

Our Voice Counts

North Somerset Parent Participation Forum

Health Workshop Notes from the Open Meeting held on 10th March 2011

1. First of all the group members introduced themselves to each other. Many people in the group identified their specific interest in the agenda item relating to the support needs of children with Autistic Spectrum conditions/Aspergers.

2. The notes from the previous Open Meeting health workshop were read through and updates on the work achieved discussed. There is a current consultation being undertaken by the UH Bristol. The Disabled Children's Working group at the Bristol Children's Hospital had been trying for some time to effectively engage parents to review their service delivery and look at what changes can be made to improve the hospital experience for children and their families. Annabel T explained that she had heard about it from a friend and subsequently had been contacted by Lisa Mason from LIAISE - Listening, Information, Advice, Involving, Support, Experiences (UH Bristol NHS Foundation Trust). The consultation will be focussing on pre-admission, the hospital experience and discharge/post hospital.

Jenny M spoke of previous work within North Somerset that had looked closely at the impact of hospital stays on life for the child and family afterwards. Jenny will share the findings of this work with the group and will also look at how the findings might usefully inform the UH Bristol consultation.

Parent in the group (and any others reading these notes) who can make a contribution to the consultation can contact Paula on paulaedmondson@vodafoneemail.co.uk or on 07717706340 and she will liaise with Lisa Mason to make it happen. Annabel T and Kaddy T are already signed up to take part.

3. The group then entered into the main discussion topic of the workshop – the issue of children who have an Autistic Spectrum condition or Asperger's Syndrome who seem to 'slip through the net' of services leaving both them and their families in isolated circumstances.

Many people within the group had personal stories/accounts. A familiar theme throughout the stories seemed to be that where the young person didn't fall into the criteria for support from the potential agencies that could be helpful, the struggles and difficulties experienced had to escalate to crisis point – before something would then be made available.

Some of the comments included:

- Really not feeling listened to – and not being taken seriously about how very serious circumstances were becoming
- Having to ‘fight’ all the time – to get the ‘real needs’ met (which are not necessarily the ones perceived by professionals as the needs to be dealt with)
- Feeling totally exhausted and no-one to turn to
- Seeing the support that is available being channelled into the school but there being little or no support for the home situation
- Sporadic, short term CAMHS support when/if a referral is made
- Long waits and lost referrals
- Discharge too early
- Only short periods of support

The group looked at what would be helpful to these particular circumstances. Feedback included:

- A clear point of contact – that takes the situation seriously and responds in a positive manner
- Individual/tailored responses from people that have a clear grasp/understanding of the impact of autism on both the child and the family as a whole
- Immediate responses
- A response that says ‘We can see you are struggling – how can we help?’. Not one that says ‘ah sorry – you don’t fit our criteria’!

The following were raised in relation to this discussion:

- The stories shared by the group contain elements of serious concern which ought to be of enough concern to alarm services and inform them that their support is clearly required. However, this does not seem to be the case and people are being left to struggle on alone (many in very isolated/single parent situations). It should be of enough concern for this point to be raised with the council/PCT– the working group will make this the focus of it’s’ work.
- The council must consider the severity of people’s circumstances – especially in relation to it’s’ responsibility to safeguard and protect (and look after children).
- The health of the children concerned is severely compromised and can lead to serious mental health issues in later life (having lived through distressing times in childhood).
- The waiting list for Occupational Therapy sensory assessments is long (if lucky enough to be on the list)
- There is a serious shortage of people working across health and social care who have an up to date knowledge and skills set in relation to people with ASD/Asperger’s syndrome (who do not have a perceived learning disability).
- Support through transition? What are the options?

4. There is clearly much passion regarding this issue. A good number of people present at the workshop signed up to become members of the working group. There is an open invitation out to any others with an interest to join us....by contacting:

paulaedmondson@vodafoneemail.co.uk

The group is going to approach key health services (and social care services where applicable) to raise the groups concerns and lobby for services to respond with strategies that make sense and work positively in each individual circumstance.