



**Autism Partnership Board**

**Minutes**

**Wednesday 5 February 2014**

|                               |                                 |
|-------------------------------|---------------------------------|
| <b>Members in attendance:</b> |                                 |
| Zita Calkin                   | Joint Commissioning Manager     |
| Susan Code                    | Parent Carer                    |
| Kathy Erangey                 | Autism Oxford                   |
| Debi Game                     | Bucks SUCO                      |
| Robin Greenfield              | Parent                          |
| Olga Hamer                    | FACT Bucks                      |
| Richard Maguire               |                                 |
| Kathy Nawaz                   |                                 |
| Ena Smale                     | Parent Carer                    |
| Polly Wilkinson               | Connexions Bucks                |
| <b>Others in attendance:</b>  |                                 |
| Jacci Fowler                  | Back2Base                       |
| Sharon Griffin                | Democratic Services Officer     |
| Amy Moore                     | Joint Commissioner, Transitions |



| No | Item   |
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| 1  | <p data-bbox="288 611 847 651"><b>Welcome and Introductions</b></p> <p data-bbox="288 808 1369 947">Members were welcomed to the inaugural meeting of the Autism Partnership Board.</p> <p data-bbox="288 1104 1465 1144">Apologies were received from Paulette Hunn and Paul Isaacs.</p> <p data-bbox="288 1301 1445 1632">Zita Calkin, Joint Commissioning Manager explained that the purpose of the meeting today is to discuss what Members would like to achieve in the next 12 months and to plan the way forward.</p> |
| 2  | <p data-bbox="288 1816 804 1856"><b>Membership of the Board</b></p> <p data-bbox="288 2013 1422 2054">The proposed membership of the Autism Partnership Board</p>  |

was discussed.

Zita Calkin explained that the proposed membership is currently missing representation from Education/Children's Commissioning. A meeting is taking place to discuss a representative attending the next meeting of the Board to give an overview of the service area.

The Autism Project Board will run alongside the Autism Partnership Board. The Project Board has been running for one year and is the steering group for developing the Autism Strategy for Buckinghamshire. Membership includes Helen Backus, Operations Commissioner for 14-19 year olds and Paulette Hunn, Senior Adult Social Care Training Consultant.

There is currently no service user/carer representation on the Project Board. Expressions of interest in attending the Project Board are welcomed. Attendance could be on a rotational basis.

### **3 Induction / Role of Board Members**

Debi Game, Bucks Suco explained that there are eight Partnership Boards (Autism, Assistive Technology, Carers, Learning Disability, Mental Health, Prevention and Wellbeing, Older People's and Physical & Sensory Disability).

The Autism Partnership Board is unique in terms of the other Boards relate Adult Social Care services. The Partnership Boards feed into the Executive Partnership Board which in turn feeds into the Health and Wellbeing Board.

Service user and carer representatives are supported by Suco. If an individual is interested in becoming a member of a Partnership Board, they are asked to complete an interest form giving details of skills, experience and areas of special interest. Representatives are able to claim expenses such as mileage, parking and for the provision of a carer whilst they are attending a meeting.

- Historically the remit of Suco was to recruit 50% service

user and carer representation to each Partnership Board. The focus has now moved to quality engagement rather than quantity.

- Being a representative on a Partnership Board gives the opportunity to take place in discussions and represent the view of the Community, to try and shape and influence County Council strategies and the development of services relating to particular conditions as well as a greater knowledge and insight into County Council services.

#### **4 Election of the Chairman / Co Chair**

Debi Game explained that Zita Calkin, Joint Commissioning Manager, Adults & Family Wellbeing is the current chairman of the Autism Partnership Board.

The directive from the Executive Partnership Board is that each of the Partnership Boards should have two co-chairs.

The co-chairs can either be from a statutory organisation or

representing users and carers to give the Board balance and the opportunity for the service user/carer community to be part of the strategic overview of the Board.

There needs to be a minimum number of seven SUCO supported service users/carers on a Partnership Board before an election can proceed. The service user and carer reps would undertake an induction workshop to gain some knowledge and experience of being on the Board. Anybody who was considering being a member of the Board would be supported through the nomination process and in their role as co-chair by SUCO.

**5 Terms of Reference**

Members of the Board were referred to the Terms of Reference (TOR) of Buckinghamshire Partnership Boards which was circulated with the agenda.

The TOR set out the governance of the meeting in terms of its

purpose, key responsibilities, constitution and membership, chairman, co-chair, elections, conduct of business, Board Member responsibilities and conduct, frequency of meetings, expenses and Code of Conduct.

The Partnership Boards currently meet on a bi-monthly basis.

There may be the need to hold additional smaller group meetings to discuss the work plan.

Historically autism is within the remit of the Mental Health and the Learning Disability Partnership Boards. There will be synergies and crossover with the Autism Partnership Board.

The Autism Strategy will be shared with the Learning Disability Partnership Board when it has been finalised.

**6 Draft Work Programme**

Zita Calkin explained that a work programme needs to be formulated for the Autism Partnership Board.

The background information leading to the creation of the Autism Partnership Board is as follows;

- In 2009 the Autism Act received Royal Assent.
- In 2010 the Government published the National Strategy for Adults with Autism and the statutory guidance 'Implementing Fulfilling and Rewarding Lives' for Local Authorities and Health organisations.
- In April 2011 a self-assessment Framework was put in place against which Local Authorities could measure performance. In 2013 a review of the Adult Autism Strategy took place.

A copy of the National Autistic Society self-assessment is to be circulated to Board Members.

**Action: Zita Calkin/Sharon Griffin**

The National Autism Strategy says the strategy and the Government guidance for Local Authorities and Health Organisations is structured under four areas;

- Local planning and leadership in relation to the provision



of services for adults with autism

- Identification and diagnosis of autism in adults
- Planning in relation to the provision of services to people with autism
- Training of staff who provide service to adults with autism

The Autism Self-Assessment for Buckinghamshire was submitted on the 1 October 2013. The document will go to various Boards (Joint Executive Team and the Health and Wellbeing Board) for questions/approval. The results will be pooled and published online in February. The Government will then refresh the strategy.

At the moment specific data around autism is not collated.

GP's use read codes to record the everyday care of a patient but autism is not used as part of the read codes. Children's services also use different categories for autism. Work is taking place with Adult Social Care around a new system that could be used to collate the data.

The decision has been made to re-write the Strategy Action Plan for Adult Services as this document needs to link in with the National Strategy.

Discussions are taking place with a GP concerning engagement with the Autism Partnership Board.

The Project Board reports to the Programme Board on a monthly basis which is in turn, feeds into the Health and Wellbeing Board.

At the moment there is not a large amount of reference to children in the Autism strategy but this can be changed.

Next steps include;

- Planning and leadership
- Autism identification and diagnosis
- Planning the provision of Services and Support
- Autism training and awareness

Some issues are being picked up by the Lead Commissioner i.e. diagnosis and assessment. There needs to be an understanding of what the contract says and the inclusion of autism.

Next steps include;

- Engagement with GPs and Cheryl Gillan MP
- Producing an 'at a glance' guide about autism for the Criminal Justice system. This could include contact details for NHS England
- Including older people with autism in the work plan
- The provision of good, clear information and advice about autism

During discussions, the following comments were made.

- There is very little information around the social care side of child Autism.
- Data collection is improving; however one of the reasons for the difficulties with the collection of data is that parents do not like the 'label' given to their child for

behavioural and emotional difficulties.

- Only 50% of children are statemented.
- Adults do not want to be labelled. They choose to either go for a diagnosis or not. There are lots of hidden numbers of individuals with autism. The prevalence figures used in the Joint Strategic Needs Assessment (JSNA) were based on large pieces of research. The JSNA advises that an estimated 1% of the national population is on the autistic spectrum. The accuracy of this figure has been questioned.
- There is a role for parents and service users in terms of promoting the diagnosis of autism as a good idea and the reasons for this.
- There needs to be consideration of need rather than diagnosis. Services have resources in place for those with recognised need. Finance would dictate how large/small the services are.
- One challenge is the funding for the diagnosis and assessment of autism sits with certain teams and there are different pathways i.e. autism and mental health,

autism and learning difficulties. There is the issue of how to address and manage the individuals who do not fit into these teams. Part of the challenge is to ensure a clear process.

- If the outcome is being looked at from the service level, this is where the most benefit would be achieved.
- It is crucial that there is better training for teachers and services.
- One issue is that quite a lot of parents are on the spectrum too and their child is the same.
- If there is the knowledge that there are the services in place, the shock of the diagnosis could be minimised.
- Without a statement the ability to get support for a child becomes restricted.
- Without a protocol it is difficult to move through the education system with the tools to get the best for the individual. There needs to be medical evidence of the issue.
- Autism is not normally picked up unless there is an issue. A lot of older people do not want to accept that they have

Asperger's/autism.

- There is the fear of the perception of the diagnosis of certain conditions. The myths that surround them need to be dispelled.
- An example of good practice is the possibility of having a pre-discussion before a diagnosis is made that is provided by Autism Oxford.
- There is no support in place after a child receives a diagnosis of autism from the CAMHS service. This can be very overwhelming for the parents and siblings.
- The voluntary sector is currently taking some pressure off the statutory sector. There is no safety net.
- Autism Oxford does not form an opinion until all of the details are in place to give them an understanding. This can sometimes take years.
- It is about which team carries out the assessment.
- There needs to be an understanding of the right questions to ask. There are some generic Social Work assessments that are body dis-connective. Parents need to be prompted to answer the questions in the

assessment. The needs of an individual with autism are different to the needs of an individual who might require a manual aid such as a hoist.

- Health and Social Care undertake out joint Community Care Assessments but they are not being carried out in the way they should. There needs to be a more integrated overview to discuss barriers etc.
- A big cultural change is needed.
- A lot of professionals have more skills than they know they have but they are not aware of the links to autism.

**In some counties autism is managed differently i.e. a virtual team model for those in the 'middle'. How is this managed in Buckinghamshire?** Social Work has been appointed to look after the 'middle' group of people. Other teams are unable to manage this group as they do not have the expertise.

**There are links into the work being done on the Local Offer by Buckinghamshire Care. Is there funding**

**available to employ someone to identify services that exist and any gaps?** The work programme for the Autism Partnership Board could include making sure that there is a link with networking groups and being part of the Local Offer. The difficulty is that the Local Offer is hosted by the Family Information Service and it is down to the provider to update the details on the website.

The suggestion was made of contacting Daniela Raffio from the Commissioning Team to discuss the work she has done on integrating Health and Social Care and Children's Services.

**Action: Zita Calkin**

**Does Buckinghamshire County Council (BCC) have a policy for specialist skills training?** BCC has Service Level Agreements in place with care providers i.e. Buckinghamshire Care to ensure that training meets the needs of the clients that members of staff are working with. Training is also part of Delivering Successful Performance, the automated performance management framework for assessing



employees.

Training is also about personal development.

Buckinghamshire Care report which staff have certain levels of training on a monthly basis to BCC. The BCC training policy and programme for frontline staff is to be circulated to Board members.

**Action: Zita Calkin/Sharon Griffin**

**People receive information but very often it doesn't help.**

**They need to have the information shown to them and for someone to talk it through with them.** The Carers training, E-Learning modules etc are supported by crib sheets and at a glance information.

An event on Autism is planned for September to include talks from organisations such as the National Autistic Society and Carers Bucks. Cheryl Gillan MP and John Bercow MP have offered to give their support at events and conferences if needed.

Kathy Erangey advised that Autism Oxford would be happy to help with the organisation of the conference.

Amy Moore advised that there is a Transitions Fair at Green Park, Aston Clinton on the 29 March 2014. A section on Autism on 14-25 year olds could be added.

It was suggested that the Autism Partnership Board should look at the following key issues as part of their work programme/priorities;

- Planning for the provision of service (adults and children)
- Training of staff to a required level and the monitoring of this (adults and children)
- Joint working with Social Care and Health, particularly assessment
- Identification and diagnosis
- Transition
- Identifying existing services

- Good access to timely information, with emphasis on the importance of accurate signposting.
- Support post 18, particularly for those moving into university education. The key here is that help and support is needed not just to meet educational needs, but wider social needs. The young adult will be moving away from home, living alone for the first time, having to be responsible for money and budgets and needing to take responsibility for all aspects of their educational and personal organisation. This is tricky for most 18 year olds, for those on the Autistic spectrum the transition will be both traumatic and overwhelming.

**7 Autism Partnership Board - Oxford**

Kathy Erangey, Autism Oxford was welcomed to the meeting.

Kathy began by explaining that there are separate

Commissioners for Mental Health and Learning Disability in

Oxford but they work with a pooled budget. The lead for

Autism is the Mental Health Commissioner, Juliet Long.

A Steering Group to develop services for adults with autism and no learning disability (i.e. average of above IQ) was formed because there were no services for this group.

Following the publication of the Autism Act and the publication of the National Strategy, the Steering Group morphed into the Partnership Board which covered all ages and all of the Autism spectrum.

The first meeting of the Partnership Board took place in September 2011. The Board has two co-chairs; the Head of Adult Services and an individual on the Autism spectrum. The Board has a very large membership which includes representation from Early Years, Adult Social Care, Service Providers, parent carers and Commissioners. There are Working Parties to look at the different parts of the Autism strategy which include;

- Diagnosis and signposting
- Supporting children and families
- Filling and rewarding lives
- Training and awareness
- Sustainable approach

Some initial pilots took place before the formation of the Partnership Board which focused on groups of adults (14+) on the Autism spectrum and carers and the training of Social Workers and Mental Health Workers around early intervention. Training has also taken place with the Social Care and Health staff, GPs and Clinicians at the seven early intervention hubs to embed knowledge and awareness of autism. Partnership working has taken place with the National Autistic Society and local autism organisations.

The Partnership Board received a small amount of money from the PCT which funded a Supported Employment project for those at the upper end of the spectrum and Asperger's. This project is being run by the Oxfordshire Employment

Service.

Autism Oxford is the provider of Oxfordshire's first Autism Alert Card Scheme. The credit card sized alert card is free to anyone on the Autism Spectrum in Oxfordshire. It gives details of the cardholders name, simple, practical advice and the names and telephone numbers for 2 emergency contacts (these may be family members, carers or friends of the cardholder, who have agreed to be a contact on the card). The card will help an individual if they find themselves in a situation where they need help or need to give an explanation. It will also assist Thames Valley Police and other emergency services to identify that they are dealing with someone on the autism spectrum. A crucial part of the scheme is the training (by our Autistic Trainers) of Police and Probation officers, court staff and organisations supporting people who enter the Criminal Justice System. Autism Oxford sits on a number of Police and CJS Groups to ensure the needs of people with autism and Asperger's are taken into account when plans are made.

Further details about the card can be found via the following link; <http://www.autismoxford.org.uk/index.php/alert-card>

During the update, the following questions were asked and points made;

**Is there a range of trainers?** Yes all of the trainers from the Autism Oxford are on the autism spectrum and able to verbalise. They are able to provide facts and technical information and show a vast variation in profile. Working as a team, they demonstrate effectively how to different people can be affected by autism. 'Autism is another way of seeing the world'.

**Are the non-verbal individuals getting a voice and being represented as they have an opinion?** The team members have different profiles. Yes, for example, one of the team is classically autistic but eventually learnt to speak. He is able to tell us what non-verbal people may be trying to say with their

behaviour. Many individuals with autism speak eloquently, but this can mask the difficulties they are living with, giving a false impression of the challenges they face daily. Our classically autistic speaker is a great example of this; people always assume he is far more able than he is – because he is such a talented speaker.

Work is taking place in Buckinghamshire on a similar Supported Employment project for 18-25 year olds, including individuals with Asperger's. This also includes the Assistive Technology Transitions project to determine if a cognitive support technology intervention could lead to increased independent living skills and to reduce the likelihood of requiring future services. The next stage is engagement with an interested employer such as Barclays Foundation London, The Bank of America, Balfour Beatty etc.

**Does there have to be a diagnosis for an individual to have an Autism Alert Card?** The Scheme is for those who have received a diagnosis and those who are seeking a



diagnosis. At the time the scheme was set up there was nowhere for Oxfordshire adults to go to for a diagnostic assessment. The name of individual and the details of two emergency contacts are on the back of the card. The purpose of the card is primarily to alert that the individual carrying the card may need particular care or attention. A crucial part of the scheme has been the training of 800 plus police and probation officers and those involved in the criminal justice system. One or two Police Officers were concerned at first during the training about people 'getting away' with criminal acts. They were reassured that it is not a 'get out of jail free' card and the team won them over to support the scheme.

The National Autistic Society has a variation on this card. The card they supply comprises of a wallet which contains a leaflet of key facts about autism, and a credit-card style insert where people can write emergency contact details. If a child is displaying socially unacceptable behaviour, the parent can hand over the card and walk away.

One issue is the huge discrepancy and the same 'labelling' used to describe the same set of difficulties in children and the lack of consistency.

**Is there ongoing funding to run the services?** At the moment the funding is ongoing from Oxfordshire CCG. There is not a cost to the individual person. Individuals are able to self refer. GP's are also able to refer but many are not aware of this. For adults speaking a diagnostic assessment, an hour long, pre-diagnosis discussion can be arranged with Autism Oxford. If the person wants to proceed, Autism Oxford refers them to one of three 'Any Qualified Provider' Autism Specialist Clinics for a diagnostic assessment.

**How many people come to Autism Oxford?** We receive about three enquiries a week. When the service first started there were 40/50 people on the waiting list, most of whom who had been diagnosed with mental conditions, but no autism spectrum conditions. When a diagnosis is made, Oxfordshire's AS Specialist Social Worker ensures that either

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|          | <p>the County Council Adult Social Care team of the Adult Mental Health team takes up their case. Each individual is offered a FAC assessment of their needs and Carers are offered a Carers' Assessment.</p> <p>Kathy was thanked for her very informative update.</p>  |
| <b>8</b> | <p><b>Date of the Next Meeting</b></p> <p>The next meeting of the Board will take place on Wednesday 30 April 2014, 10am, Council Chamber, Aylesbury Town Council, 5 Church Street Aylesbury, HP20 2QP. There will be a pre meeting for members of the Board at 9.30am</p> <p>Future meeting dates for 2014;</p> <p>11 June</p> <p>13 August</p> <p>15 October</p> <p>3 December</p> |

**Chairman**