

Portsmouth Autism Community Forum

Notes from the Forum meeting on Thursday 28 February 2019 at Buckland Community Centre, Portsmouth

1 The meeting was attended by 18 people - a mixture of autistic people, carers, parents and professionals.

2. Stuart McDowell welcomed everyone to the meeting.

3. Employment

Beatriz Lopez from the University of Portsmouth Autism Centre for Research on Employment (portsmouth.ac.uk/acre) gave a presentation on the work of the centre and her research into employment and autism.

Beatriz highlighted the new profile assessment tool being developed by the Centre. This will allow autistic people to create employment profiles outlining the strengths as well as detailing support or other needs so that an employer can make reasonable adjustments to enable them to be successful in their job. The profile application will be available online when it is launched in April.

See Beatriz's presentation: <http://healthwatchportsmouth.co.uk/wp-content/uploads/2019/03/PACF-meeting28Feb2019-BeatrizLopez-presentation.pdf>

4. Liz McDonald and Jenni Wessels from Portsmouth City Council gave an update on their progress in developing the 0-25 training and awareness pathway which was previewed at a previous forum meeting.

Following feedback from forum members and the steering group changes have been made so that it is ready for launch in national autism week in April. The aim is to offer the bite sized training to build understanding of autism among council employees.

The training's main message is that all autistic people are different but it attempts to highlight some of the factors that need to be considered in ensuring that departments meet the needs of autistic employees and service users.

It is hoped that the training programme will have a low-key launch in the council during April. It is hoped that the bite sized training will form part of a programme of training on offer by the council using autistic people. There is currently no budget to deliver this training. Forum members expressed their wish that the training be autistic-led

5. Stuart McDowell then led a discussion on the future of the forum after April 2019 when coordination of the forum will be transferred from Healthwatch Portsmouth to Portsmouth City Council.

Points raised in the discussion

Future topics for forum

- support needs of adults with autism.
- autistic people with mental health problems.

The discussion then turned into a wider discussion about autism in Portsmouth

- How do we involve more autistic people in forum?
- Need to consult with more autistic people.
- Problems with challenging NHS.
- Lack of adult advocacy service means its hard to raise concerns and complaints to NHS.
- All too often autism put in the same category as learning disability - autism is not a learning disability.
- Problem is autistic people not being in charge of autism strategy - no consultation with autistic people. Council needs to engage with autistic people.
- Need to be clear about what to change and link with the autism strategy.
- There needs to be drop-in crisis centre.

6. Jonathon Prosser of Solent NHS Trust then introduced his work on the neurodiversity pilot.

- Over recent years neurodiversity has risen up the agenda.
- Neurodiversity = people who are born with different brains.
- The medical model was adopted - neurodiverse people were labelled as having a condition.
- As there is no 'treatment' for autism, it was hard to get help from medical practitioners.
- Parents are frustrated at the need for a diagnosis of autism to force schools to change policies and introduce reasonable adjustments.
- For adults there seems to be no deep-rooted understanding of neurodiversity.
- Health services need to move away from emphasis on diagnosis towards support.
- GPs are still central to diagnosis and assessment but families need to be more involved in the process.

7. Any other business

There was no other business.

8. Next meeting

Details of the next meeting will be distributed by Stuart