



Exeter Parent Carers' Voice
Notes from the meeting held on Tuesday 17th March 2009 – Cowick Barton, Exeter

Present:

5 parents

Nicky Ruane Development Worker

Debbie Wheeler Parent Partnership

Hil Rundle Complex Cases Manager, Exeter JAS

Chris West OT Lead, Eastern JAS

Apologies:

3 parents

1. Welcome, introductions and apologies for absence

Margaret welcomed everyone to the meeting and those present introduced themselves. Apologies were given from those received

2. Minutes from previous meeting

Exeter RD&E

The issue of parents being expected to stay with their children on Bramble Ward was discussed at the County Forum. The issue is wider than being that relating to children with communication problems as even parents of children with no additional needs felt compelled to stay with their children.

CAMHS Unwrapped

The recent event in Tiverton was very successful. It had been well attended by a range of professionals and parents from across the county.

3. Chris West

Chris West spoke about the Occupational Therapy (OT) service and then answered questions from parents.

Chris began by explaining that she is both a manager and a clinician, and holds her own caseload of children. She works as part of a team which is made up of 3 full time OTs, including herself and 3 part time OTs, and they work with children with a wide range of needs and disabilities. Their aim is to get children to do the things they need to do.

She explained that there is currently a waiting list for OT services. This is longest for children with sensory needs, but the other waiting lists are currently at about 11 weeks.

Some parents have experienced difficulties in obtaining equipment. Chris explained that there is a wide range of equipment available and this can include items such as seating systems and sleep

systems. For children in mainstream schools who require equipment for use in school Education has its own budget to cover such items.

Where an OT goes into a school to make assessments they try to ensure that only one OT is involved with each school.

Chris was asked how the core offer to special schools will affect things. She explained that there will be no additional resources given to the OT service to meet this.

Some groups of children will need an OT service and therefore see it as an intervention whereas for others it is about assessing a problem and providing the necessary equipment. Their job is to enable children to do the things they need to do, whether that is walking, playing or managing in everyday life.

One parent asked how the OT service gets to hear about children and how do parents know what is available as there were concerns that perhaps some health visitors do not know enough about what is available and are therefore not referring children to the service for assessment. Chris felt that where Health Visitors had concerns about a child they could be signposted to the Joint Agency Service to see whether an Early Integrated Assessment should be undertaken.

There followed a discussion around the need for clear pathways to be identified for certain groups of children, such as those with Downs Syndrome, who would have need of the OT service so that all professionals involved with the family would be clear as to what was available and who to contact.

Chris was asked about what they can offer in relation to children with hearing impairments. Where the need is purely for hearing loss there is a specialist service for hearing impaired.

She was then asked about children with Autistic Spectrum Disorders. She explained that they can offer a 5 week assessment during which they can identify a sensory profile for the child. They do have a screening tool which can help to determine whether the OT service is the most appropriate service for the child prior to undertaking the assessment. In view of the current waiting list for assessments Chris suggested that parents may like to request the screening tool to ensure that they are not waiting for something that is not appropriate, and they can request this by telephoning 01392 383764.

Chris also suggested a useful website and some books that she felt parents may find useful to look at:

- Too Loud, Too Fast, Too Bright, Too Tight – Sharon Heller
- Sensational Kids – Lucy Miller
- The Goodenoughs Get in Sync – Carol Stock-Kranowitz
- www.sensory-processing-disorder.com

She reiterated that parents can self- refer their children and will be offered the screening tool as a first stage to identify whether the service was the most appropriate. She is happy to speak to parents who have concerns and can be reached on 01392 383760.

There followed a discussion on whether changes to schools over the last 20-30 years from a regimented, structured environment to a more flowing, less regimented environment has made an

impact upon the numbers of children being diagnosed with an ASD that might previously not have been recognised.

Cultural changes where children now have less physical activity than in previous years means that the calming effect on the arousal system does not happen the way in which it may have done previously.

4. Children's Services – updates and parents' questions

Joint Agency Services

The plans to ensure that all families have a designated contact are moving forward and it is currently on target to be running throughout the Eastern region by the autumn and countywide for next year. It has not yet been decided what these contacts will be called so they may not be called designated key workers.

There followed some discussion over where the boundaries for particular JAS areas lay. Previously the boundary had been where the GP accessed health services if a child met the JAS threshold, but there appears to be some discrepancies with parents being uncertain if they are in the correct area. Where there is an issue Hils will look at individual cases to determine which JAS a family should be in contact with.

There has been an issue with the length of the waiting list for Learning Disability Nurses. From 1st April they should be providing a clinic based service in an attempt to reduce the numbers of families waiting. Further assessment needs can be decided at that clinic appointment.

Hils offered to bring Carol Elstubb and Bev Price to a future meeting to talk about what was happening.

5. Other updates/information

Parent Partnership Service

Debbie Wheeler reported that the training for the Independent Parental Supporters (IPS) has started and is going well.

The education day that was held in South Devon recently went well and a future day will be held next week in East Devon.

They continue to hold meetings with SENCOs and TAs, and these are also going well.

County Forum

Margaret reported that the draft for the new direct payments guidance had come back to the County Forum and was much better than the previous version.

6. Local issues and individual questions from parents

Transition

Margaret raised a concern that the process of transition is not working. The 'e-brokering' system that is being used by Adult Services is not in line with the person centred planning that is advocated in Children's Services.

It was agreed that Nicky would raise the matter with the Learning Disability Development Worker in the first instance.

7. Any other business

CEDA

There are currently spaces available for children at their Saturday Club.

Next meeting

We are looking at holding our next meeting in an evening to allow those parents who are unable to attend during the day the opportunity to come along. Details will be sent out as soon as they have been finalised.

Margaret thanked everyone for attending.

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