help and support into employment.
- Of the 25 unable to work, 16 attended a day centre and 9 did not.

Health

- 36 (75%) found their Doctor and other Health services helpful, 2 (4%) did sometimes, 3 (6%) did not find their Doctor or Health services helpful and 7 (15%) left the question unanswered.

Housing:

- 21 (44%) lived in the family home, 13 (27%) lived in residential care homes, 10 (21%) lived in supported accommodation and 4 (8%) lived in other accommodation. Of the 21 living at home, 7 had severe needs
- 41 (85%) liked where they live. Of the 7 who did not or were unsure, 3 lived in supported accommodation, 2 in residential care homes and 2 in the family home.

Leisure/Social:

- 46 of the 48 respondents had hobbies or activities they really enjoy and of these 46, only 4 (9%) claimed they were not able to do them.
- 34 (71%) said they were happy with their daily activities, 2 said they were happy some of the time, 8 (17%) said they were unhappy and 4 did not answer.

Social Care:

- 22 (46%) found people from WBC helpful, 3 (6%) did sometimes, 10 (21%) did not find people from the Council helpful and 13 (27%) left the question unanswered.

Support:

- 12 (25%) had an advocate or befriender and all (100%) found this person helpful.
- 31 (65%) felt they were allowed choice in what they do, 3 (6%) felt they could choose sometimes, 5 (10%) felt they were not allowed to choose what they do and 9 (19%) either left the question unanswered or stated 'Don't know'.

Additional respondent comments:

A large space was provided on the Questionnaire to encourage additional feedback and this was used by 13 respondents to make a total of 28 comments. To simplify this needs analysis, and keep all such feedback under one heading, the additional comments from the postal survey have been added to the section below.

Interview Feedback and All Other Comments:

All feedback and comments are shown in Appendix 2 and those who provided the comments during formal interview are categorised as follows:

- Members of the Autism Sub-Group provided 9 comments
- 11 parent/carers provided 49 comments during interviews
- 6 people with an ASD provided 20 comments during interviews
- 16 service providers provided 61 comments during interviews
- 1 person from the voluntary sector provided 3 comments during interview
- Questionnaire respondents (11 parent/carers and 2 people with an ASD) provided the remaining 28 comments listed

Please note that all contactable people (parent/carers and people with an ASD) who completed the Questionnaire / Survey - and who were prepared to provide additional face to face feedback – were formally interviewed. Service provider and other feedback was gained by identifying and formally interviewing a representative cross-section of key people from education, health, housing, social care and voluntary backgrounds.

Additional feedback was gained at a variety of less formal events and meetings. These are all acknowledged in Appendix 3 and include regular informal conversations with Wokingham people (both people with an ASD and their parents and carers) who attend the Berkshire Autistic Society and Wokingham Mencap adult social groups.

Summary and Conclusions of Interview Feedback

It became very clear during the fieldwork and evidence-gathering for this report that there is a correlation between ability and the meeting of need; and that the needs of people on the spectrum could be broadly divided into two. Firstly the less able adults with an ASD whose needs are generally met (albeit not perfectly) and secondly the more able adults whose needs are generally unmet. The summary and conclusions below apply to both groups, but a heading has been added at the end of this section to provide more specific data on the more able adults, i.e. those with Asperger Syndrome or High Functioning Autism.

- Awareness: Awareness, knowledge and understanding need to be raised and demand for appropriate autism training encouraged
- Education: There is not just a lack of Wokingham facilities but a lack of facilities across Berkshire and appropriate courses (that include individualised social skills and independent living training) for autistic people in an autism-friendly environment are needed
- Employment: There is a need for improved employment opportunities, better quality support into work, better quality support at work and improved employer awareness. There also appears to be a need to inform those looking for work where to get help into employment and how working affects Benefits

- Health: There is clear demand for an easier route to adult diagnosis and for more regular preventative health checks. Diagnosis is considered helpful if an adult is to gain (i) protection under the Disability Discrimination Act, (ii) improved access to services and support including Benefits, (iii) greater understanding by people he or she comes into contact with and (iv) greater understanding of themselves.
- Housing: From the feedback gained it is clear that people on the autism spectrum need structure and routine, consistency of approach by support workers, clear verbal communication, compatibility with other residents and an understanding of their sensory needs. Based on these needs, the requirement for improved housing provision within Wokingham is clear, with demand for (a) more range and choice (b) accommodation that offers independent living combined with communal facilities (c) better quality, autism-trained staff with less staff turnover and (d) quality accreditation in housing services to ensure minimum standards are met
- Leisure/Social: The organisation of social groups and inclusion in mainstream activities could overcome a general lack of social opportunities, particularly in the evening, at weekends and during college holidays
- Social Care: It is clear that designing the right care package is difficult, because people on the spectrum are all different and do not conveniently fit into a box, but 'Social Services' do come in for criticism and there is a need for a clearer route to services with perhaps a specialist Community Care team taking responsibility for ASD. This, in turn, would help increase expertise and thereby improve the care provided. It would also help eliminate the fact that in the past some people fell between mental health and learning disability services.
- Support: There is no doubt that additional emotional support (particularly at the time of a late diagnosis) would be beneficial and that demand exceeds supply for advocacy, befriending and counselling services
- Other: The Benefits system appears designed to discourage full-time employment and is confusing and difficult to access.

Please note that the above conclusions are based on the feedback and comments listed in Appendix 2 and it is **important** these are referred to when reading this section of the report.

Numbers requiring services:

Needs and aspirations have been identified from the questionnaire and interview results above. The numbers of people for whom these needs should be met will be estimated for the next five years from:

- Current service provision numbers, less any people who are likely to die or move away.
- Any who are not listed but who should be.
- Those in transition (14 to 19 year olds) and therefore requiring services over the next five years.
- Those living in the family home whose parents, within the next five years, will no longer be able to provide support.
- Those returning to or moving into the Borough

Figures from the CTPLD, CMHT, NHS (both PCT and Healthcare Trust), other adult agencies and the DCT can provide the basis for these estimates and those that are currently available are summarised below:

<u>CTPLD 'Clients' with autism</u>	<u>IQ above 70</u>	<u>IQ below 70</u>	<u>Total</u>
Aged 18 – 19	2	4	6
Aged 20+	<u>21</u>	<u>88</u>	<u>109</u>
Total	23	92	115

The disparity between the above and the prevalence figures quoted under Section 4 has already been commented on, but it is also likely that additional numbers of undiagnosed people with autism and a learning difficulty (IQ < 70) are included in the total number of 436 adults cared for by the CTPLD. Of the 115 adults with autism they care for:

- 45 are aged 18 to 29, 29 are aged 30 to 39, 23 are aged 40 to 49, 15 are aged 50 to 59 and 3 are above 60.
- 56 are categorised as Severe, 37 as Moderate and 19 as Mild (+ 3 not known).
- 18 are listed as having autism but no formal diagnosis (average age 39)
- 53 live in Residential Care Homes (25 of which are out of area), 15 are in a Supported Living environment and 9 are supported in other ways (e.g. residential schools) with 37 living in the family home and 1 living independently.
- 17 use Short-Break / Respite services, 32 receive Specialist Education services, 26 use Day-care services and 15 receive Transport support
- 11 (10%) have offended
- Only those adults funded by WBC are included, so residents at Ravenswood (apart from those funded by the CTPLD) are excluded.

Wokingham CMHT

Advise 16 clients with a diagnosis and several more suspected to have an ASD.

Berkshire West PCT Mental Health Facilitation Team

In the first six months of 2008, 363 people were referred to the team based at Wokingham Hospital, of whom they estimate 38 (just over 10%) were on the autism spectrum (both diagnosed and undiagnosed).

WEBCAS Clients

Of the 66 Wokingham clients seen in the first six months of 2008, 7 (or 11%) had an autism diagnosis and a further 8 (or 12%) were believed to be on the autism spectrum. These figures could indicate that for every adult with an autism diagnosis there is an autistic adult without a diagnosis who is seeking help.

DCT Clients likely to require Adult services (FACS Critical):

<u>2008</u>	<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>
11	9	7	11	8	12

The above DCT figures should be looked at in the following context:

- 262 out of 19,264 (or 1.3%) pupils aged between 5 and 16 have a diagnosis
- This is an average of 22 pupils per annum
- Those that are likely to meet the eligibility criteria for adult services average 10 per annum (as shown above)

Conclusions re numbers requiring services:

It is not possible to accurately identify numbers requiring services from these figures without data from the Berkshire Healthcare Trust and other agencies. In addition, names from all service providers are needed to ensure there is no ‘double-counting’. Numbers ‘coming through’ can be estimated however (as these can be based on numbers provided by the DCT) but without information on each individual, exact service needs cannot be predicted. What can be stated with certainty is that there is going to be a dramatic increase in the numbers requiring services. This can be seen from the figures below, which show the number of people with ASD who became eligible for CTPLD services for the first time, for each of the last three 10 year periods, compared to the number who will become eligible over the next 6 years (assuming access age 18):

<u>1978-1987</u>	<u>1988-1997</u>	<u>1998-2007</u>	<u>2008-2013</u>
21 (2 p.a.)	30 (3 p.a.)	40 (4 p.a.)	58 (10 p.a.)

Transition:

Periods of transition – particularly negotiating the change to adulthood and moving home – can be difficult for people on the autism spectrum and one of the objectives of this project is better transition planning.

It could be assumed that if Children Services ‘look up’, Adult Services ‘look down’ and the two are brought together effectively by the newly appointed Transition Worker, then most needs would be met. However, this simple approach overlooks the need for a high degree of inter-agency co-operation and local parents’ concerns at what they see as a variety of unmet needs. These unmet needs are summarised as below:

- A Wokingham based unit in a mainstream secondary school - together with an outreach team - to help overcome a lack of awareness and knowledge, maximise pupils potential and to help smooth transition.
- The involvement of all agencies at age 14 (Housing, LSC, Connexions, Adult services, Children services, Health, CAMHS, SEN etc.) and improved communications between them.
- A Wokingham based facility offering post-school education opportunities and an understanding environment for people with an ASD.
- Better information on available services and support, particularly post-16 education, employment opportunities, housing options and social and leisure opportunities.
- A more pro-active approach to transition, including the provision of peer support and mentoring.

Needs of those with Asperger Syndrome or High Functioning Autism:

There appears to be a lack of understanding amongst some service providers that people with autism who do not have a learning disability and who do not have a current mental health diagnosis are still severely affected by their autism and often in need of support throughout their lives. It also seems cruel to provide services (via the DCT) during childhood and then take them away from someone who has clear needs but does not meet the stricter adult eligibility criteria. It is accepted that not all people at what is described as the more able end of the autism spectrum need or want help – many learn to cope or are supported by their families – but there is an undoubted and significant shortfall between the number of adults with clear needs and the number enjoying service provision.

Indeed there is clear evidence from interviews with Wokingham people that adults at the more able end of the spectrum who may not be FACS eligible can ‘fall through’ local services with neither mental health nor learning disability services acknowledging their needs and taking responsibility. As stated by the Department of Health in ‘Better Services for People with an Autistic Spectrum Disorder’ this is contrary to the intention of government policy. Fair and equal access to assessment is also a legal right under *The NHS and Community Care Act 1990*.

As adults with Asperger Syndrome can be extremely vulnerable, further investigations were conducted and the following Wokingham adults identified:

- 4 young men who are in the criminal justice system (3 of them for inappropriate sexual behaviour)
- 2 young men who have had severe mental health problems, one of whom was hospitalised and did not work for several years
- 2 young men who will not go out and have no social contact
- A young lady who was victimised at work and who suffers from depression and suicidal thoughts
- A young man who felt misunderstood at work and who is now unemployed
- A person who was living at home in a reasonable state but who was misunderstood by social workers and now lives in a care home

It is believed that the above will only represent a small proportion of adults (with A.S. or HFA) in Wokingham who because of their autism and lack of support are having difficulties with life. Some will not yet have an autism diagnosis and (as with the people listed above) very few will enjoy service provision except in a crisis.

Furthermore there are 11 CTPLD ‘clients’ - or 10% of those with autism - who have offended and of these, 6 have Asperger Syndrome and 4 are not considered severe. This compares to around 2% of the total population who offend (although prevalence does vary considerably by age and peaks at about 7% for all 18 year olds - ONS).

There is strong evidence to suggest that if these people had been understood and their needs had been met from an early age, the problems listed above could have been avoided. The main unmet needs would be education and support programmes designed to (i) minimise criminal behaviour, mental health problems and dependence on benefits (and parents) and (ii) to maximise independence and inclusion. Regarding mental health, it should be noted that Jarbrink and Knapp in their 2001 ‘Impact of Autism’ report for the All Party Parliamentary Group on Autism calculated that the use of in-patient psychiatrist services is at least four times higher for people with High-Functioning Autism than for the general population.

Other clearly identified needs of more able adults with autism include:

- Support into employment
- Help in getting appropriate accommodation
- Social skills and independent living training
- Emotional support including counselling, mentoring, peer group support and help with anger management, coping strategies and self esteem
- Help in getting a diagnosis
- Support into social activities

7. CURRENT SERVICE PROVISION FOR ADULTS

Service providers, together with additional data and comment, are summarised below. (Please note that Children's Services are included when they also cover the transitional years, as are services outside Wokingham boundaries that are open to WBC residents). A full list including website addresses, ages catered for and locations can be supplied separately if required:

Awareness: Autism training is not on WBC's core programme. It can be commissioned if requested, but to date, autism training has only been arranged for Children (not Adult) Services.

Education: Karten Ctec Centre, Crowthorne; Berkshire College of Agriculture, Maidenhead; Bracknell & Wokingham College (very limited facilities and courses); East Berkshire College (recently closed its Asperger Unit); Henley College (priority given to Oxfordshire students); Newbury College (priority given to West Berkshire); Thames Valley University, Reading (priority given to Reading); Addington School, Woodley; Educational Psychology Service, Wokingham; Parent Partnership, Wokingham.

Of the courses and facilities offered by Berkshire's six main Further Education colleges (BCA, Bracknell & Wokingham, East Berkshire, Henley, TVU and Newbury) all claim to run courses suitable for people with autism but only East Berkshire College run a course specifically designed for people with autism. There are around 300 places available in the county for people up to the age of 25 with special needs, including autism. Three colleges state they are fully subscribed and three state they are over-subscribed. None of these courses is available within Wokingham and it is clear that facilities for students with autism are inadequate throughout the whole county.

Employment: Connexions, Wokingham; conTACT Supported Employment, Reading; Job Centre Plus, Bracknell; Remploy (national); Next Step Berkshire, Reading; Shaw Trust (national); Support Horizons, Wokingham; Thrive, Beech Hill; Ways and Means Trust, Caversham; It's Working, Wokingham; Wokingham Borough Employment Support Service (ex WESS); Wokingham Job Support Centre (The Cornerstone)

Support from the newly formed Wokingham Borough Employment Support Service is designed to be comprehensive – assistance with job search, CV writing, support at work, benefit advice etc. - but past experience indicates service gaps and provision by people with little knowledge of autism or aware of the opportunities (such as those described on Page 46 of the NAS 'Communications' magazine Autumn 2008) available for adults with Asperger Syndrome.

Health: Dingley Child Development Centre, Reading; Patient Advice and Liaison Service, Reading; Speech & Language Therapy, Wokingham; Berkshire West PCT Mental Health Facilitation Team, Wokingham; Child and Adolescent Mental Health Service, Wokingham

There is no autism-specific provider for adults or for adult diagnosis, while the change in FACS eligibility criteria has made it harder to undertake preventative health work. Although joint structures are in place, commissioners and providers (Berkshire Healthcare Trust, Berkshire West PCT and WBC) do not always appear to work together and this may also inhibit service provision.

Housing (and Accommodation Support): The numbers of people with autism supported by Wokingham’s Community Team for People with Learning Disabilities are analysed, with annual total care package costs (£000’s), as below (figures supplied by the CTPLD):

<u>Where they live</u>	<u>In Berkshire</u>			<u>Out of County</u>		
	<u>No.</u>	<u>£Cost</u>	<u>£Ave.</u>	<u>No.</u>	<u>£Cost</u>	<u>£Ave.</u>
Family Home	35	680	19	2	119	59
Supported Living	14	528	38	1	44	44
Residential Care	28	2175	78	25	1682	67
Other	<u>2</u>	<u>0</u>	<u>0</u>	<u>8</u>	<u>279</u>	<u>35</u>
Totals	79	3383	43	36	2124	59

Main providers to WBC and the numbers of people they care for are listed below:

<u>Residential Care</u>	<u>Supported Living</u>		<u>In the Family Home</u>		
Dimensions	10	Dimensions	10	Dimensions	10
Atlas	8	Others	5	WBC	6
Milbury/Voyage	7			Others	5
Others	<u>28</u>			No service	<u>17</u>
Total	53		15		38

Other local housing providers include Ability Housing Association, Choice Limited, Disabilities Trust, Jigsaw Creative Care Ltd., Norwood/Ravenswood Village, Kingwood Trust and Tact Supported Living. Of these, only Loddon Court Short Break (ground floor), Oaklands Drive and Woodmere (all Dimensions), Jigsaw Creative Care and the Tager Centre, Ravenswood have a recognised autism accreditation which ensures that minimum standards are met

Out of county providers have been used because of the lack of suitable local services, and by general consensus there is insufficient housing provision within Wokingham Borough. However, it is expected that the soon to be published Learning Disability Housing Strategy will address these points.

The above data shows that 47% of those in residential care are in out of county placements, residential care is more expensive than supported living and there is a high number of housing providers commissioned by WBC. While out of county accommodation is generally more expensive, this is (perhaps surprisingly) not the case with residential care. Costs however, do not inhibit placing people locally, as factors such as citizenship, local links, inclusion, the right for people to live in the community where they were raised, building a local skilled workforce who understand autism etc. are over-riding factors.

The numbers of people with autism living in the family home should also be recognised. Around one-third of people eligible for CTPLD services live in the family home and there is a huge amount of care that is provided by relatives and friends. This also highlights the needs of carers and the importance of Wokingham’s Carers Strategy.

Leisure/Social: The Ark, Crowthorne; Friday Night Project, Wokingham; LEAP, Earley; Me2 Club, Wokingham; Number One Club, Sindlesham; Riding for the Disabled; Thames Valley Adventure Playground, Taplow; Thumbs Up Club, Woodley; Leisure Plus projects, Wokingham; Sun Club, Reading.

These excellent (and mainly voluntary sector) facilities unfortunately have limited appeal for more able adults with ASD. However the Berkshire Autistic Society Adult Social Groups and Wokingham Mencap's 'Friday Alternative' provide opportunities for social contact in Berkshire four or five times a month.

Social Care (including Day Care and Support): Earley Crescent Resource Centre; Acorn Centre, Woosehill; ASSIST; Community Mental Health Team; Community Resource Service, Community Team - Complex Difficulties; Community Team for People with a Learning Disability; Disabled Children's Team, Transition Mapping Group

WBC does not comply with the All Party Parliamentary Group on Autism objective that a named manager takes responsibility for adults with autism and there is currently no Community Care team in Wokingham to cater specifically for people with autism (although Person Centred Planning would reduce the impact of this, if assessments were made by people with autism insight). The CTPLD has most responsibility (even though many people with autism have no learning disability) while, in general, mental illness not autism underpins the CMHT's remit (even though they work with people who have an ASD). Social Care services provided by these teams are generally only offered to those who are assessed as 'critical' under FACS eligibility criteria.

It should also be noted that an 'At-Risk' (18+) Co-ordinator who will work with people with complex needs has recently been appointed, while there are plans for a temporary ASD Support Worker and consideration of investment in an outreach team.

Support: ASD Family Help, Wokingham; NAS (national); Princess Royal Trust, Reading; ARC Counselling Service, Wokingham; Berkshire Autistic Society, Reading; Citizens Advice Bureau, Wokingham; Crossroads Caring for Carers, Wokingham; Mental Health Advocacy, Berkshire; Surrey Community Development Trust, Wokingham; WEBCAS, Wokingham; Wokingham & District Mencap; CLASP, Wokingham; Family Information Service, Woodley

Emotional support, information and advice is mainly provided by the voluntary sector and includes some advocacy and counselling, but demand exceeds supply and needs are not adequately met. It should be noted that additional resource will be available when the 'Improving Access to Psychological Therapies' (IAPT) programme reaches Wokingham but timescales are not yet known.

Support services for carers – primarily provided by the voluntary sector - are currently available however.

8. NEEDS / PROVISION COMPARISON - SUMMARY AND CONCLUSIONS

Awareness: There is a clear gap between the knowledge and understanding required to provide services and that possessed by some service providers. It is also clear there is a big difference between training and knowledge and actual understanding or insight. Ideally only people with insight into the autistic mind should plan and provide services.

“Living and working with people with autistic disorders is not like living and working with anyone else with or without disabilities. Past experiences of social interaction and a desire to help are not sufficient guides. It is essential to understand the nature of autistic conditions. People with these disorders, because of their social impairments cannot meet you half way. You have to make an imaginative leap into their world and try to see things from their point of view”. (Lorna Wing 1995)

Education: Only East Berkshire College provides a further education course specifically designed for people with autism and this is over-subscribed, while all other courses in Berkshire that are considered suitable for people on the spectrum are either fully subscribed or over-subscribed. As none are available within WBC boundaries, there is a clear gap between need and provision of both courses and facilities.

Employment: Support is available but may not always meet need. For example, interviews are particularly difficult for people with an ASD because of the problems they can experience maintaining eye contact and answering questions to the point. The need to ‘sell oneself’ is also hard because of the tendency to stick rigidly to facts and a black and white approach to answering questions, yet in the past some support services have been reluctant to support people at interview. In summary there are clear needs for improved employment opportunities, more appropriate support into work and at work, improved employer awareness and better access to information on how work affects benefits and where to gain support. There appears to be plenty of provision (Connexions, Job Centre, Next Step, WBESS, third sector organisations etc.) but too many agencies duplicate each other while leaving gaps between what is needed and what is provided.

Health: Adult diagnoses (where desired) are difficult to obtain and the need for regular health checks is not being met. Inadequate provision to reduce vulnerability to mental health problems and prevent crises is also a clear service gap

Housing: While many people seem to like where they live, there is a clear gap between the need for, and provision of, a range and choice of suitable accommodation within the Borough. There is also a need for better quality staff and lower staff turnover while autism quality accreditation (e.g. NAS or BILD) is a pre-requisite for guaranteeing a minimum standard in housing services.

Leisure/Social: While less able people are generally happy with their daily activities there is clear demand to increase social opportunities in the evening, at weekends and during college holidays for the more able. Activities such as eating out, games evenings, cinema visits and excursions would be most appropriate.

Social Care: There appears to be a need for a specialist autism service for adults. The autism spectrum is very wide so supports cannot be universal and with no single team taking specific responsibility for autism there is a consequent lack of expertise in designing care packages to meet the precise individual need required under current policies and guidance. People at the more able end of the spectrum, who do not meet FACS eligibility criteria, also need to be better served by prevention services.

Support: Demand exceeds provision for advocacy, befriending, counselling, emotional support and other support services while access to WEBCAS can be difficult for those not referred by the CTPLD or CMHT. Most services are provided by the voluntary sector. **Transition** support needs a more pro-active approach, improved communications between relevant agencies, better understanding among school staff and improved information for parents.

Needs of those with HFA or Asperger Syndrome: There is a clear gap between the needs of this highly vulnerable group and the almost non-existent service provision, particularly in the areas of preventative health, emotional support and help into employment, social activities and independent living. Of most importance however is the need to introduce preventative education and support services designed to minimise criminal behaviour, mental health problems, unemployment and dependency on either benefits or parents.

9. EXAMPLES OF BEST PRACTICE

Before completing the Recommendations section, adult autism services were looked at in a number of other UK Councils and organisations and the following examples of best practice were found. It is interesting to note that the vast majority of initiatives are focused on those at the more able end of the spectrum.

1. EAST BERKSHIRE COLLEGE

- From 2000 an ASD Co-ordinator has been employed to ensure that the educational needs of students with an ASD are met.
- Their Foundation Studies course helps more able students with an ASD to move forward in their vocational, social and emotional development and includes work experience and employment support
- Their Life Skills course helps develop social and communication skills through teamwork and participation in producing the 'Get This' newsletter

2. ROYAL BOROUGH OF WINDSOR & MAIDENHEAD

- Operating for several years, their Specialist Autism Mainstream Service (SAMS) supports pupils in mainstream schools. The 5 person team also provides whole-school training and advice to school staff and parents
- From January 2007 to January 2009 RBWM funded a project to identify the needs of adults with an ASD - primarily those who have neither a learning disability nor a current mental health issue. Of 146 people audited, 36 (25%) fell into this specific category and of these 90% lived in the family home, 90% said they had no friends and 75% had no work.
- RBWM employment services, careers advisors etc. are being given specific training on how to help people with an ASD into employment.
- A 3-person local authority-employed team to work specifically with adults on the autism spectrum started work on 1st July 2008. The support is mainly help into work, independent living, benefit advice, leisure and social activities, advocacy, behaviour management and psychological well-being. One of the main purposes of the team is to support adults with unmet needs. Other objectives include helping professional colleagues understand adults with autism; auditing the numbers of people with ASD; helping with transition; working with the CTPLD and CMHT and providing training and advice. After 8 months, 134 people with ASD are known to the team, the largest group of which is high functioning 20 to 30 year olds who are now in need of intensive support because of a lack of preventative measures at an earlier age. Most fell through the gap between mental health and learning disability services and not all have a diagnosis. They will have been self-referring; referred by the CMHT; or found by interviewing people who were eligible for children's services but who are not eligible for adult services.
- RBWM staff believe the main lesson learnt to date is that providing services to those at the more able end of the spectrum can save significant sums of money by preventing homelessness, preventing mental health admission and by supporting people into work.

3. CARMARTHENSHIRE COUNTY COUNCIL

- Their Intensive Support Service aims to provide a range of daytime programmes and activities geared to the needs of adults with autism spectrum disorders and related conditions.
- This service has joined the Autism Quality Network managed by BILD

4. CUMBRIA COUNTY COUNCIL

- Undertook mapping exercises into the prevalence of autism in the county in 2003 and 2006. (The 2006 audit showed a 60% increase in the number of adults recorded since 2003.)
- Appointed an Autism Development Officer (Children and Adults) in 2002 and formed an Autism Development Group (Adults) in 2005

5. DUDLEY METROPOLITAN BOROUGH COUNCIL

- Has developed a strategy for people aged 16 and over with Asperger Syndrome and High-Functioning Autism
- Set up the Dudley Autistic Resource Team (DART) to raise awareness, promote independence and assist self-determination and social inclusion. It runs a drop-in service, parent support group and adult social club

6. ONE STOP SHOP ADVICE & INFORMATION SERVICE, EDINBURGH

- This service, originally funded by the Scottish Executive via Lothian Health, is for adults with Asperger Syndrome and High Functioning Autism in Lothians. It provides a wide range of low level supports (drop-in, social groups, advice, information, volunteer support), aiming to prevent the need for more intensive, costly interventions at a later date.

7. HERTFORDSHIRE COUNTY COUNCIL

- Commissioned a two year project (January 2005 to December 2006) to look at support for people with Asperger Syndrome.
- Held a conference in November 2005 to make people more aware of Asperger Syndrome, followed by training for staff, carers and private and voluntary organisations. During 2007 and 2008 over 200 people were trained at a cost of £153,000 and there is clear evidence that not only has quality of life been enhanced, but training costs are potentially a fraction of the savings in adult care costs. Indeed due to increased independence, care costs were reduced by £491,000 during this two year period and savings are estimated to increase to £799,000 by end 2009. (Figures are extracted from a report written by the Herts County Council Asperger Lead in December 2008.)
- Opened 2 new places to live for young people with Asperger Syndrome who are learning to be independent. Also started a service where people can get support in their own home
- Started partnership working between adult care and local mental health services to make plans for people with Asperger Syndrome.
- Started a successful social group for adults with either Asperger Syndrome or High Functioning Autism in 2007. Activities include pool, table tennis, board and computer games, while group discussions are held weekly on subjects such as anxiety, depression, relationships and keeping safe.

8. KINGSTON ASPERGER SYNDROME SERVICE

- In 2007 the Royal Borough of Kingston upon Thames introduced training to develop skills and confidence, a drop-in facility and social activities, with a view to helping adults with Asperger Syndrome live more independently. It operates as a specialist service with referrals from the local CTPLD and CMHT particularly for those adults who do not meet eligibility criteria for community care services.

9. LIVERPOOL ASPERGER TEAM

- Established in 2003 and jointly funded by the local authority and PCT, 400 people have been referred for assessment, diagnosis and intervention to this 11 strong multi-agency team

10. NEWHAM ASPERGER SERVICE

- Jointly funded by the local PCT, local NHS mental health trust and Newham Social Services, the service provides diagnostic assessments, training for service providers/professionals, social groups, activities and carer support
- Benefits quoted by the service include reduced mental health problems, reduced contact with the criminal justice system and 'huge' savings for the local authority

11. CITY COLLEGE, NORWICH

- Their Foundation Course – specifically for people with an ASD – integrates the development of personal and life skills with learning support. Dedicated resources for over 120 students with Asperger Syndrome include the 'Rug Room' facility which provides computer games, social activities and special interest clubs.

12. NOTTINGHAMSHIRE COUNTY COUNCIL

- In conjunction with Nottingham PCT an Adult Social Care and Commissioning Strategy has been developed. This incorporates a strategy to meet the needs of people with Asperger Syndrome and includes housing and support solutions.
- Provided £360,000 of development funding in 2007/8 to support up to 25 people with Asperger Syndrome.
- In the knowledge that autism is often an 'invisible' disability a Disabled Person's Registration Card is available as a quick and easy way of proving that the cardholder has a disability and may need to use facilities provided for disabled people.

13. OLDHAM METROPOLITAN BOROUGH

- All Oldham's learning disability services have been autism accredited since 2006
- There has been significant investment in autism training and other agencies (police, housing providers, health, probation etc.) now access Oldham's expertise
- A specialist autism post has been appointed
- In recognition that some adults were not fitting into existing teams, Oldham has developed a Vulnerable Adults Team. A large proportion of its clients have Asperger Syndrome or High Functioning Autism
- Oldham has established preventative services such as befriending and social groups for those who do not qualify for support through FACS eligibility criteria.

14. SURREY COUNTY COUNCIL

- Set up the Surrey County Autism Project in 2005 to make services for people with ASD in Surrey more responsive and effective.
- A major report on needs was published in 2005, an ASD Handbook was published in 2007 and 7 Surrey services have registered with the NAS Autism Accreditation programme.
- Set up a network of Autism Champions to provide training and mentoring across the county. This was recognised as an example of good practice by the Department of Health's 'Better Services for People with an ASD' document.
- Jointly financed with Surrey Primary Care Trust, set up the 'Asperger Support, Signposting and Information Services Team (ASSIST) to provide support to those who either have, or are actively seeking an Asperger diagnosis. Support is also extended to families and carers

15. SUSSEX AUTISTIC COMMUNITY TRUST SUPPORTED LIVING PROJECT

- Provide specialised individual accommodation for adults with High-Functioning Autism and Asperger Syndrome. Staffed 24 hours a day by a team trained to understand the specific support needs of individuals with ASD, residents have their own self-contained accommodation plus access to communal areas and a resource centre

10. RECOMMENDATIONS

The Wokingham-specific evidence gathered for this report indicates that the following detailed points need implementing. The recommendations also try to recognise (i) current policies and guidance on choice, control and personalisation and (ii) the width of the autism spectrum and consequent difficulty in designing universal supports:

1. Increased Awareness, Knowledge and Understanding amongst service providers

- a. An ASD Training Programme to increase professional understanding within relevant community services (education, employment, health, housing, leisure/social, social care and general support). Involving adults with autism would help give service providers insight into the autistic mind.
- b. An Autism Champions Network (including the production of an autism handbook) to increase awareness and knowledge across a wide range of community services and beyond
- c. The widespread promotion of this Autism Strategy report, once approved

2. Improved Education Opportunities for all adults on the autism spectrum

- a. The introduction of courses and facilities, specifically designed for people with ASD, to meet demand both in Wokingham and the wider county of Berkshire. These courses should cater for different ability levels and be conducted in an autism-friendly environment. Primarily for 18 to 25 year olds they should cover personal management, preparation for work and vocational skills such as IT, horticulture, music, art and drama.
- b. The introduction of communication skills, social skills and independent living skills training both inside and outside the college environment

3. Improved Employment Opportunities and Support for those able to work

- a. Improved access to information on how work affects Benefits and where to gain support, with clearer information detailing different organisations and the types of support available from each
- b. Better support into work, including support at interview if required
- c. Support extended to those believed to have an ASD, but without a formal autism diagnosis, and who are clearly having difficulty in accessing work or holding down a job. (Some criteria would need to apply).
- d. More support at work (on the job) including help with cases of discrimination, bullying or a lack of understanding in the workplace, plus publicity to pro-actively promote this service to potential employees.
- e. Improved relationships with, and training provision for, potential employers. It would help considerably if, as the largest employer in the area, WBC embraced the disability agenda at corporate level and led by example
- f. Consideration to the setting up of a social enterprise (perhaps a cleaning, gardening and recycling service) that provides work experience and, where appropriate, longer term employment
- g. A 'summit' of all providers to decide what is needed and to co-ordinate provision across all agencies

4. Better Access to Health Services particularly for those with A.S. and HFA

- a. A clear NHS pathway regarding assessment and possible diagnosis for adults. This would support The Royal College of Psychiatrists Report (April 2006) 'Psychiatric Services for Adolescents & Adults with Asperger Syndrome and Other Autistic Spectrum Disorders' recommendation that health commissioners should ensure access to local diagnostic expertise.
- b. Preventative health measures and interventions to reduce mental health difficulties and help people avoid reaching a crisis point. This is particularly relevant because FACS guidance stresses that councils should not only identify immediate needs but also those that would worsen for the lack of timely help.
- c. Improved communications and clearer lines of responsibility between WBC, the PCT and Healthcare Trust may also improve health provision

5. More and Improved Housing Provision and Accommodation Support for all

- a. A clear plan based on need (by numbers and types of accommodation required) should be devised. This should plan to provide more range and choice and enable more housing provision in the Borough through developing local expertise; building local infrastructure; and the capacity of local providers. It should be noted that most people with ASD in need of housing provision prefer accommodation that offers independent living combined with communal facilities.
- b. Better quality care and support staff, better trained staff and less staff turnover. This will enable the structure and routine, clear verbal communication and consistency of approach required by people with autism in a residential setting, and reduce the significant distress which can be caused by inappropriate staffing
- c. NAS Accreditation or BILD's Autism Quality Network to be a requirement of service providers, together with improved record-keeping on provider standards by commissioners and purchasers.

6. Improved Leisure and Social Opportunities particularly for those living more independently

- a. Engage with, and provide support to, the voluntary sector so that there are more activities available, particularly in the evening, at weekends and during college holidays
- b. Provide a resource that enables a drop-in service for adults on the spectrum and a facility/focal point for social and leisure activities

7. Social Care specifically designed for all those with an ASD

- a. The appointment of a senior manager to lead a new team with specific responsibility for autism – both assessing need and providing services. Ideally with experience and expertise in autism together with links to both Health and Social Services, this person's appointment would enable WBC to comply with Director of Adult Social Services guidance on the subject. The development of an autism-specific team is also clearly supported by the Department of Health who in their 'Better Services for People with an Autistic Spectrum Disorder' document state "*The services required to meet identified needs are best provided by local services that have the right skills and trained staff to provide what an individual requires. This is better than deciding that either mental health, learning disability or physical disability services should provide all ASC related services as a matter of principle*". This is endorsed again in 'Valuing People Now' and is, without doubt, the central recommendation of this report, as it would impact on service provision in all other areas and help facilitate greater choice and control and more personalised services. Nor need it be expensive (beyond the initial cost of the senior manager) if the RBWM model is followed
- b. This team to be developed into a fourth Community Care service (alongside Learning Disabilities, Mental Health and Older People/Physical Disability). This would (i) recognise the high numbers involved or 'coming through' (Wokingham Autism Partnership put this figure at 262 five to sixteen year olds, all of whom will become adults with autism), (ii) recognise the special nature of autism, the width of the spectrum and the expertise and complexity involved in providing a good service, (iii) allow the needs of those who are currently not eligible for services to be met, (iv) provide training, support and advice to other service providers and (v) provide outreach services. The team should be multi-agency (if not in staff certainly in finance) and occupational therapists, speech and language therapists etc. should all be part of a well resourced team
- c. A system in place to accurately record numbers of people with ASD in Wokingham. Without this, it is impossible to accurately plan and deliver services that people with autism really need, or provide prevention services to those not currently known to Community Care.
- d. Refine and retain the Autism Sub-Group to ensure continued multi-disciplinary planning and that local people continue to work together

8. Increased Support (particularly for those with A.S. and HFA)

- a. The extension of advocacy services to include all those with an ASD and not just those referred by the CTPLD
- b. Increased provision for counselling and emotional support
- c. Engaging and supporting the voluntary sector to provide additional low level services, e.g. social groups and befriending (particularly for those at the more able end of the autism spectrum), advice, information and signposting, plus parent/carer support

9. Better Partnership working with Government and other agencies

- a. Government should be consulted on ways to change the Benefits System, so that it no longer discourages employment or encourages dependency (usually at the Council's cost)
- b. Criminal justice system staff, including local Youth Offending Teams, need to be better trained in recognising and dealing with autism. This also applies to agencies such as Connexions and the Learning & Skills Council
- c. Government and other agencies should be encouraged to support and finance local initiatives that save money from 'the public purse'

10. Improved availability of prevention services for more able adults with an ASD

- a. People on the autism spectrum who have no learning disability or current mental health diagnosis are still disabled by their autism and in need of support. It needs to be better recognised that these more able adults may still experience significant risks to their independence and their difficulties are likely to increase for the lack of timely support. This is also a central recommendation and in full accord with Wokingham Borough's Corporate Prevention Strategy (2008). Furthermore it is believed that improved availability of prevention services to the more able adults on the spectrum (including those with A.S. and HFA) could save public sector money by reducing criminal and inappropriate behaviour; the numbers with mental health problems; and dependence on benefits and services. Fortunately this principle of cost-effective preventative measures and consequent earlier intervention has already been recognised by WBC in the Scrutiny Review on Special Education Needs (published on 18th November 2008) which states "*Early intervention and provision will require significant investment to be made in early years education services. However, the return on this would be more than recovered through significant reductions in the provision required in later years in education, social, health, community safety and other services*".
- b. Main services required are listed under previous recommendations, but are primarily a clear route for adults with Asperger Syndrome or High-Functioning Autism to access assessment, and diagnosis (if relevant); support into education (particularly social and independent living skills), employment; housing and social activities; and most importantly easy access to emotional support as and when a need (not a crisis) arises

11. Additional recommendations based on achieving key outcomes

The above recommendations (1 to 10) are designed to meet the needs of Wokingham people, as identified by the project research. Additional recommendations to meet the key outcomes listed on Page 7 are summarised as below:

Better outcomes for adults with an ASD (primarily more independent lives, better access to services and greater social inclusion) should follow if the recommendations above are implemented

Fewer preventable out of area placements: Some service providers have vacancies in registered Care Homes which could be filled by bringing back people currently placed out of county, but this is not recommended unless there are clear benefits for the person concerned. Additional recommendations to help meet this outcome are:

- a. To actively encourage service providers, Housing Associations and social register landlords to build or purchase suitable accommodation within Wokingham – a business opportunity for them.
- b. Section 106 building designated for ASD-specific accommodation

Reduced spend against current profile: If recommendations 1 to 10 are implemented there will be costs for training; education facilities; an autism-specific manager and team; and better support; but this should mean less unemployment; fewer mental health problems; lower housing costs; less criminal activity; and fewer people dependent on benefits. Preventative measures (as allowed under FACS guidance) and a more proactive, less reactive/crisis management approach by people who understand autism are considered the keys to reducing need and therefore costs. This is particularly true for housing where with the right support, some people in residential care could move to supported living and some in supported living could move to independence. These opportunities for cost savings were recognised by Jarbrink and Knapp in their 2001 'Impact of Autism' report for the APPGA which estimated the average lifetime cost per person with autism at £2,940,358. However they stated this could be lowered if (i) money is invested in preventative services to save expensive crisis management and (ii) support is made available to help people with autism fulfil their potential, make a contribution to society and reduce reliance on Benefits.

It is also recommended that:

- c. Alternative funding streams and joint ventures with health and neighbouring unitaries are used where possible

More local provision and greater expertise amongst service providers should follow if recommendations are implemented.

Better transition planning is needed and additional recommendations are as follows:

- d. A Wokingham based autism unit alongside a mainstream secondary school. Allowing opportunities for integration it should be similar to those at Blessed Hugh Faringdon, Reading and Wexham Park, Slough for example. Such a unit would also help overcome a lack of understanding and help pupils maximise their potential, thereby reducing problems in later life. As such a unit would only cater for a small number of pupils it should also incorporate a well-resourced outreach service similar to RBWM's SAMS service.

(It is understood that a consultant has recently been appointed by WBC to see if Wokingham needs a specialist school for autism and/or units in mainstream schools)

- e. A more pro-active approach, including the provision of peer support and mentoring, and specialist advisers such as careers advisors
- f. Better information on available services and support, particularly post-16 education; employment opportunities; housing options; and social and leisure opportunities. This means that Wokingham's comprehensive yet under-utilised 'Transition Handbook' should be regularly updated and referred to as appropriate
- g. A specially designated 'Transition House' to give more time for assessment, training and support. This could be provided at little extra cost as it would not add to the total numbers accessing accommodation and support
- h. Consideration to an extension of the transition period beyond age 19. This final recommendation has been added as it was noted that several young, but very able people on the autism spectrum were maturing more slowly and at an older age

12. Recommendations on Commissioning

The only recommendation is for commissioners to read 'Improving Commissioning Standards in Services for Children and Adults with Autism Spectrum Disorders' (2006) which was produced (with the support of the National Autistic Society) by a working group of commissioners and autism-specific service providers in the North West. As the title indicates, this publication is designed to stimulate the development of autism-competent services across education, health, housing and social care while recognising the complexity of providing such services.

13. Priorities

In priority order the recommendations that are absolutely central to this report are:

- **7(a) & 7(b):** The establishment of a specialist ASD Team and its development into a fourth Community Care service (alongside Learning Disabilities, Mental Health and Older People/Physical Disability)
- **10(a):** Improved availability of prevention services for more able people on the autism spectrum (including those without a learning disability or a current mental health diagnosis)
- **1(a):** A Borough-wide, comprehensive and in-depth Training Programme

11 MAKING IT HAPPEN

Vision Statement:

One of the purposes of the Wokingham autism project is to provide a long term vision.

To create a mental picture of how the future should look and to provide a clear sense of purpose and direction, the following Vision Statement was agreed by the Autism Sub-Group:

“WE WANT A BOROUGH WHERE AUTISM IS UNDERSTOOD AND ALL PEOPLE ON THE SPECTRUM HAVE THE SERVICES AND SUPPORT THEY NEED TO ENJOY THE SAME LIFE OPPORTUNITIES AS ALL OTHER WOKINGHAM RESIDENTS”

Action Plans:

Comprehensive action plans are not included as (i) the strategy and recommendations require prior approval, (ii) costings need to be completed and (iii) those who will implement the recommendations need – as part of good management practice - to be involved in the action planning. However the following points should be noted:

- There are many professionals in the field of autism training who could devise affordable training programmes and provide costings at short notice. The benefits across all services would be immediate. (Note: Herts CC paid £840 per person for a 5 day training course)
- Work on an Autism Champions network and the promotion of this strategy can start immediately and without cost
- In the short term, space could be rented to provide education facilities, and teaching staff could be recruited at relatively short notice. In the longer term, joint funding with neighbouring Councils and other agencies could make the building of a purpose-built facility affordable
- Improvements to employment and health services could be made without additional cost to WBC
- Housing and accommodation support providers can be instructed to gain quality accreditation at no cost to WBC

APPENDIX 1

BIBLIOGRAPHY

REPORTS OF SIMILAR PROJECTS & OTHER RELATED PUBLICATIONS

SECTOR	ORGANISATION	TITLE
GOVERNMENT	APPGA	MANIFESTO + EUROPEAN CHARTER
GOVERNMENT	APPGA	THE IMPACT OF AUTISM
GOVERNMENT	APPGA	POLICY INTO PRACTICE
GOVERNMENT	DOH	BETTER SERVICES FOR PEOPLE WITH AN ASD
GOVERNMENT	DOH	COMMISSIONING ADULT LD HEALTH SERVICES
GOVERNMENT	DOH	OUR HEALTH, OUR CARE, OUR SAY
GOVERNMENT	DOH	PUTTING PEOPLE FIRST
GOVERNMENT	DOH	SERVICES FOR PEOPLE WITH LD ETC. (MANSELL 2)
GOVERNMENT	DOH	TRANSITION: MOVING ON WELL
GOVERNMENT	DOH	VALUING PEOPLE
GOVERNMENT	DOH	VALUING PEOPLE NOW
GOVERNMENT	NORTHERN IRELAND	BAMFORD REVIEW OF MENTAL HEALTH & LD
GOVERNMENT	NORTHERN IRELAND	REPORT OF THE TASK GROUP ON AUTISM
GOVERNMENT	SCOTTISH ASSEMBLY	AUDIT OF SERVICES FOR PEOPLE WITH ASD
GOVERNMENT	SCOTTISH ASSEMBLY	COMMISSIONING SERVICES FOR PEOPLE WITH ASD
GOVERNMENT	SCLD	NATIONAL LEARNING DISABILITY & ASD DATASET
GOVERNMENT	WELSH ASSEMBLY	STRATEGIC ACTION PLAN
GOVERNMENT	WELSH ASSEMBLY	APRIL 2008 STRATEGIC ACTION PLAN EXEC SUMMARY
GOVERNMENT	WEST MIDS. SEN	REPORT ON ASD'S
GOVERNMENT	WHSSB	ACTION PLAN FOR STRATEGIC FRAMEWORK FOR ASD
LOCAL AUTHORITY	BEDFORD LDPB	STRATEGY FOR COMMISSIONING LD SERVICES
LOCAL AUTHORITY	BRIGHTON & HOVE	ASPERGER STAKEHOLDER DAY 17/09/04
LOCAL AUTHORITY	CAMBRIDGE	STRATEGY FOR THE DELIVERY OF SERVICES
LOCAL AUTHORITY	CARMARTHENSHIRE	DAY & OUTREACH INTENSIVE SUPPORT SERVICE
LOCAL AUTHORITY	CUMBRIA	A SCRUTINY REVIEW OF SERVICES TO ASD ADULTS
LOCAL AUTHORITY	DUDLEY	A 3 YEAR STRATEGY FOR ABLE ADULTS WITH AUTISM
LOCAL AUTHORITY	DUNDEE	POLICY STATEMENT ON PROVISION
LOCAL AUTHORITY	HAMPSHIRE	LEARNING DISABILITY STRATEGY
LOCAL AUTHORITY	KINGSTON	MEETING THE NEED
LOCAL AUTHORITY	NOTTINGHAMSHIRE	COMMISSIONING STRATEGY FOR PEOPLE WITH AS
LOCAL AUTHORITY	OLDHAM	SUPPORTING PEOPLE 5 YEAR STRATEGY
LOCAL AUTHORITY	READING	SURVEY
LOCAL AUTHORITY	SHEFFIELD	LEARNING DISABILITY STRATEGY
LOCAL AUTHORITY	SOMERSET	AUTISM SERVICE
LOCAL AUTHORITY	SURREY	SURREY AUTISM PROJECT + AUDIT
LOCAL AUTHORITY	WOKINGHAM	BETTER CARE, HIGHER STANDARDS
LOCAL AUTHORITY	WOKINGHAM	AUTISM STRATEGY & AN ASSESSMENT OF NEED
LOCAL AUTHORITY	WOKINGHAM	CARERS STRATEGY
LOCAL AUTHORITY	WOKINGHAM	COMMUNITY CARE OVERVIEW STRATEGY
LOCAL AUTHORITY	WOKINGHAM	CORPORATE PREVENTION STRATEGY 2008
LOCAL AUTHORITY	WOKINGHAM	FACS ELIGIBILITY CRITERIA
LOCAL AUTHORITY	WOKINGHAM	LEARNING DISABILITIES BENCHMARKING
LOCAL AUTHORITY	WOKINGHAM	LDPB & WBC HOUSING STRATEGY
LOCAL AUTHORITY	WOKINGHAM	LDPB INFO PACK
LOCAL AUTHORITY	WOKINGHAM	LEARNING DISABILITIES STRATEGY 2008-11
LOCAL AUTHORITY	WOKINGHAM	OUTCOMES FOCUSED FRAMEWORK FOR ADULTS
LOCAL AUTHORITY	WOKINGHAM	SCHOOL PROVISION RESEARCH
LOCAL AUTHORITY	WOKINGHAM	TRANSITION HANDBOOK
LOCAL AUTHORITY	WOKINGHAM	VALUING PEOPLE IMPLEMENTATION PLAN
LOCAL AUTHORITY	WOKINGHAM	WASP DEVELOPMENT PLAN + ACTION PLAN
LOCAL AUTHORITY	WOKINGHAM	WASP SWOT & SERVICE GAPS MEETINGS

W'HAM MENCAP	CHRIS DAVIS	DRAFT REPORT
W'HAM MENCAP	BESSELL / DAVIS	SURVEY QUESTIONNAIRES
W'HAM MENCAP	JANE BESSELL	DRAFT REPORT
W'HAM MENCAP	JANE BESSELL	STATS / AUDIT
MISCELLANEOUS	ELLEN NOTBOHM	TEN THINGS
MISCELLANEOUS	JOANNE EAST	WING & MYERS
MISCELLANEOUS	VARIOUS	NOTES
MISCELLANEOUS	VARIOUS	FUNDING POSSIBILITIES
MISCELLANEOUS	VARIOUS	TRAINING POSSIBILITIES
MULTI-AGENCY	GRAHAM BOX	AUDIT OF AS ADULTS IN BERKSHIRE
MULTI-AGENCY	NEAC	STRATEGIC DEVELOPMENT PLAN 2007 - 2010
MULTI-AGENCY	NWATG	NORTH WEST AUTISM TASK GROUP REPORT
MULTI-AGENCY	NWATG	IMPROVING COMMISSIONING
MULTI-AGENCY	OXON & BUCKS	STEERING GROUP REPORT
MULTI-AGENCY	WOBMAWG	SWOT
VOLUNTARY	AUTISM ALLIANCE	COMMISSIONING AND ASD
VOLUNTARY	BAS	DEVELOPMENT WORKERS REPORT+ MILESTONES
VOLUNTARY	BAS	EMPLOYMENT PROJECT & MISC. EMPLOYMENT
VOLUNTARY	BAS	NEEDS / SUE PORTWAY
VOLUNTARY	BAS	RBWM STAKEHOLDER EVENT 19/03/04
VOLUNTARY	BEARDON/EDMONDS	A NATIONAL REPORT ON THE NEEDS OF AS ADULTS
VOLUNTARY	DISABILITIES TRUST	FUNDING FOR AUTISM
VOLUNTARY	LD FOUNDATION	A GUIDE TO SERVICES FOR ADULTS WITH ASD
VOLUNTARY	LD FOUNDATION	THE ECONOMIC CONSEQUENCES OF AUTISM IN THE UK
VOLUNTARY	LD FOUNDATION	EDUCATION AND EMPLOYMENT FOR PEOPLE WITH LD
VOLUNTARY	LD FOUNDATION	MODERN LEARNING DISABILITY SERVICES
VOLUNTARY	LD FOUNDATION	THE LIVES OF PEOPLE WITH LD - A POLICY BRIEFING
VOLUNTARY	LD FOUNDATION	WHAT IS IMPORTANT TO YOU
VOLUNTARY	MENCAP	MANIFESTO
VOLUNTARY	NORWOOD	NEW AUTISTIC SERVICE BUSINESS PLAN
VOLUNTARY	RESEARCH AUTISM	FORUM WORKSHOP NOTES
VOLUNTARY	NAS	TAKING RESPONSIBILITY
VOLUNTARY	NAS	A GUIDE FOR PUBLIC AUTHORITIES
VOLUNTARY	NAS	A LIFE IN THE COMMUNITY
VOLUNTARY	NAS	A PLACE IN SOCIETY
VOLUNTARY	NAS	ADULT SERVICES PUTTING PEOPLE FIRST
VOLUNTARY	NAS	ADVOCACY FOR ADULTS WITH ASD'S - A GUIDE
VOLUNTARY	NAS	AUTISM & INDEPENDENCE
VOLUNTARY	NAS	BREAKING DOWN BARRIERS TO LEARNING
VOLUNTARY	NAS	CARE SERVICES FOR ADULTS
VOLUNTARY	NAS	COSTS & BENEFITS OF SUPPORT
VOLUNTARY	NAS	I EXIST
VOLUNTARY	NAS	IGNORED OR INELIGIBLE
VOLUNTARY	NAS	IMPROVING COMMISSIONING STANDARDS
VOLUNTARY	NAS	MAPPING AUTISM RESEARCH
VOLUNTARY	NAS	MOVING ON UP / NEGOTIATING TRANSITION
VOLUNTARY	NAS	NATIONAL AUTISM PLAN FOR CHILDREN
VOLUNTARY	NAS	RIGHTS IN REALITY
VOLUNTARY	NAS	TOMORROWS BIG PROBLEM

APPENDIX 2

INTERVIEW FEEDBACK AND OTHER COMMENTS

SUBJECT HEADING	COMMENTS / FEEDBACK	BY PERSON TYPE
AWARENESS	AUTISM TRAINING HAS TO BE RIGHT TO BE EFFECTIVE	EXPERT/SUB-GROUP
AWARENESS	WE NEED AN AUTISM CHAMPIONS REGISTER	EXPERT/SUB-GROUP
AWARENESS	WE NEED AUTISM INSIGHT TRAINING FOR SOCIAL CARE STAFF	EXPERT/SUB-GROUP
AWARENESS	WE NEED IMPROVED AWARENESS	EXPERT/SUB-GROUP
AWARENESS	SUPPORT WORKERS NEED MORE TRAINING	PARENT/CARER
AWARENESS	CHILDREN MIMIC HIM AND WE NOW AVOID GOING OUT AT HALF TERM. AWARENESS AIMED AT SCHOOLCHILDREN WOULD BE BENEFICIAL	PARENT/CARER
AWARENESS	IT WOULD MAKE LIFE EASIER IF THE GENERAL PUBLIC HAD AN AWARENESS OF BEHAVIOURS OF INDIVIDUALS ON THE AUTISTIC SPECTRUM	PARENT/CARER
AWARENESS	KEEP ASKING WHY AND IT COMES BACK TO LACK OF UNDERSTANDING - AND LACK OF MONEY	PARENT/CARER
AWARENESS	MY OTHER SON IS VERY UNHAPPY - NO-ONE UNDERSTANDS HIS AUTISM	PARENT/CARER
AWARENESS	A LOT OF PROBLEMS GO BACK TO A LACK OF UNDERSTANDING BY THE SERVICE PROVIDER	PARENT/CARER
AWARENESS	THEY ARE NOT TRAINED ENOUGH BECAUSE THEY JUST DON'T UNDERSTAND	PARENT/CARER
AWARENESS	I FEEL A LOT OF PEOPLE DON'T UNDERSTAND THE CONDITION	PERSON WITH AN ASD
AWARENESS	THE TEAM ARE AWARE BUT NOT KNOWLEDGEABLE OR TRAINED AS AUTISM IS NOT WITHIN THEIR REMIT	SERVICE PROVIDER
AWARENESS	AUTISM SPECIFIC SERVICES PROVIDED BY AUTISM SPECIALISTS ARE NEEDED	SERVICE PROVIDER
AWARENESS	A LACK OF UNDERSTANDING OF AUTISM IS THE MAIN PROBLEM WITHIN WOKINGHAM	SERVICE PROVIDER
AWARENESS	ASD TRAINING FOR LEARNING DISABILITY SERVICES IS CRITICAL	SERVICE PROVIDER
AWARENESS	NEEDS ARE DIFFERENT FOR THOSE WITH LD ONLY AND THOSE WITH LD AND ASD - 2 TEAMS COULD WORK BUT WE MUST BRING AUTISM EXPERTISE INTO LEARNING DISABILITY SERVICES	SERVICE PROVIDER
AWARENESS	AWARENESS NEEDS RAISING IN THE NHS	SERVICE PROVIDER
AWARENESS	THE STAFF ARE FANTASTIC BUT MORE AUTISM TRAINING IS REQUIRED	SERVICE PROVIDER
AWARENESS	NOT ENOUGH TRAINED STAFF IN WOKINGHAM	SERVICE PROVIDER
AWARENESS	WE DEFINITELY NEED AUTISM TRAINING	SERVICE PROVIDER
AWARENESS	THE GP ADMITTED IGNORANCE OF AUTISM	VOLUNTARY/OTHER
AWARENESS	TRAINING IS THE KEY	VOLUNTARY/OTHER
EDUCATION	WE NEED IMPROVED EDUCATION SERVICES	EXPERT/SUB-GROUP
EDUCATION	HE WILL BE GOING AS A DAY STUDENT TO A COLLEGE IN EAST SUSSEX. THE AVAILABILITY OF A LOCAL COLLEGE ABLE TO MEET HIS NEEDS WOULD BE VERY HELPFUL	PARENT/CARER
EDUCATION	HE IS LOOKING FORWARD TO GOING TO COLLEGE BUT WE HAVE NOT YET FOUND THE COURSES HE WOULD LIKE TO DO	PARENT/CARER
EDUCATION	UNFORTUNATELY TVU WAS TOO NOISY FOR HIM	PARENT/CARER
EDUCATION	ADDINGTON TREAT THE LEARNING DISABILITY NOT THE AUTISM	PARENT/CARER
EDUCATION	HE IS AT COLLEGE IN READING BECAUSE THERE ARE NO 18+ EDUCATION FACILITIES IN WOKINGHAM BUT I WOULD PREFER HIM TO BE CLOSER TO HOME	PARENT/CARER
EDUCATION	HE NEEDS ON-GOING SOCIAL SKILLS AND INDEPENDENT LIVING TRAINING. IF IT'S NOT ON-GOING HE REGRESSES	PARENT/CARER
EDUCATION	WE BELIEVE IT REASONABLE TO EXPECT HIS NEEDS TO BE MET LOCALLY BUT THERE WASN'T THE GOOD QUALITY, FULL TIME EDUCATION AVAILABLE	PARENT/CARER
EDUCATION	WHAT HELPED ME MOST WAS WHEN MY LEARNING SUPPORT ASSISTANT TOOK THE TIME TO GET TO KNOW ME AND ASKED WHAT I WANTED. ONLY THEN I FELT VALUED AND IN CONTROL. MUSIC THERAPY WAS ALSO VERY HELPFUL.	PERSON WITH AN ASD
EDUCATION	IT'S DISAPPOINTING NO-ONE HAS HELPED ME READ AND WRITE PROPERLY	PERSON WITH AN ASD
EDUCATION	THERE SHOULD BE PROVISION FOR SHORT DAYTIME COURSES SPECIFICALLY DESIGNED FOR PEOPLE WITH ASPERGERS, E.G. 1 DAY A WEEK FOR 6 WEEKS ON LOCAL HISTORY WITH A SIMPLE LUNCH INCLUDED	PERSON WITH AN ASD

EDUCATION	WOKINGHAM NEEDS A MAINSTREAM SECONDARY SCHOOL WITH A SPECIAL ASD UNIT. SUCH AN INVESTMENT WILL ACT AS A COST SAVING MEASURE FOR ADULT SERVICES	SERVICE PROVIDER
EDUCATION	DEMAND FOR SUITABLE COURSES EXCEEDS SUPPLY AT TVU AND IT IS LIKELY THAT WOKINGHAM STUDENTS WILL BE A LOWER PRIORITY THAN READING STUDENTS	SERVICE PROVIDER
EDUCATION	DEMAND FOR OTHER SERVICES PEAK WHEN THE COLLEGES ARE CLOSED - CAN'T THEY BE USED DURING HOLIDAY TIMES?	SERVICE PROVIDER
EMPLOYMENT	WE NEED IMPROVED EMPLOYMENT OPPORTUNITIES	EXPERT/SUB-GROUP
EMPLOYMENT	HE DOES NOT NEED HELP IN LOOKING FOR A JOB, WRITING A CV OR INTERVIEW TECHNIQUES. HE NEEDS AN EMPLOYER TO UNDERSTAND HIM AND THEN HE WILL FLY	PARENT/CARER
EMPLOYMENT	EMPLOYMENT OPPORTUNITIES WOULD BE GREATLY INCREASED IF TRAINING CENTRES WERE RE-INTRODUCED	PARENT/CARER
EMPLOYMENT	CONNEXIONS WERE USELESS IN THEIR SUGGESTIONS FOR EMPLOYMENT	PARENT/CARER
EMPLOYMENT	ITS WORKING PROVIDE A JOB COACH BUT IT WAS A STRUGGLE TO GET ONE AS AT FIRST THEY DIDN'T UNDERSTAND MY NEEDS	PERSON WITH AN ASD
EMPLOYMENT	AN A.S. PERSON SHOULD LOOK FOR WORK IN A FIELD RELATED TO THEIR OBSESSION. EMPLOYERS ALSO NEED TO UNDERSTAND.	PERSON WITH AN ASD
EMPLOYMENT	I FIND MY SUPERVISOR DIFFICULT TO WORK WITH - HE HAS SWORN AT ME AND I FEEL BULLIED BY HIM	PERSON WITH AN ASD
EMPLOYMENT	THE MOST IMPORTANT ELEMENT OF EMPLOYMENT SUPPORT IS ON-GOING SUPPORT IN THE WORKPLACE OR ON THE JOB COACHING	SERVICE PROVIDER
EMPLOYMENT	I SUPPORT PEOPLE IN OUTREACH WHO COULD WORK	SERVICE PROVIDER
HEALTH	WE NEED EASIER ADULT DIAGNOSIS AND IMPROVED SERVICES	EXPERT/SUB-GROUP
HEALTH	UNTIL THE CMHT UNDERSTAND AUTISM THEY WILL TREAT PEOPLE FOR MENTAL HEALTH ISSUES WHEN THESE ARE JUST THE SYMPTOMS AND IT IS THE AUTISM THAT NEEDS ADDRESSING	PARENT/CARER
HEALTH	SHE IS UNDER THE CMHT BECAUSE SHE WAS DIAGNOSED WITH DEPRESSION BUT IT WAS NEVER REALLY DEPRESSION - HER BEHAVIOURS ARE DRIVEN BY HER ASPERGER SYNDROME	PARENT/CARER
HEALTH	HE HAS NO CONCEPT OF HEALTH ISSUES AND THEREFORE NEEDS AN ANNUAL HEALTH CHECK ORGANISED FOR HIM	PARENT/CARER
HEALTH	MY DOCTOR SAID I WAS LAZY AND EXAGGERATING MY DIFFICULTIES - HE DIDN'T UNDERSTAND AUTISM	PERSON WITH AN ASD
HEALTH	MENTAL HEALTH SERVICES NEED TO KNOW ABOUT ASPERGERS AS IT COULD BE THE DRIVER OF THE MENTAL HEALTH PROBLEM	PERSON WITH AN ASD
HEALTH	IT IS VERY DIFFICULT FOR ADULTS TO GET A CLEAR DIAGNOSIS	SERVICE PROVIDER
HEALTH	PEOPLE SHOULD NOT HAVE TO WAIT FOR A CRISIS BEFORE HELP IS GIVEN, THERE SHOULD BE REGULAR CHECK-UPS	SERVICE PROVIDER
HEALTH	HEALTH WILL ONLY TREAT THOSE WHO HAVE ACTUAL MENTAL HEALTH PROBLEMS BUT PREVENTATIVE HEALTH COULD STOP REFERRALS AND SAVE MONEY	SERVICE PROVIDER
HEALTH	THERE SEEMED TO BE AN OBSTRUCTION IN ATTEMPTS TO OBTAIN AN ADULT DIAGNOSIS	VOLUNTARY/OTHER
HOUSING	WE NEED A RANGE AND CHOICE OF FACILITIES	EXPERT/SUB-GROUP
HOUSING	WE NEED MORE FACILITIES IN WBC (AS OPPOSED TO OUT OF BOROUGH)	EXPERT/SUB-GROUP
HOUSING	MORE SUITABLE ACCOMMODATION IS NEEDED	PARENT/CARER
HOUSING	HE LIKES WHERE HE LIVES BUT DOES NOT LIKE SOME OF THE PEOPLE HE LIVES WITH	PARENT/CARER
HOUSING	HIS HOME IS CURRENTLY BEING ASSESSED FOR AUTISM ACCREDITATION AND THIS SHOULD MAKE LIFE EASIER	PARENT/CARER
HOUSING	HE HAS CARERS PURCHASED THROUGH THE DIRECT PAYMENTS SCHEME BUT THEY ARE ALWAYS LEAVING TO TAKE UP PERMANENT POSITIONS ELSEWHERE	PARENT/CARER
HOUSING	I'M AFRAID THAT DIMENSIONS STAFF ARE NOT VERY GOOD - STAFF SHORTAGES, STAFF CHANGES, LACK OF EFFORT, HYGIENE PROBLEMS AND A LACK OF UNDERSTANDING - BUT IF YOU DON'T PAY PEOPLE WELL THEY WILL NOT BE VERY GOOD	PARENT/CARER
HOUSING	LODDON COURT FLATS ARE LOVELY BUT STAFF JUST WALK IN, SO THERE'S NO PRIVACY IN YOUR OWN HOME. ALSO THERE ARE NO COMMUNAL AREAS	PARENT/CARER

HOUSING	THE BIGGEST PROBLEM OF ALL IS THE QUALITY, TURNOVER AND SHORTAGE OF STAFF. THERE HAVE BEEN TIMES I HAVE TAKEN MY SON HOME BECAUSE I DON'T TRUST THE DIMENSIONS STAFF TO LOOK AFTER HIM	PARENT/CARER
HOUSING	THERE IS A LACK OF UNDERSTANDING OF HOW TO LOOK AFTER PEOPLE, LET ALONE PEOPLE WITH AUTISM	PARENT/CARER
HOUSING	MY SON IS AT HIS HAPPIEST NOW - HE IS AT LAST IN A HOME WHERE THERE IS LITTLE STAFF TURNOVER, THE STAFF UNDERSTAND AUTISM AND UNDERSTAND HIM	PARENT/CARER
HOUSING	THERE HAVE BEEN LOTS OF CHANGES SINCE MOVING IN - STAFFING ISSUES ARE ONE OF THE MAIN PROBLEMS	PARENT/CARER
HOUSING	SHE NEEDS TO BE ON HER OWN A LOT OF THE TIME BUT WHEN SHE NEEDS COMPANY SHE MUST HAVE IT OR SHE WILL FEEL EXCLUDED AND ANXIOUS	PARENT/CARER
HOUSING	DIFFERENT MEMBERS OF THE STAFF SAY DIFFERENT THINGS. THIS SHOULD BE STOPPED AS IT CREATES SERIOUS CONFUSION AND ANXIETY	PARENT/CARER
HOUSING	SHE IS IN SUPPORTED LIVING WHEN SHE IS MORE THAN CAPABLE OF INDEPENDENT LIVING, BUT SHE HAS ALWAYS LACKED THE NECESSARY SUPPORT TO LIVE INDEPENDENTLY	PARENT/CARER
HOUSING	THIS ISN'T JUST A PLACEMENT FOR MY SON IT'S HIS LIFE	PARENT/CARER
HOUSING	HE DISLIKES NOISE AND BEING TOO CLOSE TO OTHER PEOPLE AND WE ARE NOT SURE HIS NEEDS WILL BE MET BUT WE DEPEND COMPLETELY ON THE SERVICES COMMISSIONED BY THE BOROUGH COUNCIL	PARENT/CARER
HOUSING	HE SHOULDN'T BE LIVING IN THE FAMILY HOME - HE NEEDS TO BE INDEPENDENT SO HE IS READY FOR THE DAY WHEN I'M NOT THERE TO LOOK AFTER HIM	PARENT/CARER
HOUSING	THE IDEAL HOUSING ENVIRONMENT IS ONE WHERE HE CAN SHUT HIS DOOR FOR PRIVACY BUT THERE ARE COMMUNAL AREAS WHEN HE NEEDS THEM	PARENT/CARER
HOUSING	WE NEED MORE PURPOSE BUILT LIVING ACCOMMODATION LIKE LODDON COURT WITH A COMMUNITY ROOM, LAUNDRY ROOM AND KITCHEN - AND SITUATED CLOSE TO A DOCTOR AND SHOPS	PERSON WITH AN ASD
HOUSING	I'M AGAINST SHARED HOUSING AS I WOULD NOT NECESSARILY GET ON WITH EVERYONE. WHEN THERE ARE 3 IN A HOUSE 1 PERSON USUALLY SUFFERS	PERSON WITH AN ASD
HOUSING	PEOPLE WITH AUTISM CAN'T OFTEN LIVE TOGETHER BECAUSE OF THEIR SENSITIVITY TO OTHER PEOPLE, NOISE ETC. 1 OR EVEN 2 PEOPLE IN A HOME IS OK BUT 3 AND ABOVE DOES NOT USUALLY WORK IF THEY ARE SEVERELY AUTISTIC	SERVICE PROVIDER
HOUSING	WBC IS NOT A HOUSING ASSOCIATION SO IT HAS TO ENCOURAGE SERVICE PROVIDERS TO SET UP IN WOKINGHAM	SERVICE PROVIDER
HOUSING	WE MUST TRY TO GIVE PEOPLE WITH ASD INDEPENDENCE - GROUPING THEM TOGETHER IS PROBABLY THE LAST THING THEY WANT	SERVICE PROVIDER
HOUSING	WOKINGHAM PEOPLE SHOULD LIVE IN WOKINGHAM - WE ENCOURAGE PEOPLE TO BE INCLUDED IN THE COMMUNITY BUT IT SHOULD BE THE COMMUNITY THEY COME FROM	SERVICE PROVIDER
HOUSING	IT CAN HELP IF LIFE IS BUILT AROUND THE PERSON'S SPECIAL INTEREST	SERVICE PROVIDER
HOUSING	RESIDENTIAL CARE DOESN'T WORK WELL IN BIG SETTINGS	SERVICE PROVIDER
HOUSING	THEIR NEEDS ARE VERY SPECIFIC, SO CARE STAFF NEED TO KNOW ABOUT AUTISM	SERVICE PROVIDER
HOUSING	SOME BEHAVIOURAL PROBLEMS ARE CAUSED BECAUSE THE ADULT IS NO LONGER SUITED TO LIVING IN THE FAMILY HOME	SERVICE PROVIDER
HOUSING	PEOPLE WITH A LEARNING DISABILITY SHOULD BE GIVEN EXTRA HOUSING POINTS	SERVICE PROVIDER
HOUSING	DEMAND AT LODDON COURT EXCEEDS SUPPLY	SERVICE PROVIDER
HOUSING	IT WOULD BE BETTER IF FACILITIES LIKE THIS WERE DESIGNED FOR ONE ABILITY LEVEL	SERVICE PROVIDER
HOUSING	NOT ENOUGH SPECIALIST ACCOMMODATION IN WOKINGHAM	SERVICE PROVIDER
HOUSING	WE REQUIRE MORE SUITABLE SUPPORTED LIVING ACCOMMODATION - PEOPLE WITH ASD DO NOT WANT TO LIVE WITH PEOPLE WITH LEARNING DIFFICULTIES, THEY WANT TO SHUT THEIR FRONT DOOR	SERVICE PROVIDER
LEISURE/SOCIAL	HE WOULD BENEFIT FROM MEETING MORE YOUNG PEOPLE OF A SIMILAR AGE SOCIALLY	PARENT/CARER
LEISURE/SOCIAL	IT WOULD BE GOOD FOR HIM TO BE OCCUPIED DURING HIS LONG SUMMER BREAKS FROM COLLEGE	PARENT/CARER

LEISURE/SOCIAL	HE NEEDS A PERSON TO INTERACT WITH - THIS WILL HELP DEVELOP HIS LANGUAGE AND SOCIAL SKILLS	PARENT/CARER
LEISURE/SOCIAL	HE MISSES OUT ON SOCIAL LIFE IN THE EVENINGS	PARENT/CARER
LEISURE/SOCIAL	HE IS DEEPLY FRUSTRATED BY HIS LACK OF SOCIAL OPPORTUNITIES	PARENT/CARER
LEISURE/SOCIAL	HE WOULD LIKE TO BREAK OUT OF THE RUT OF BEING CONSTANTLY WITH PEOPLE WITH SEVERE LEARNING DIFFICULTIES AND DISRUPTIVE BEHAVIOUR AND WOULD LOVE TO MEET OTHER YOUNG PEOPLE WHO DO NOT HAVE THESE PROBLEMS	PARENT/CARER
LEISURE/SOCIAL	HE'S SOCIABLE BUT DOESN'T KNOW HOW TO MAKE FRIENDS SO A SOCIAL GROUP WOULD BE VERY HELPFUL TO HIM	PARENT/CARER
LEISURE/SOCIAL	I WOULD LIKE MORE INDEPENDENT TRAVEL WITHOUT MY PARENTS	PERSON WITH AN ASD
LEISURE/SOCIAL	I WOULD LIKE MORE OUTINGS WITH FRIENDS	PERSON WITH AN ASD
LEISURE/SOCIAL	I WANT TO FIND A CLUB, SOCIALISE MEET SIMILAR PEOPLE AND MAKE FRIENDS BUT NOT WITH THE LEARNING DISABLED OR ELDERLY	PERSON WITH AN ASD
LEISURE/SOCIAL	I WOULD LIKE MORE 3 TO 4 DAY SHORT BREAKS LIKE THOSE TO THE LAKE DISTRICT AND CORFE CASTLE ORGANISED BY READING COLLEGE AND LEAP	PERSON WITH AN ASD
LEISURE/SOCIAL	PEOPLE WITH ASPERGERS DON'T OFTEN NEED MUCH - JUST TO BE INCLUDED	SERVICE PROVIDER
LEISURE/SOCIAL	A FORTNIGHTLY - EVEN WEEKLY - SOCIAL GROUP WOULD BE HELPFUL	SERVICE PROVIDER
LEISURE/SOCIAL	LACK OF ENTERTAINMENT OPPORTUNITIES IS A PROBLEM	SERVICE PROVIDER
OTHER	OPPORTUNITIES FOR EMPLOYMENT ARE LIMITED BY THE BENEFITS SYSTEM. IF HE EARNS OVER £50 PER WEEK HE LOSES HIS HOUSING BENEFIT	PARENT/CARER
OTHER	DIRECT PAYMENTS ARE AN ABDICATION OF THE COUNCILS RESPONSIBILITIES	PARENT/CARER
OTHER	HE CAN'T GET A NEST EGG TOGETHER AS HE IS NOT ALLOWED TO SET UP SAVINGS ON HIS OWN	PARENT/CARER
OTHER	DIRECT PAYMENTS ARE HELPFUL TO ME	PARENT/CARER
OTHER	BENEFITS SHOULD NOT BE STOPPED WHEN A REVIEW OR RE-ASSESSMENT STARTS AS I HAVE SEEN THIS CAUSE ACUTE DISTRESS	SERVICE PROVIDER
SOCIAL CARE	PROFESSIONALS NEED TO LISTEN TO PEOPLE WITH AS AND THEIR FAMILIES, NOT TREAT THEM WITH CONTEMPT	PARENT/CARER
SOCIAL CARE	SOCIAL WORKERS NEED TO BE MORE AWARE AND HANDS ON AND NOT GIVE UP ONCE A PLACEMENT IS MADE	PARENT/CARER
SOCIAL CARE	ASD PEOPLE ARE LEFT IN LIMBO	PARENT/CARER
SOCIAL CARE	SOCIAL SERVICES REGARD ASD AS NOT REQUIRING THEIR HELP	PARENT/CARER
SOCIAL CARE	WE HAVE HAD REALLY GOOD SUPPORT FROM THE CTPLD. I HAVE NOTHING BUT PRAISE FOR THE LOCAL AUTHORITY	PARENT/CARER
SOCIAL CARE	IF A PERSON IS BLIND, OR DEAF OR IN A WHEELCHAIR THEY WILL GET SERVICES BUT IF THEY HAVE AN AUTISM DIAGNOSIS THEY OFTEN WILL NOT. THIS IS DISCRIMINATION	PARENT/CARER
SOCIAL CARE	WHEN PEOPLE HAVE BOTH AUTISM AND A LEARNING DISABILITY, SERVICES ARE PROVIDED FOR THE LEARNING DISABILITY - NOT FOR THE AUTISM	PARENT/CARER
SOCIAL CARE	CHILDRENS SERVICES COST ADULT SERVICES A FORTUNE BECAUSE THE RIGHT INTERVENTION AT AN EARLY AGE WOULD MEAN LESS ADULT PROVISION	PARENT/CARER
SOCIAL CARE	SOCIAL SERVICES HAVE TO GET THINGS RIGHT FIRST TIME - SETTING PEOPLE UP TO FAIL IS A FALSE ECONOMY	PARENT/CARER
SOCIAL CARE	SERVICES OFTEN FAIL CHILDREN AND THIS CAN LEAD TO EXPENSIVE LIFE-TIME CARE. CHILDREN'S SERVICES COULD SAVE ADULT SERVICES A LOT OF MONEY IF THEY IDENTIFY THE NEED AND PROVIDE THE RIGHT SERVICES FROM AN EARLY AGE	PARENT/CARER
SOCIAL CARE	I'VE BEEN ASKING FOR A CARE PLAN AND A PERSON CENTRED PLAN FOR YEARS BUT WE STILL HAVEN'T GOT ONE	PARENT/CARER
SOCIAL CARE	EVERYONE HAS SOMETHING TO OFFER IN LIFE AND PEOPLE SHOULDN'T BE LABELLED SERVICE USERS. THEY SHOULD BE VALUED MORE AND TREATED WITH MORE RESPECT - THEN THEY WILL POSITIVELY RESPOND	PARENT/CARER
SOCIAL CARE	MY DAUGHTER HAS HAD 5 SOCIAL WORKERS IN THE PAST 15 YEARS. THEY HAVE ALL MADE MISTAKES - PROBABLY DUE TO A LACK OF KNOWLEDGE AND UNDERSTANDING.	PARENT/CARER
SOCIAL CARE	HE NEEDS HELP WITH HIS BEHAVIOURS NOW BUT WE ARE ALMOST CERTAINLY GOING TO HAVE TO WAIT	PARENT/CARER
SOCIAL CARE	THE SOCIAL WORKER IS A COMPLETE WASTE OF TIME	PARENT/CARER

SOCIAL CARE	CARE PLANS FOR ADULTS WITH SEVERE LEARNING DISABILITIES NEED FULL PARENTAL INPUT. THERE IS A LACK OF AWARENESS THAT PARENTS HAVE A BIG ROLE TO PLAY - THEY KNOW WHAT THEIR CHILD NEEDS	PARENT/CARER
SOCIAL CARE	SOCIAL SERVICES LET YOU GET TO BREAKING POINT BEFORE YOU GET REAL PRACTICAL HELP	PARENT/CARER
SOCIAL CARE	SERVICES SEEM TO BE PROVIDED ON A ONE SIZE FITS ALL BASIS - THERE NEEDS TO BE DIFFERENTIATION BASED ON ABILITY AND NEED	PARENT/CARER
SOCIAL CARE	CTPLD'S OCCUPATIONAL THERAPIST SHOULD DO MORE TO HELP PEOPLE WITH AUTISM	PERSON WITH AN ASD
SOCIAL CARE	WHEN I GOT ACCEPTED BY SOCIAL SERVICES I DID AN IQ TEST BUT IF YOU'RE AVERAGE OR HIGH IQ, SOCIAL SERVICES CANNOT ACCEPT YOU AND A LOT OF AUTISTIC PEOPLE SLIP THROUGH THE NET	PERSON WITH AN ASD
SOCIAL CARE	SPECIALIST TEAMS LEAD TO EXCLUSIONS SO A VULNERABLE ADULTS TEAM IS RECOMMENDED	SERVICE PROVIDER
SOCIAL CARE	WITHIN WOKINGHAM, COMMUNITY CARE NEEDS TO TAKE RESPONSIBILITY FOR AUTISM, PREFERABLY IN PARTNERSHIP WITH HEALTH SERVICES	SERVICE PROVIDER
SOCIAL CARE	OUR EXPERIENCE IS THAT PEOPLE WITH AUTISM OFTEN GET BATTED BETWEEN CMHT AND CTPLD AND CAN FALL BETWEEN THE TWO SERVICES	SERVICE PROVIDER
SOCIAL CARE	AUTISM SHOULD NOT BE THE RESPONSIBILITY OF THE CMHT OR CTPLD AS IT SHOULDN'T BE A BOLT-ON TO AN EXISTING SERVICE - IT IS A BIG ENOUGH AREA TO BE RECOGNISED AS A SERVICE IN ITS OWN RIGHT	SERVICE PROVIDER
SOCIAL CARE	DAY CENTRES ARE GENERALLY NOT AUTISM FRIENDLY	SERVICE PROVIDER
SOCIAL CARE	WE NEED TO ENSURE PEOPLE HAVE THE RIGHT CARE PACKAGE IN THE RIGHT SETTING - THE TWO MUST GO TOGETHER	SERVICE PROVIDER
SOCIAL CARE	A CHILD IS REFERRED TO A PAEDIATRICIAN BUT ADULTS GET SHUNTED AROUND WITH NO-ONE TAKING RESPONSIBILITY	SERVICE PROVIDER
SOCIAL CARE	SERVICES FOR PEOPLE WITH AUTISM DIE AT 18	SERVICE PROVIDER
SOCIAL CARE	A VARIETY OR PACKAGE OF CARE IS REQUIRED FOR EACH INDIVIDUAL	SERVICE PROVIDER
SOCIAL CARE	THERE IS LITTLE PARTNERSHIP WORKING BETWEEN THE COUNCIL, THE PCT AND THE HEALTHCARE TRUST. THEY ALL WORK INDEPENDENTLY IN THEIR BOXES	SERVICE PROVIDER
SOCIAL CARE	HOW MANY ASPERGER PEOPLE ARE IN PRISON? PREVENTATIVE MEASURES WOULD SAVE MONEY	SERVICE PROVIDER
SOCIAL CARE	THERE ARE NOT ENOUGH DAY SUPPORT FACILITIES IN WOKINGHAM - ONLY ACORN PLUS THE TIME BOUGHT AT CRESCENT	SERVICE PROVIDER
SOCIAL CARE	IF PEOPLE DON'T FALL INTO THE CATEGORIES WE WORK TO THEY WON'T GET A SERVICE	SERVICE PROVIDER
SOCIAL CARE	THE SOCIAL AND EMOTIONAL NEEDS OF THOSE AT THE MORE ABLE END OF THE SPECTRUM ARE LARGELY UNMET	SERVICE PROVIDER
SOCIAL CARE	PEOPLE WITH AUTISM CAN BE PUSHED FROM PILLAR TO POST WITH CTPLD OFTEN ENDING UP AS THE SAFETY NET ORGANISATION BUT A VULNERABLE ADULT TEAM IS IN PLACE IN OTHER LOCAL AUTHORITIES AND SHOULD BE IN WOKINGHAM	SERVICE PROVIDER
SUPPORT	IT WOULD BE GOOD FOR SOMEONE HIS OWN AGE TO TAKE HIM OUT FOR SOCIAL ACTIVITIES	PARENT/CARER
SUPPORT	HE WOULD BENEFIT FROM THE SUPPORT OF A BEFRIENDER	PARENT/CARER
SUPPORT	I HAVE TO ACT AS AN ADVOCATE FOR MY DAUGHTER. NO-ONE ELSE WILL AND WITHOUT AN ADVOCATE MEETINGS ARE POINTLESS	PARENT/CARER
SUPPORT	TRANSITION IS SUCH A CRITICAL TIME THAT IF IT IS MISHANDLED ALL THE GOOD WORK AND EXPENDITURE THAT HAS GONE BEFORE WILL BE LARGELY WASTED	PARENT/CARER
SUPPORT	ADVOCACY AND BEFRIENDING WOULD BE HELPFUL	PARENT/CARER
SUPPORT	I FEEL THERE NEEDS TO BE MORE SUPPORT AND UNDERSTANDING	PERSON WITH AN ASD
SUPPORT	I WOULD FIND A BEFRIENDER HELPFUL	PERSON WITH AN ASD
SUPPORT	SUPPORT NEEDS TO BE ON-GOING, FOR EXAMPLE EVERY TIME I GET SOMETHING NEW I NEED TO BE SHOWN HOW IT WORKS	PERSON WITH AN ASD
SUPPORT	COUNSELLING IS AVAILABLE BUT THEY'VE BEEN VERY BUSY RECENTLY AND WON'T BE ABLE TO SEE ME FOR SOME WEEKS	PERSON WITH AN ASD
SUPPORT	PEOPLE WITH MILD AUTISM HAVE THE MOST DIFFICULTY AS IT'S HARDER TO GET SUPPORT	PERSON WITH AN ASD
SUPPORT	PEOPLE WITH NEUROLOGICAL DISORDERS LIKE ME DON'T GET SUPPORT BECAUSE THEY DON'T LOOK DISABLED	PERSON WITH AN ASD

SUPPORT	ADVOCACY COULD BE USEFUL	PERSON WITH AN ASD
SUPPORT	I WOULD LIKE A BUDDY TO TAKE ME ON DAYS OUT	PERSON WITH AN ASD
SUPPORT	I DON'T WANT TO WAIT 2 OR 3 WEEKS FOR COUNSELLING	PERSON WITH AN ASD
SUPPORT	THERE IS NOT ENOUGH RESPITE CARE AVAILABLE FOR ADULTS WITH AUTISM	SERVICE PROVIDER
SUPPORT	ONE TO ONE BEFRIENDING WOULD BE HELPFUL	SERVICE PROVIDER
SUPPORT	WHERE THERE HAS BEEN A LATE DIAGNOSIS A NAS HELP OR EARLY BIRD TYPE PROGRAMME FOR PARENTS AND CARERS OF ADULTS WOULD BE USEFUL	SERVICE PROVIDER
SUPPORT	LOW LEVEL SUPPORT SERVICES CAN ACT AS EFFECTIVE LOW COST PREVENTATIVE MEASURES	SERVICE PROVIDER
SUPPORT	WE NEED TO PREPARE INDIVIDUALS FOR INDEPENDENT LIVING - A TRANSITION HOUSE WOULD BE A GOOD SOLUTION	SERVICE PROVIDER
SUPPORT	A LACK OF TRANSPORT INHIBITS PEOPLE ACCESSING SOME SERVICES AND OPPORTUNITIES	SERVICE PROVIDER
SUPPORT	EMOTIONAL SUPPORT IS PARAMOUNT	SERVICE PROVIDER
SUPPORT	BEING ABLE TO TALK ABOUT HOW IT FEELS IS SO IMPORTANT THAT COUNSELLING IS THE ONE SERVICE I WOULD PROVIDE ABOVE ALL OTHERS	SERVICE PROVIDER
SUPPORT	ADVOCACY IS ONLY PROVIDED BY WEBCAS IF THE PERSON IS FUNDED	SERVICE PROVIDER
SUPPORT	DEMAND FOR ADVOCACY EXCEEDS SUPPLY	SERVICE PROVIDER
SUPPORT	WE WOULD LIKE A BEFRIENDING SERVICE IN WOKINGHAM	SERVICE PROVIDER

APPENDIX 3 FEEDBACK SOURCES & ACKNOWLEDGEMENTS

MEETINGS, GROUPS & EVENTS ATTENDED/CONSULTED PLUS INDIVIDUAL ACKNOWLEDGEMENTS

MEETINGS ETC:

- ABILITY HOUSING ASSOCIATION
- ASD FAMILY HELP (formerly WOKINGHAM AUTISM SUPPORT for PARENTS)
- BERKSHIRE AUTISTIC SOCIETY (BAS)
- BERKSHIRE AUTISTIC SOCIETY ADULT SOCIAL GROUP
- BERKSHIRE WEST PCT MENTAL HEALTH FACILITATION TEAM
- CORNERSTONES REVISITED
- DIMENSIONS
- JIGSAW CREATIVE CARE LIMITED
- FRIDAY ALTERNATIVE SOCIAL GROUP (run by Wokingham Mencap)
- NATIONAL AUTISTIC SOCIETY
- RAVENSWOOD VILLAGE
- WBC AUTISTIC SPECTRUM SERVICE for INFORMATION SUPPORT and TRAINING (ASSIST)
- WBC COMMUNITY MENTAL HEALTH TEAM (CMHT)
- WBC COMMUNITY RESOURCE SERVICE (CRS)
- WBC COMMUNITY TEAM for PEOPLE WITH LEARNING DISABILITIES (CTPLD)
- WBC DISABILITY SERVICES
- WBC DISABLED CHILDREN'S TEAM (DCT)
- WBC LEARNING DIFFICULTIES & DISABILITY SERVICE
- WEST BERKSHIRE ADVOCACY SERVICE (WEBCAS)
- WOKINGHAM AUTISM PARTNERSHIP (WAP)
- WOKINGHAM EMPLOYMENT SUPPORT SERVICE (WESS)
- WOKINGHAM LEARNING DISABILITY PARTNERSHIP BOARD (LDPB)
- WOKINGHAM LDPB AUTISM SUB-GROUP
- WOKINGHAM LDPB HEALTH SUB-GROUP
- WOKINGHAM LDPB TRANSITION SUB-GROUP
- WOKINGHAM & DISTRICT MENCAP CARERS MEETINGS

ACKNOWLEDGEMENTS:

- ALL MEMBERS OF WOKINGHAM LDPB AUTISM SUB-GROUP
- ALL QUESTIONNAIRE RESPONDENTS
- ALL WOKINGHAM MEMBERS OF BAS ADULT SOCIAL GROUP (People with ASD)
- ALL WOKINGHAM MEMBERS OF FRIDAY ALTERNATIVE SOCIAL GROUP (People with ASD)
- STEVEN ALLEN (Person with ASD)
- MR & MRS ALLEN (Parent/Carers)
- JANE BARTLETT (Service Provider)
- BECKY BACON (Person with ASD)
- PAMELA BRESLIN (Service Provider)

- HARVEY CAMPBELL (Service Provider)
- DIANE CLEMENTSON (Service Provider)
- MARY CODLING (Service Provider)
- SYLVIA COGLIATTI (Service Provider)
- LOUISE CONNOLLY (Service Provider)
- DEE CONSTABLE (Disabilities Trust)
- MRS CRACKNELL (Parent/Carer)
- MARINA DOBSON (Service Provider)
- JOANNE EAST (Berkshire Autistic Society)
- CATHY FASTNEDGE (Parent/Carer)
- ROS FERNLEY (Parent/Carer)
- JANE FLOWER (Service Provider)
- SALLY GRANT (Service Provider)
- SALLY HADLEY (Service Provider)
- HELEN HARRIS (Berkshire Autistic Society)
- JENNY HARRIS (Service Provider)
- KEVIN HICKSON (Service Provider)
- FIONA HUDSON (Parent/Carer)
- ROSE HILL (Service Provider)
- METTE LE JAKOBSEN (Service Provider)
- BARBARA JENKINS (Service Provider)
- TINA KISLINGBURY (Service Provider)
- HELEN LODGE (Parent/Carer)
- MICHAEL LODGE (Person with ASD)
- MORAG MALVERN (Parent/Carer)
- MRS NARAYAN (Parent/Carer)
- SHERRY OVER (Service Provider)
- SALLY PALMER (RBWM)
- MICHELLE PEARCE (Parent/Carer)
- JANET REYNOLDS (Parent/Carer)
- DYANA RUSH (Service Provider)
- SONIA SAVAGE (Parent/Carer)
- JULIE STEVENS (Service Provider)
- JO SWINN (Parent/Carer)
- ANN TAYLOR (Berkshire Autistic Society)
- LEE THORNTON (Person with ASD)
- JILL WOODS (Service Provider)
- HEATHER YOUNG (Parent/Carer)