

**REVIEW OF AUTISTIC SPECTRUM DISORDERS**

**IN WEST BERKSHIRE**

**COMMISSIONED BY WEST BERKSHIRE COUNCIL**

By  
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## **REVIEW of AUTISTIC SPECTRUM DISORDER.**

### **REPORT FOR WEST BERKSHIRE COUNCIL.**

#### **1. INTRODUCTION**

1.1 This report is an overarching review of the known prevalence, current service provision, and gaps in provision for both children and adults living in West Berkshire who have an autistic spectrum disorder. The report has been divided into two parts because Children and Young Peoples' Services which includes Education have quite different responsibilities and services in comparison to Adult Services. Adult Services have responsibility for social care only and have a duty to provide services to those in greatest need using a standard set of eligibility criteria. There is therefore a distinct difference between the range and types of services provided to children and adults who have an autistic spectrum disorder.

1.2 Thus only adults who meet the eligibility criteria tend to get a service and as the eligibility criteria tend to be care group specific those who do get a service tend to have a learning disability, mental illness or physical disability as well as their autistic condition. This applies most local authorities. The National Autistic Society via their "I Exist Campaign" have been lobbying both nationally and locally to change this situation because there is growing evidence that a large number of people with autism who do not meet current eligibility for services struggle to cope with everyday life and tend to end up in excluded situations either via homelessness, substance misuse, mental illness, or through the criminal justice system. Often they come to the notice of statutory and universal services, but because their underlying condition is not recognised any help they receive does not tend to meet their quite specific needs. However there is also another large group of people with autistic spectrum disorders who function at a level that enables them to deal quite adequately with life on their own and who do not need or want any help.

1.3 Autism is defined as a triad of impairments. These are:-

- Difficulty in social communication
- An inability to understand the feelings and emotions of others or to express their own
- An inability to understand and predict other people's behaviour or to imagine situations beyond their daily routine. (Routine is often very important to people with these conditions).

1.4 A major issue nationally and locally is that there is no consistently reliable information about the numbers of people in any area who are autistic, how many of them need help, and what kind of services best support those people who do need help. However the National Autistic Society has developed a formula to predict the number of people in the population who are likely to have an autistic spectrum disorder.

1.5 Using the NAS formula it is estimated in the work done for this report that there are approximately 1200 people in West Berkshire with one of the conditions in the spectrum.

1.6 There are 309 known cases of autism amongst children and young people in West Berkshire.

## **2. NATIONAL CONTEXT**

2.1 In September 2008 the National Audit Office carried out a survey all local authorities to find out what was known about the number of adults with an autistic spectrum disorder and the services currently being provided. The results of this have been published in, “Supporting people with autism through adulthood” (June 2009). In April 2009 the Department of Health announced the intention to have a national strategy for autism and have completed a national consultation for that strategy via a document “A Better Future”. (Consultation ended on 15<sup>th</sup> September 2009)

2.2 The Autism Act based on this consultation passes into law on 12<sup>th</sup> November 2009. It makes two key provisions:-

- 1) That the Government produce an autism strategy by 1<sup>st</sup> April 2010.
- 2) That the Secretary of State issue statutory guidance in this area by 31<sup>st</sup> December 2010.

2.3 The Autism Strategy is likely to have the following key areas for improvement based on the consultation responses:-

- Raising public awareness and acceptance of ASC
- Improving key professionals’ level of training
- Improving access to local services
- Improving local leadership
- Personalising services
- Taking account of sensory issues
- Improving diagnostic pathway
- Ensuring adults with an ASC can access the healthcare they need.

2.4 The Statutory Guidance is likely to cover the following areas:-

- ❖ Identifying adults with autism
- ❖ Providing services for diagnosing autism in adults
- ❖ Carrying out needs assessments for adults with autism
- ❖ Planning appropriate services to young people with autism as they move from children’s’ to adult services
- ❖ Local planning to provide appropriate services to adults with autism
- ❖ Training staff who provide services to adults with autism
- ❖ Local leadership with regard to providing services to adults with autism.

In addition to this work being carried out by central government the National Autistic Society both nationally and locally have produced recommendations.

2.5 *The national NAS has produced the priorities set out below:*

- *Specialist teams to be set up in every local authority/PCT boundary*
- *Diagnostic services available locally (linked to the development of the team)*
- *Autism Planning Group to be set up in every local authority area/PCT boundary*
- *Inclusion of the needs of adults with autism in the Joint Strategic Needs Assessment*
- *Clear structures for reporting and delivery, including at local level a local autism lead*

- *Extensive training strategy (prioritising GPs and professionals who carry out care assessments)*
- *Improved support from Job Centre Plus.*

2.6 West Berkshire Branch National Autistic Society has carried out its own local survey and has also produced a set of priorities. These are:-

- *Strategic planning to meet the needs of people with autism*
- *A specialist adult autism team*
- *Youth services and support for young people with autism making a transition to adult services*
- *Effective training for all staff who come into contact with people with autism*
- *Information and support for families, particularly increased short break provision*
- *People with autism and parents and carers to be involved in strategic planning and service development*

### **3. LOCAL CONTEXT**

**The Council has reviewed its provision to both children and adults living in West Berkshire who have an autistic spectrum disorder. This review has been carried out within the context of the national consultation that will inform the new Autism Strategy. A summary of West Berkshire's local review is set out below.**

#### **3.1 CHILDREN AND YOUNG PEOPLE**

##### **CURRENT SERVICES**

###### **Education**

- Pre-School Teacher Counselling Service which supports children under 5 with SEN, including children with ASD and social communication difficulties.
- Mainstream schools with additional support.
- Training programme and guidance for school staff, including bespoke training for individual schools.
- ASD Advisory Teachers who provide support and guidance to schools on meeting the needs of children with ASD.
- ASD Development Worker who supports parents of children diagnosed with autism and runs training courses for parents.
- Special School Consultancy Service which provides support and guidance to schools on meeting the needs of children with ASD who also have learning difficulties.
- Resourced mainstream schools for children with ASD, one primary and one secondary.
- Special schools, Brookfields School and The Castle School which cater for children with significant learning difficulties, including children with learning difficulties and ASD.
- Speech and language therapy and occupational therapy in mainstream, resourced and special schools.

- ASD Project Workers / Family Support Workers who support families of children with ASD, mostly children attending the special schools.
- Out of Area School Placements for children whose needs cannot be met locally.
- Further Education at both Newbury College and Thames Valley University
- Support in Higher Education for students with ASD.
- Parent Partnership Service which provides independent support for parents of children with SEN, including parents of children with ASD.

### **Social Care**

- Disabled Children's Team which supports families who have a child with significant, long term needs.
- Occupational Therapy support to provide equipment in the home and adaptations to the home environment where required.
- Castlegate Centre which provides outreach services and short breaks including overnight stays.
- Locality Teams provide social work support where it is needed for those children not eligible for support from Disabled Children's Team.

### **Health**

- SOCOM (Social Communication Disorders Service) which provides diagnosis of ASD and support following diagnosis.
- Community and Adolescent Mental Health Service which can provide ongoing support following diagnosis, where appropriate, including cognitive behavioural therapy, psychotherapy and family work / therapy.
- Speech and Language Therapy assessments and some direct therapy (mostly for children under 5 and non statemented children)
- Occupational Therapy assessments and some direct therapy (mostly for children under 5 and non statemented children).

### **Out of School/ Recreational Opportunities**

- Mainstream after school and holiday clubs, with one to one support where required.
- Support to access recreational opportunities
- Specialist after school and holiday schemes.
- Spectrum Club: NAS Youth Club for young people with ASD up to the age of 14.
- Youth Club for young people with ASD over 14– being set up using Aiming High funding
- Aiming High for Disabled Children Short Breaks Initiative, which has made funding available to increase a range of short break services including more sitting services and more funding for Direct Payments to families.
- Youth worker for young people with SEN / disabilities.

### **Voluntary Organisations**

- National Autistic Society
- Mencap

### **Transition**

- Significant improvements in transition process over past 2 years
- Aiming High for Disabled Children Transition Initiative has funded a pilot of person centred planning, work on joint assessment and a single plan at transition and the part time youth worker for young people with SEN / disabilities.

### **Information for parents / carers**

- SEN area of West Berkshire Council's Website
- Parent Partnership Service information
- Mencap booklet commissioned for West Berkshire
- DVD on transition for young people with disabilities
- New post in Children's Information Service to develop information for families who have a child with a disability.

### **GAPS IN SERVICES/ISSUES FOR CONSIDERATION**

The following areas have been identified as potential gaps in services:

- Intensive intervention for very young children following a diagnosis of autism
- Support for parents following diagnosis of ASD
- Ability of all mainstream schools to meet the needs of children with ASD
- Addressing bullying in schools and providing social skills training
- Primary resourced provision – possible need for expansion
- Lack of provision for children with learning difficulties, ASD and severely challenging behaviour
- Lack of post 16 provision at The Castle School for young people with learning difficulties, ASD and challenging behaviour
- Lack of suitable educational provision for young people with ASD and Behavioural, Emotional and Social Difficulties (BESD)
- Difficulty accessing FE Colleges for young people who have ASD but do not have learning difficulties
- Lack of suitable home education when children with ASD are excluded from school
- Shortage of out of school/recreational opportunities for children and young people with ASD
- Need for specialist support for families of children with ASD from Children's Social Care
- Family support workers for families of children with ASD attending mainstream schools
- Speech and language and occupational therapy assessment waiting times
- Counselling for young people with ASD
- Further improvements to transition to adulthood

- Better information for families and young people

## **RESOURCE IMPLICATIONS**

Some of the areas for development referred to in Section 3.2 of this report are already underway and resources have been identified, e.g. the training programme for mainstream schools, reprovision of The Castle School's Post 16 Department on the Newbury College site, the Youth Club for young people with ASD aged 14 to 19, recruitment of a youth worker for young people with SEN / disabilities.

It is not possible to identify resource implications for all of the potential gaps in provision listed as some of these would need to be investigated in more detail to establish whether there is evidence of a genuine gap in the service, whether it is feasible to meet the need locally, how the need would best be met and therefore what the resource implications would be.

## **CONCLUSION**

This report has been based on information available within the Children and Young People's Service at West Berkshire Council and collated from other agencies involved in providing services for children with autism. It has also taken into account work done by the Children's Autism Implementation Group over the last year to map services and identify gaps. The Autism Implementation group is a multi agency group representing all services involved with children with ASD in West Berkshire. It includes NAS and parent representation. The report also takes into consideration the recent report of the West Berkshire Branch of the National Autistic Society, "Accept Difference not Indifference".

There have been significant developments and investment in services for children with ASD in West Berkshire in the last 12 years. It is acknowledged however that there is scope for further development in order to provide the most effective services possible for this very vulnerable group of young people.

Updated by  
Jane Seymour  
January 2010

## **3.2. ADULT SERVICES.**

### **CURRENT SERVICES**

#### **Social Care**

- Multi-agency Transition Forum and Protocol that includes young people with autism is now in place
- 1 Adult Transition Care Manager in CTPLD
- CTPLD, CMHT, and Physical Disability Teams all currently work with adults who are autistic however these people also have a primary disability in another area.
- The Complex Needs supported living development now underway in West Berkshire
- CTPLD is aware of having received 29 referrals for vulnerable adults who do not meet social care eligibility criteria over the past 2 years – many of them have an ASD diagnosis.
- Social Care are commissioning services costing approx. £3 million for the small group of people with ASD and a learning disability

#### **Health**

- CTPLD is a multi-disciplinary team which includes; psychiatrist, psychologists, specialist nurses, OT, physiotherapy; access to speech and language therapy, and dietetics
- CMHT is a multi-disciplinary team which provides services to a small number of people with Aspergers syndrome and ADHD who also have mental health needs
- There is a small, short-term residential forensic unit at Bracknell provided by Berkshire Health Care Trust.

#### **Voluntary Sector**

- National Autistic Society – local branch provides advice and support to people with ASD and their families
- Mencap and Thrive both provide services commissioned by WBC e.g. Link Up and horticultural therapy which will include people with ASD

#### **Independent Sector**

- A number of local care providers are supporting people with low level ASD in supported living and residential care commissioned by Social Care and Supporting People. This is currently not accounted for as these people may or may not have a formal diagnosis of ASD and unless they are also eligible for social care other needs may not be recognised.

#### **Benefits Advice.**

- Benefits advice is available to anyone via the Council's Customers Financial Services team and one of the officers in this team has produced specific benefits guidance for parents of young people with autism.

### **GAPS IN SERVICES/ISSUES FOR CONSIDERATION**

There is good work going on at present in West Berkshire with the adults with ASD who meet the current eligibility criteria. There is also a significant amount of funding paying for those who need very specialist services and an active strategy to commission better services for this small group. However this audit has uncovered the following gaps.-



- Specialist team. There is no specialist team for adults with ASD in West Berkshire and no funding currently available to establish one. Whilst specialist teams have been successful in a other areas the specialist team concept runs counter to the national agenda for social care which is for better information, guidance and access to universal services.
- Specialist workers for ASD located somewhere in Adult services.
- A strategic approach across services to meeting the needs of those currently not eligible for social care services.
- A local adult services lead for ASD
- Specialist training for designated staff
- General awareness raising for staff in all public services in the needs of people with ASD
- Person-centred planning
- Discussion with Health, Housing, Education, Voluntary Sector and local providers about what is and could be provided locally
- Social groups and information services specifically for people with ASD
- Consultation with local people who have ASD and their families about what would help.

## RESOURCE IMPLICATIONS

Until there is agreement about what other services may be needed it is difficult to quantify resources required

## 4. CONCLUSION.

Whilst there are many good services available in West Berkshire for people with ASD, the length and intensity of the whole document reflects the complexity of needs and the perceived deficits both nationally and locally.

There would seem to be a need for further work on the strategic direction West Berkshire as a whole community wishes to take in its approach and service responses to people with ASD.

In line with national thinking, it would seem an opportune time to consider a local Autism Forum that includes local organisations and stakeholders to consider the emerging national and local priorities outlined above and, within resources available, to review and align local services.

Updated by  
Alison Love  
January 2010.

**This review has identified a number of areas for improvement. The new Autism Strategy and the priorities of both the national and local National Autistic Society give us a clear indication of what these areas are and we would like to propose the following Action Plan to begin to work on those areas. (See Appendix 1).**

## APPENDIX 1.

### ACTION PLAN.

Set out below is an initial action plan which has been agreed by senior managers of West Berkshire Council. This is intended as the initial stages of an action plan which can be added to once wider discussion has taken place.

<b>Area for Improvement</b>	<b>Action</b>	<b>Who is Responsible</b>	<b>Timescale</b>	<b>Measure of Success/Outcome</b>
No current local Autism Strategy Group.	1. Re-establish the Autism Strategy Group and arrange an initial meeting.	Alison Love/ Jane Seymour	May/June 2010	The meeting is attended by relevant agencies and stakeholders. A way forward is agreed.
No strategic lead manager for adult services	2. Appoint a lead manager.	Jan Evans/Teresa Bell	February 2010	Alison Love nominated lead manager.
Training for professional staff	3. Commission training for relevant social care and health staff. 4. Engage the private and voluntary sector in the development of training.	Alison Love/ Jane Seymour	By September 2010	Training arranged.
Public awareness of autism	5. Devise a strategy for raising public awareness			
Access to information and local services.				
Personalised services.				
Transition				
Sensory Needs	Establish links with the new sensory needs service in West Berkshire			
Diagnostic Pathway				
Employment	Links with P2E			

	and local supported employment services.			
Access to healthcare				
Specialist skills and knowledge of ASD.				