



# Autism Partnership Board

## Minutes

Wednesday 11 June 2014

<b>Members in attendance:</b>	
Zita Calkin	Joint Commissioning Manager
Coral Collisson	Aylesbury Vale National Autistic Society
Robin Greenfield	
Olga Hamer	FACT Bucks
Ian King	The National Autism Society (Aylesbury Vale)
Kathy Nawaz	Carer
Clare Samways	Greater Resources for Aspergers Supporting Parent & Siblings (GRASP)
Ena Smale	FACT / parent
Shoshana Willets	GRASP

<b>Others in attendance:</b>	
Sharon Griffin	Bucks County Council
Amy Moore	Joint Commissioner - Transitions
Philippa Taylor	Carers Bucks



<b>No</b>	<b>Item</b>
<b>1</b>	<b>Environmental Check</b>
<b>2</b>	<p><b>Apologies for Absence / Changes in Membership</b></p> <p>Apologies for absence were received from Melissa Bloomfield, Lisa Burrige, Susan Code, Debi Game, Paulette Hunn, Richard Maguire, Sally Slade and Polly Wilkinson.</p>
<b>3</b>	<p><b>Minutes and Matters Arising</b></p> <p>The minutes of the meeting held on 11 June 2014 were agreed as a correct record.</p>
<b>4</b>	<p><b>Carers Bucks - supporting carers and young carers</b></p> <p>Phillipa Taylor, Young Carers Support Team, Carers Bucks, was welcomed to the meeting.</p> <p>Phillipa explained that Young Carers works with children and young people aged 5-18 who have a caring role and support a family member. The definition of a young carer is:</p> <ul style="list-style-type: none"> <li>• 5-18 years old</li> </ul>

- Caring for a family member with a physical or mental illness, disability, drug or alcohol addiction.

The person cared for may be a parent, sibling or other relative living in the same household.

Young Carers Bucks can offer a break from their caring responsibility in the form of club nights, group work and one to one sessions.

The young person would meet with an assigned team, have an assessment of their needs and the appropriate support decided.

Club nights are split into three age groups; 6-9 years of age; 10-12 and 12 plus. The club nights are held once every half term and similar to After School Clubs. They are designed for the Young Carers to have a break and to have fun. The club for young people aged 12 plus is more structured. The youngest group is more structured than the other two groups. Staff are on hand to talk to individuals if required.

Small working groups are held which gives Young Carers the opportunity to talk about common issues or issues and to rebuild self-esteem. A Sibling Support Group for those who support or care for a sibling, is also held for each age range. The youngest group tends to focus more on worries and the 10-12 age group on anger.

The Autism Spectrum Disorder (ASD) trees activity is used to help Young Carers gain an understanding of how autism/ASD/Asperger's syndrome affects their brother or sister. There are four common areas; language; social skills; imagination and rigid thinking; sensory. Coping strategies are also discussed.

The 1:1 sessions cover similar topics to the group work. They help Young Carers to understand autism and their own feeling and are an introduction in the groups and clubs. Bereavement is also covered during the 1:1's.

During the update, the following questions were asked and comments made:

**What to the sessions on self-esteem involve and who are they run by?** The self-esteem sessions are about positively boosting confidence. They are run by Young Carers Bucks.

**One very pressing emerging issue is that it can be very difficult to engage with a young person with depression. How could the Autism Partnership Board help with this issue?** Part of the reason for the creation of the Boost Groups was to address the issue of depression and engagement. Sylvia Kelly, Family Resilience, is carrying out work to look at this issue. Jane Turner, Acting Principle Educational Psychologist is keen to get services in place as a lot of siblings suffer from undiagnosed depression.

**Many young carers are depressed because they feel that their sibling(s) are not getting the support they need and they are responsible for the provision of caring role. Is this a common theme in all of the age groups?** The feeling of a lack of support for siblings tends to be the common theme for the older groups. The common themes in the younger groups are everyday annoyances and understanding why the sibling gets more attention.

Part of depression is about losing the voice of the child and their identity. It focus is on the child with special needs. There needs to be a platform for a Young Carer to have a voice. Dialogue is key to addressing depression and giving the individual a chance to say how they feel.

Educational Psychology can lend some support to schools. There have been incidents of siblings become upset whilst at school and staff at a loss as how to provide support.

**Do parent/carers have to tell schools that they have a child with special needs in the family?** Young Carers Bucks carry out training and awareness sessions in schools. If a young carer has an assessment, one of the questions asked is, are the school aware that the school is aware of special needs. Carers Bucks are happy to contact the school on behalf of the individual.

**Is there evidence about siblings failing at school and the outcomes?** There is antidotal evidence of siblings failing at school. The statistics can be obtained if required. The potential cost to the public purse when a child becomes an adult is significant.

**Do CAMHS have information about children being referred to their services? CAMHS offer free workshops for children with autism. Could there be similar workshops for siblings?** Susan Birch, Educational Psychologist has been involved in the Targeted Mental Health in Schools (TaMHS) Project which is an evidence based, whole school approach to supporting Emotional Wellbeing and Mental Health needs in schools. Local Authorities sometimes have a problem 'getting into' schools as they have to be invited by the school.

- It is about identifying schools as examples of good practice and using the model.
- Most secondary schools have access to a number of counselling skills.
- The Autism Strategy needs to recognise that it is not only the person with autism who is affected.
- When the Local Offer is published, it could include a provision for siblings.
- There needs to be recognition that the Local Authority has a limited say about what happens in schools. Work needs to take place with FACT Bucks to ensure that this is taken onboard.
- Do Ofsted have a role to play in terms of an element of inspection?
- There is nothing in the statutory guidance in the Local Offer which includes siblings. Could a local guide be produced?
- Does Duty of Care not have to be taken into account/considered?
- It is about working together. The Local Authority can do

	<p>what it can but parents need to flag up any issues.</p> <ul style="list-style-type: none"><li>• The Autism Partnership Board can influence and flag up good practice.</li></ul> <p>A Working Group is to be set up to look at supporting Young Carers. The suggestion was made of contacting Angela Kent, Governor Support Officer to help with this piece of work.</p> <p style="text-align: right;"><b>Action: Zita Calkin</b></p>
<b>5</b>	<p><b>Think Autism - strategy update</b></p> <p>Zita Calkin explained that Government update for the National Strategy emphasises the original strategy and also includes some extras. There are lots of examples of good practice and details of other services available.</p> <p>The Strategy has four main areas;</p> <ul style="list-style-type: none"><li>• Increasing awareness and understanding of autism</li><li>• Access to diagnosis and assessment</li><li>• Access to services and support</li><li>• Improve Planning so We Can Develop the Services People with Autism Need</li></ul> <p>The strategy suggests exploring the development of local areas to become more autism understanding communities (replicating that in dementia), for example autism friendly theatre/cinema performances, the use of an autism identity card and supporting local organisations to be autism aware.</p> <p>£4.5m of revenue and capital funding is available to support the delivery of some of the key themes including local innovation and awareness. The criteria to apply for funding have not been released as yet.</p> <p>Data collection is a bugbear for many services. Each service uses a different system which makes it difficult to integrate information and data. Mental Health use Rio; Children's</p>

Services use ICS and Livelink; the Local Authority uses Swift.

Adult Services are about to update their system to AIS (Adult Integrated System) which is a new 'front' to Swift. Different categories have been added i.e. the autism label.

Autism is a priority for the Royal College of General Practitioners (RCGP) over the next 3 years. The RCGP are the body who make recommendations to GPs about the provision of resources and training as well as guidance. It is not mandatory for GPs to take on the recommendations.

Part of the review is the self-assessment process. Members of the Autism Partnership Board will be involved in the assessment being carried out in November 2014.

During the update, the following questions were asked;

**Will the training be for existing as well as new GPs and who is responsible for cascading the information within the practices?** GPs are responsible for their own training. The County Council can offer training and staff to facilitate it but it depends on governance and budgetary constraints.

**The National Autism Society is very often asked if GPs and Dentists specialise in autism. Have any GPs expressed an interest in specialising in autism?** There have not been any expression of interests in specialising in autism as yet but it is worth exploring this more. It would be good to hear from individuals who have good experiences of health services.

**Parents are frequently coming to GRASP to ask for help and advice around autism. Is there a team who can go out to GP surgeries to carry out awareness training?** One of the aims of local plans is to raise awareness and to improve people/services understanding of autism. There isn't a team of people to go out but this is something for us to develop/commission. The challenge is to get on to GP practice agendas for training.

## 6 Action Plan progress

The 2014-2017 Action Plan was circulated for discussion.

*Increasing the awareness and understanding of autism*  
The training programme has to be wide ranging, in both audience and level, to improve awareness and skills across the whole community.

Paulette Hunn, Senior Training Consultant, Adult Social Care, is leading on work to look at training. Some of the members of the Autism Partnership Board have volunteered to help with this work.

The existing e-learning modules may need complete re-writing.

Autism will be part of all customer service training and included as part of the equality and diversity training.

Following feedback/requests from BCC staff, a series of lunchtime seminars are being held across the county for council staff.

An autism event will take place on the 17 October at The Oculus, Aylesbury Vale District Council. Mrs Cheryl Gillan, Conservative MP for Chesham and Amersham will be attending. Ann Whiteley, Carers Bucks is organising the event. A planning group has been set up to assist. (Olga, Ena, Ian and Coral).

A working group has been set up to look at carers and parents and those with autism delivering training. If funding can be obtained, there is the possibility of pump priming an organisation to deliver autism



training/awareness.

Autism Oxford is commissioned to delivery training for all elements of the Criminal Justice System, as they have already done in Oxford.

Autism Awareness training is being developed to meet the needs of transport staff at AMEY.

A decision is to be made about an 'Autism Alert Card' in Buckinghamshire. Discussion points:

**As funds are limited, would the best option be to make use of the Autism Alert Card produced by the National Autism Society?**

**How much is the Oxford Autism Alert card localised to the National Autism Society?**

**A local card would be best as it would have a gravitas that local businesses would recognise.**

**It is very expensive to produce an Autism Alert Card. Autism Oxford manages a database but it is not compatible with the County Council system.**

**The following needs to be clarified; why Bucks wants an Autism Alert Card, who the card will be given to, how effective will it be, how would the use of the card be promoted, how are existing alert card promoted?**

**Does Autism Oxford have sponsorship for the alert card?** Autism Oxford is a small independent charity. They commission services from Oxford Health & Social Care. A large amount of their income is generated from

events and training and subsidises the work they do.

The National Autism Society will be contacted to discuss the possibility of localising the existing Autism Alert Card. Samples can be brought to the next meeting.

**Action: Ian King**

Discussion points on staff training:

**Is there a training plan in place?** Autism training is in place for Adult Social Care staff. Training/awareness would also take place for teams who work with adults with autism. The County Council access specialised autism training from outside the county.

**How many people have taken up the training programme?** A monthly report is produced advising the number of staff who have completed training.

**Is the training programme monitored and if so, who does this?** The completion of training is monitored as part of the annual Delivering Successful Performance (DSP) process for each member of staff. The manager for each Service Area also monitors training. The aim is for the training plan to be completed in a year. The team would identify any training gaps. Any particular specialist training needs would be picked up by the Manager.

**Who monitors training for Aylesbury Vale District Council (AVDC) employees?** The County Council have no input into the training programme for AVDC staff.

**How successful has the training been in terms of**

**staff raising their competency levels and implementing the learning in their day to day work?**

The outcome would be monitored through regular supervision, Service user reviews and contract managers for services. Part of the Transition training involved the set-up of post groups and the creation of an outcome monitoring tool.

**Is it possible to get support from CAMHS in terms of the re-enforcement of the benefits of autism training?** Aylesbury Vale National Autistic Society has been working with the heads of CAMHS to look at autism training.

*Access to diagnosis and assessment*

Work is taking place with Oxford Health about the provision of services for adults who do not have a primary diagnosis. There has been a slight delay in finalising the process in order to ensure clear guidelines to help GPs make referrals. Oxford Health will deliver the assessment service in Buckinghamshire. The gateway for diagnosis will always be the GP. In Oxford where the service has been in place for a year, there have been a significant number of inappropriate referrals which has caused long delays and a high number of negative diagnoses.

*Improving planning so we can develop services people with Autism need*

An Autism Worker post is being established in the Local Authority to provide a central contact point for expertise, advice, information about pre-diagnosis and to identify services/support. The post will be 100% funded by health money but will be managed by the Local Authority. Recruitment to the post is underway. The job description for the Autism Worker will be email

to Board members for information.

**Action: Zita Calkin/Sharon Griffin**

Amy Moore explained that local councils will have to draw up an education, health and care (EHC) plan instead of a statement of SEN, publish a 'local offer' of services and offer a personal budget. The law will come into force from September 2014.

Discussion points on diagnosis and assessment:

**If a Care Manager carries out an assessment and the suspects that the individual has autism, what is the process?** The Care Manager could suggest that the individual goes to their GP. The new diagnostic pathway is aimed at improving this for GPs to make clear referrals. A Care Manager carries out assessment of social care needs. People may not be eligible for social care services.

Amy Moore explained that a business case is being put forward for the proactive outreach provision for the homeless. The possibility of a pilot is being discussed.

**What is the role of Floating Support Service?**

Housing related support is to prevent an individual losing their tenancy i.e. helping them to gain independent living skills, giving advice on how to be a tenant and about budgeting/debt support etc.

**Who can make a referral to the Floating Support Service?** An individual can self-refer to the Floating Support Service or via their Housing Officer.

*National Strategy Innovation Fund ideas:*

**Could part of the Autism Innovation Fund be used**

**to support the provision of bereavement training for families/parents/siblings etc?** Coral said that CAMHS provide a similar programme of bereavement training which could be built upon.

There is a third element of training around how families of children who are newly diagnosed with autism navigate around the SEN 'jungle' in terms of schools, budgets and SEN statements.

Another suggestion is to use some of the funding to help people access GPs/dentists via applications on iPhones and iPads etc. This would link in with the promotion of hospital visual/social stories.

Macclesfield District General Hospital has become the first hospital in the UK to be given an Autism Access Award by the National Autistic Society (NAS), the UK's leading charity for people affected by autism.

**7 Any Other Business**

*FACT Bucks*

A piece of work is taking place to put copies of the seminars delivered to parents on-line. There still needs to be a face to face element of seminars.

*Transitions Fair*

As part of the Local Offer, the Local Authority needs to hold yearly events to publicise the support and services available in Bucks for young people with special needs when they become adults.

Fact Bucks held its first Transitions Information Fair for Children and Young Adults 14 – 25 years with special educational needs and/or disabilities in Buckinghamshire in March. Issues discussed included ways of disseminating information and the pathway for diagnosis.

### *Autism meetings*

The Autism Project Board currently meets on the first Wednesday of every month and has similar agendas to the Autism Partnership Board. The possibility of combining the two meetings will be looked into.

**Action: Zita Calkin**

### *Provision of services for 14-21 year olds*

The lack of the provision of services and information for 14-21 year olds once they have been diagnosed as having autism needs to be looked into. The number of referrals has increased but there is a shortage of appropriate services.

The following comments were made;

- There are issues for those aged 18-21 in terms of when their Statement of Special Needs finishes Adults and Family Wellbeing do not collect data. Data is only collected by voluntary organisations.
- By the time a 14 year old is diagnosed with autism, their problems and needs have intensified in comparison to a younger child.
- There needs to be more details of what services are available or are being commissioned for those with autism who need a higher degree of support. This includes adults in day services and supporting living.
- There needs to be combined support from the Local Authority and Health.
- Existing services struggle to maintain a proactive level of support.
- The pathway for adults needs to be looked at to ensure that their needs are met. The number of people in the 40-50 age group being assessed as having autism is increasing.
- There needs to be a programme of improvement which includes building on existing services.
- Adults also need a Statement of Care. A lot of the framework disappears in terms of CAMHS and Education.

The next meeting of the Board will take place on Wednesday  
13 August 2014, 10am, Mezzanine 1, County Hall, Aylesbury.

Future meeting dates for 2014;

15 October

3 December

**Chairman**