



Autism Partnership Board

Minutes

Wednesday 30 April 2014

Members in attendance:	
Melissa Bloomfield	Oxford Health
Lisa Burridge	Parent Carer
Zita Calkin	Joint Commissioning Manager
Susan Code	Parent Carer
Debi Game	Bucks Service User and Carer Organisation (SUCO)
Sam Girling	Connexions Bucks
Olga Hamer	FACT Bucks
Paul Isaacs	
Ian King	The National Autism Society (Aylesbury Vale)
Richard Maguire	
Kathy Nawaz	Carer
Clare Samways	Greater Resources for Aspergers

	Supporting Parent & Siblings (GRASP)
Ena Smale	FACT / parent
Others in attendance:	
Catherine Black	Autism Oxford
Emma Corless	Autism Oxford
Kathy Erangey	Autism Oxford
Jacci Fowler	Back2Base
Sharon Griffin	
Paulette Hunn	Bucks County Council
Amy Moore	Joint Commissioner - Transitions
Sally Slade	Buckinghamshire Care



No	Item
1	Apologies for Absence / Changes in Membership Apologies for absence were received from Robin Greenwood.
2	Minutes and Matters Arising The minutes of the meeting held on the 5 February 2014 were agreed as a correct record.

3 Update from SUCO

Debi Game, SUCO reported that there has been a lot of interest from service users and carers in becoming involved in the Autism Partnership Board.

Thanks were given to Richard Maguire for his help in identifying potential Board members.

The membership of the Board now includes 10 service user/carer representatives (the requirement is 8). Music Therapy has also expressed interest about joining the Board.

An induction session took place for service users/carers at the end of March. A further training session will be held later this year.

Elections for a Chair and Co-chair will be held once the service users and carers have had the opportunity to see how the Board functions.

4 Joint Autism Strategy for Buckinghamshire - final version

Members advised that they would like the Autism Partnership Board to achieve the following;

- Increased awareness of autism
- Service users and carers having real input and drive of the direction of the Board
- A smooth process for referrals
- Reinforcing the way work is being done
- Bucks to be a place where autistic people can be happy
- A seamless provision from autism which transcends change
- Increased availability of bespoke services for those with autism who move from the homes of their parents into the community
- More services for adults in High Wycombe i.e. social groups for those with Asperger's and Learning Difficulties
- Increased understanding and awareness of information from the Health Service (there is a lot of crossover of services)
- Better services for young children and families in particular, those who have no difficulties but are at the high end of the spectrum
- Better support in schools

- Better representation for the needs of girls and young women
- Happiness, understanding and awareness building
- Support for adults and young women
- Raising professional understanding when carrying out assessment of needs
- Making the process of getting a diagnosis easier for children who want to have a diagnosis as well as clarity of the criteria and signposting of services
- Parents, carers and young people feeling equipped in making sure that the Local Authority is doing what it should be doing (responding to changes to Acts etc)

The Bucks version of the Joint Autism Strategy will be circulated when the document has been signed off by the Cabinet Member. The document sets out the National Strategy, the situation in Buckinghamshire, the main aims (these reflect the National Strategy) and the action strategy.

During discussion, the following questions were asked;

The figures that are shown for women are more likely to be a 50/50 split. The figures used are prevalent as there are no existing ones. The aim would be to update the strategy on a yearly basis.

The National Autism Strategy is for adults. The Bucks Autism Strategy covers all ages. It was pointed out at the last meeting that the membership of the Autism Board does include representation from children's services. The post of children's commissioner should be appointed to later this year which will enable the strategy to be made more robust and to provide an overview. There is not a joint post for Health and Children's Services. The most appropriate representation on the Board for Education also needs decided.

5 National Autism Strategy update - 2nd April

Zita Calkin explained that there are a number of different documents with similar names.

The National Strategy is entitled 'Think Autism - Fulfilling and Rewarding Lives' which was published in 2010 after the

Autism Act. The strategy lists the 15 priorities (see below) and on how the strategy should be applied locally.

Priorities

An equal part of my local community

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance to autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local, autism peer groups, family groups and low level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want staff who work with them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of

discrimination, hate, crime and abuse.

6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

The right support at the right time during my lifetime

7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.

8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.

9. I want staff in health and social care services to understand that I have autism and how this affects me.

10. I want to know that my family can get help and support when they need it.

11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.

12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.

13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

Developing my skills and independence and working to the best of my ability

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.

15. I want support to get a job and support from my employer to help me keep it.

Page 9 – point 3.5 of the strategy advises that in 2014/15, £4.5m of revenue and capital funding is available to support the delivery of some of the key themes set out in the update, including local innovation and awareness. There is the

opportunity to apply for some of this funding. Members of the Board were asked to forward suggestions for areas of funding to Zita Calkin.

Action: All

Summary notes of the strategy are to be circulated to Board Members.

Action: Zita Calkin

The Autism self- assessment is completed on a yearly basis and gives an indication of where each Local Authority is in relation to the National Strategy. The self- assessment is used to update the National Strategy. A further self- assessment is being carried out later in 2014.

6 Work Programme

A copy of the Buckinghamshire Joint Autism Strategy 2014-16 – Partnership Board work plan was circulated for discussion.

Zita Calkin explained that each of the Partnership Boards has a work plan which gives details of what they would like to achieve. Some of the actions sit with the Project Board i.e.

diagnostic assessment. The name of the person responsible for the action and dates need to be included in the work plan.

There are four general aims in the action plan;

- Increasing awareness and understanding of autism
- Access to diagnosis and assessment
- Access to services and support
- Improve planning so we can develop the services people with autism need

There are currently two pathways for accessing diagnosis and assessment; an adult with a learning difficulty is referred to the learning difficulties team for diagnosis; an adult with a mental health issue would go via the mental health team in Oxford.

There is a huge group of people who 'sit' in the middle.

Discussions are taking place with Oxford Health about the provision of services for those in the 'middle' of the process and to design tool to help GP's with the diagnosis of autism.

The process is to be finalised but would include the impact on

the individual's life, what the diagnosis means to them and why do they want the diagnosis. This service needs to be carefully promoted as there is limited funding available.

During discussion, the following comments were made;

- The mental health team in Oxford is not commissioned to provide assessments for autism.
- Advice given is that referrals can be made out of county if the individual would like them to be
- A lot of adults self identify as a result of a family member being diagnosed with autism
- It is about looking at why the individual wants the diagnosis
- There is the need to define the threshold. An individual appears to be coping but at what point does anxiety have an impact?
- There is the issue of support after diagnosis to be taken into account
- There is the genetic connection of having autism and an

individual finding out they have autism as a result of their child/children being diagnosed – this is a double issue which has a big impact on the family.

- Part of the criteria should be the inclusion of helping adults who want a diagnosis
- Diagnosis of autism is life changing. When a diagnosis is received is like putting on the right glasses.
- The impact of not having support is vast as well as knowing what is going on. Once the individual knows about the diagnosis, it is vital to have strategies in place.
- What is the role of the Autism Partnership Board in terms of support?
- People go back to their GP continually. As the picture becomes clear, a lot of what can be done is remarkably simple.
- Some cases of diagnosis of autism in 11-16 year olds show that the category of diagnosis is incorrect. There is also the battle of removing inappropriate labels.
- One frequent question is raised by Autism trainers is whether there something more complex that

professionals should be telling people about autism? The answer to this is no – it is simple once the diagnosis is understood and the right resources are in place.

- It shouldn't be difficult to get a diagnosis for autism - the opportunity should be available.
- If an autism strategy is implemented such as lights or a calming environment, it benefits all.
- The local branch of the National Autism Society receives lots of requests for about the availability and provision of services. Enquiries are increasingly about the provision of adult services i.e. the assessment of Aspergers.
- There needs to be post diagnosis support in place. Better training in counselling to support families, couples etc is vital.
- A number of parents with a child diagnosed with autism have had a bad sensory experience. There is no lead of information in the pre-consultation about what to expect.
- Autism Oxford provides pre-diagnostic counselling sessions. Could this model be replicated in Buckinghamshire?

- The Autism Partnership Board has a role in making sure information is fed down.
- The Care Bill is about the prevention of people coming into services. This would be a good argument for reducing costs etc.

If an individual is diagnosed with a mental health issue, there is a clear referral route. If an individual is struggling and does not understand the impact of the diagnosis, another referral route would be given.

Contracts with Oxford and Southern Health state that the services provided should include looking at autism. Oxford Health and Southern Health are to be contacted to discuss.

Action: Zita Calkin

The figures and population information are an example of the extent of the issue not being known until it is looked into in more detail. A meeting has taken place with Education and Children's services to discuss the figures i.e. 100 children were identified as having particular needs and have been

categorised as such. The figures several years ago showed 5 of the children had autism; the figure for this year is 95. The increase is due to the information being looked into in greater detail.

There is a disconnect around what is being commissioned to those presenting and what is happening in Oxford Health. Is it part of the role of the Autism Partnership Board to look at this? The contracts have been revised. A letter is to be sent to Kurt Moxley, Oxford Health to advise issues raised.

Action: Zita Calkin

The following suggestions were made for inclusion in the Action Plan;

Increasing awareness and understanding of Autism

- A Dutch study has shown that 1:3 people receiving treatment for drugs and alcohol addiction are also autistic.

This needs to be taken into account in the action plan.

Access to Diagnosis

- Families can be overwhelmed. Some want a diagnosis and support; some do not want a diagnosis.

- The NAS provide an early bird healthy minds support programme for parents

<http://www.autism.org.uk/our-services/residential-community-and-social-support/parent-and-family-training-and-support/early-intervention-training/healthy-minds.aspx>

- CAMHS run two after diagnosis workshops which address general Autism Spectrum Disorder issues such as anxiety and anger management.
- There needs to be better training around post diagnosis support. When a child receives a diagnosis, the family are very often abandoned. The impact of the diagnosis on the family, siblings and the way forward needs to be taken into account.
- A lot of families have tried desperately to get help but have been unable to find a counsellor who understands their needs.
- It would almost be useful to have relationship counselling at the point of diagnosis i.e. 1 week of sessions with Relate. Relate counsellors have recently had autism training.
- Diagnostic pathway for children – there is a complete lack of

consistency in how children are diagnosed. Under 11's are seen by a Paediatrician and the 3Di assessment is used. This is a standard diagnostic interview where a lot of questions are asked about what the child does/does not do. The results of the assessment are fed into a computer to compile objectives for parents and for a school score. A diagnosis is made from the results. Most children go via a Paediatrician to get a 3Di. Children over the age of 11 go via Tier 3 services. They see a psychiatrist and complete a Conners questionnaire.

- There are lots of different routes of diagnosis which is very frustrating for parents.
- Autism in girls usually has a more subtle presentation. Diagnosis for girls on the spectrum needs to be looked into as the current diagnostic procedures don't pick up autism.
- Those on the spectrum present differently. Atypical presentation is more common than people realise. There needs to be correlation in the training of professionals.
- Schools, education, teachers, SENCO, nursery teachers, reception staff at schools etc need to be added to this

aim/objective as there is the worry about staff being able to support children with complex autistic needs without the appropriate knowledge.

- Gateway, Oxford has a trained counsellor for autism which makes life simpler for professionals and GPs.
- Talks have taken place with Autism Oxford about the provision of a similar model in Buckinghamshire. The recruitment process for the post has just started.

Autism alert card

- Is it possible to use the alert card produced by the NAS?
- Oxford and the NAS have their own scheme. If the purpose of the card is just to present information to professionals, why are Buckinghamshire looking to providing their own scheme if there is a card already in existence?
- There is also the Safe Place Scheme. A sticker in the window of a business identifies the premises as a safe place for vulnerable people in the community.
- If Bucks use the NAS card, would it be possible to include the NAS logo?

- There are 3 different ways of alerting members of the public that an individual is autistic; At a Glance cards for frontline staff, Autism alert cards and Health Passports. The Board need to discuss the best way to take this action forward in terms of streamlining the process and ensuring safer communities and standards. It is about a caring society who accepts people.

Autism Event – September/October 2014

- The event is aimed at parents and carers with some elements of signposting.
- Can the event be publicised in terms of articles in the local press to celebrate autism which would help to remove the barriers and concerns which are often associated. The publicity should include that autism can bring a huge diversity and different skills. There needs to be a cultural shift of the perception of autism.
- Members of the Autism Partnership Board could be instrumental in the shaping and publicising the event in terms of promotion of attendance from their own

organisations/groups.

- The event would be a good opportunity to prove that there is work being done to promote the awareness of autism – not just an empty promise.

Developing a training programme

- Oxford Health has just gone through a re-modelling process of the services it provides. There are now 2 adult mental health teams covering Chiltern, Wycombe and South Bucks (there were previously 6). The team carry out assessments of new patients as well as the treatment function i.e. caseloads and long term management. There is a team of 10 to carry out the assessments.
- Kurt Moxley is to be contacted to discuss the possibility of a training session about Autism for Oxford Health.

Action: Zita Calkin

- Oxford Health is keen to involve service users/carers in the shaping and development of the delivery of training. The possibility of including autism can be discussed with Rachel Cryer.

Action: Zita Calkin

- NAS Milton Keynes has a group of service users who are trained as trainers and are autism experts.
- There is a lot of good practice about autism within pockets i.e. People's Voices and Bucks New University. There needs to be identification of where good practice exists and for information to be shared widely.
- An online information and advice portal could be developed which would show that the Board is delivering on the requirements set out in the Care Bill.

- *Access to service and support*
- There needs to be support for families and children. What services have been commissioned to support families at the fringe of services i.e. family resilience is unable to accept any new referrals. The demand for the service was underestimated when it was commissioned. This has resulted in the voluntary sector taking on referrals/cases.
- The Care Bill is asking for the County Council to do more and more in terms of the provision of services for carers and service users.

7 Any Other Business

Autism Project Board

Members are welcome to attend meetings of the Autism Project Board.

Autism event in October

Carers Bucks are facilitating an event for Autism in October. Funding has been secured for the event. An initial meeting has taken place to discuss the date, venue, speakers etc.

Carers Bucks

Carers Bucks work with young carers. They also produce online guidance for young carers;

<http://www.youngcarersbucks.org/youngcarershome.html>

Sally Mansi, Young Carers Service Manager is to be invited to a future meeting of the Board.

Action: Zita Calkin/Sharon Griffin

Since April 2014 Carers Bucks have been delivering a new carers' support service as a Business Partner of Buckinghamshire County Council. This is part of a response to

the extension of carers' rights in the new Care Bill and the Children and Families Act. Stephen Archibald is to be invited to a future meeting of the Board to give an update.

Action: Zita Calkin/Sharon Griffin

Future Meetings of the Board

Suggestions for agenda items and contributors to attend future meetings of the Board are welcomed.

Action: All

Membership of the Board

During discussion of the membership of the Board, the inclusion of the representation from the following was suggested.

- an OT commissioner
- educational psychology
- Buckinghamshire Community Child Minding Network

8 Date of the Next Meeting

The next meeting of the Board will take place on Wednesday 11 June 2014, Mezzanine 1, County Hall, Aylesbury.

	Future meeting dates for 2014;
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13 August

15 October

3 December

Chairman