

## Feedback – event for people with autism

13<sup>th</sup> August 2015, Somerdale Pavilion (new Fry's Centre)

20 people attended the session to discuss the experiences and needs of adults with autism in B&NES. These included 11 carers of adults with autism, 8 'professionals' and one adult with autism.

Participants listened to presentations on the national and local autism strategies and the 'Your Care Your Way' review of community health and social care services.

There was an opportunity for questions and discussion following the presentations, which resulted in some queries including:

- The process around transition – there was a discussion around Education, Health and Care Plans (EHCPs) and that children and young people with high functioning autism / Asperger's syndrome can fall between the gaps and not receive an EHCP
- The Autism Partnership Board – concern that not enough was known about the work of the APB, when it meets, what it discusses and a wish to have involvement of parents and carers. Reassurance was given that there are plans to have meetings for autistic adults and for parents/carers to meet between each Board meeting and for one or two representatives from these groups to attend the Board meetings.
- The Council Website – some links don't work. (eg. Care and Support) Seemingly no information on what training opportunities are available (BASS). Acknowledged that work needs to be done on this.
- Waiting time for referral to diagnosis – aim is for none

Following a break, participants had the opportunity to review the feedback that had been received from the previous session on the 11<sup>th</sup> with adults with autism.

Participants were then divided into four tables and asked to consider three questions related to their experiences and the experiences of the adults with autism they support:

1. What works well at the moment?
2. What should we be focussing on?
3. What could be improved?

The following notes are a combination of what was written on the flip charts and the verbal feedback from participants given at the end of the session.

### Table 1

#### What is working well?

- Individual professionals
- Carers centre support

#### What should we be focussing on?

- Joined up thinking
- Diagnosis much quicker
- Hotline for support
- Does system work well enough e.g. is it too lengthy
- Easier access to employment support for both employer and employee
- Managing not fixing
- Social opportunities and supporting in communities
- Magic wand
  - Focus on what can do

- How do you make it possible and remove system / policy blocks
- Community based solutions

### **What could be improved?**

- Less talk more action
- Advocacy
- Advice, guidance and follow up, accountability
- General awareness raising:
  - Communication
  - Interaction
  - Social barriers
- Housing access and thinking around categories / needs
- Don't miss support opportunities – increased prevention
- Employment support for both and during employment
- Early life skills:
  - What happens in schools
  - ? number of people going through mainstream schools
  - Sign language and other total communication skills
- Improved advice and information

### **Table 2**

#### **What is working well?**

- Carers centre – helpful and available, breaks were good
- Avon Branch/Diana Elliott
- So much better than 3 – 4 years ago
- Autism referral team
- BASS
- Employment Inclusion Team/Avril Mendel
- General awareness (through TV etc. – people are just more aware)

#### **What should we be focussing on?**

- Housing:
  - Application forms still confusing / difficult
  - Physical difficulties are accounted for
  - Sensory needs not so much
  - 'problems with drugs and alcohol' taken literally – i.e. the person has a problem with other peoples use of drugs and alcohol
- Lack of suitable housing
  - Noise, lighting etc.
  - Can't access sheltered housing – not for younger people
- Social workers
  - Doing social work and not just form filling, processing and signposting
  - To develop better relationships as often autistic individuals not good at asking for help
- Joining up of mental health and autism teams and hospital services
  - Preventative awareness vs confidentiality
  - Generalised vs specialist services

### **What could be improved?**

- Housing consideration to 'communal' issues (positives and negatives)
- University support
  - Educational support
  - Social / wellbeing needs

- 'Ordinary residence' query for University students – are they ordinarily resident in B&NES if they are registered with a B&NES GP?
- Including probation service
- Experience with police service
  - Appropriate adult
  - Considerations to mental health
  - Training for police needed
- Apprenticeships
- One stop shop
  - No disabled parking
  - Too noisy – can't hear and can overhear other people's issues
  - Crowded
  - Machines issuing change v noisy
  - Inconsistent information
- Join the dots
- Have a flag on the health / social care system to say person has autism / Asperger's to alert staff. Currently need to get the individual's permission to do this?

### **Table 3**

#### **What is working well?**

- Having 'named' staff at
  - Job centre
  - Housing
  - Can the parent / carer ask to speak to the named person too? This would help
- Employment inclusion team
- Consistency of autism leads and their effectiveness and commitment
  - This consistency is important in other areas (e.g. social worker) so good that B&NES is leading by example
- Changes to APG are welcome and should help ensure feedback is as broad as possible

#### **What should we be focussing on?**

- Information sharing
  - What services exist
  - How do we find out about them
    - Website (Council)
    - GP surgeries
    - Social worker signposting
    - BASS
- Housing and independent living
  - Housing liaison officer a welcome start
- Community / mass transit access
  - Would lead to more community awareness
  - Acts as a preventative service
- Awareness raising and stigma busting
- Social opportunities without labels!
  - Different strokes – some people with autism don't want to go to 'disability' social groups
  - Broader community access
- Some social opportunities need 'labels' to be accessed (how else would we hear about them)

#### **What could be improved?**

- More social opportunities like BASS Create Centre

- Information retention – why do I need to endlessly repeat my story?!
- Social workers could signpost more effectively
- Listening to individual / person centred
  - Parent / carer involvement if desired by the individual
  - I am the person that best knows my needs
  - Professionals shouldn't use medical jargon
- Are social services overburdened?
- More female groups to go along with higher female diagnosis rates
- Proper notice of change (if an appointment changes, people with autism need to know)
- Training is one thing, knowledge is another
  - Assessors must have decent working knowledge
- Bus passes – autism / Asperger's should qualify you for a pass but doesn't

#### **Table 4**

##### **What is working well?**

- Some daily activity services – rake up and grow – need more similar to this
- Concept of supported living – work in progress!
- Sirona / B&NES workshops for families

##### **What should we be focussing on?**

- Communication
- Consistency of information
- Parental inclusion – have their views and experiences respected and included, including by BASS
- Holistic approach
- Technology:
  - Case notes on laptops for social workers
- Focus on what the person can do, not what they can't do

##### **What could be improved?**

- Consistency of support workers and social workers
- Communication regarding daily services
- Reward for voluntary working – timebank / vouchers?
- Young person paying for working e.g. swallow café (this was part of a larger discussion in relation to young people paying using their DP to be part of a working environment and not being paid for their work)
- Training of potential employers
- Incentive for potential employers
- Passport of care needs for disabled person to pass to work managers
- Health issues – passport of care – awareness within services
- Finances!
- Support of choices, especially healthy eating (this came from a discussion of supported living whereby young people with autism went shopping with different support workers, bought 4 x mars bars with both support workers and ate them all. The support workers didn't know about the other shopping and it wasn't monitored. The parents picked up that all 8 had been eaten in the space of a couple of days).