



Exeter Parent Carers' Voice
Notes from the meeting held on Tuesday 20th January 2009 – Cowick Barton, Exeter

Present:

4 Parents

Nicky Ruane	Development Worker
Debbie Wheeler	Parent Partnership
Hil Rundle	Complex Cases Manager, Exeter JAS
Steve West	CAMHS Manager, Eastern Region

Apologies:

5 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

This issue had been discussed at the previous meeting after a visit to the hospital where a Doctor had asked the child a question and when the parent tried to answer on behalf of the child she was told quite abruptly that he was talking to the child. As the child had a learning disability and was unable to respond that parent felt that the way she had been spoken to was inappropriate.

The parent has since made herself a small card which she can carry and when she takes her child to the hospital can show them the card at the beginning of the consultation without having to explain the situation in front of her child.

Although this worked it was felt that a parent should not have to go to these lengths and that what was needed was a greater awareness among staff at the hospital and that perhaps there needed to be something on the child's medical notes that alerts staff that the child either has a learning disability or a communication problem and that the parent may need to answer on their behalf. It was felt that the problem was not necessarily confined to when a child attended an outpatients appointment but that there was also a problem when a child was admitted to the hospital. It was felt that staff expected parents to remain with their child on Bramble Ward. Parents felt that if they did not remain with their child the staff would be unable to meet the needs of their children as many of the require 11 support.

Steve said that CAMHS has a paediatric mental health nurse based n Bramble Ward and questioned why there was no specialist nurse to liaise with families who visited the hospital with a child with a learning or other disability.

Hils agreed to discuss the situation with Carol Elstub. Ultimately it may be a commissioning matter which would need to go to John Shaw.

The issue of medication was also discussed as for children who take regular medication this can cause problems on admission if parents take the medication in.

Keyworkers

Where families are currently supported by the Care Co-ordination team, as opposed to having a named key worker, the plan is to provide each family with a named contact within that team who will support them. Parents who currently keywork their own child will be unaffected by the change and will still have their parent key worker contact for any queries or problems.

Exeter is to pilot this scheme this year, so hopefully the changes will be in place by this time next year across the County.

Parent partnership Service

The response to the Independent Parental Supporter (IPS) sessions was overwhelming.

Inclusive Playpark

The Playpark is now up and running although the official opening of it has not yet taken place

Training

No suitable training has been found for parents who experience violent and aggressive behaviour from their children.

There is a definite need for some advice to parents, however the subject poses many difficulties as there is a real potential for injury. Advice on conflict management may also be beneficial. Steve agreed to give it some thought and come back to the forum with any ideas.

3. Updates

Hil Rundle, Exeter Joint Agency Service

Families should have a named worker to contact by this time next year.

The Integrated Assessment Team (IAT) is now located at Capital Court, Sowton. The Complex Cases Team is remaining at George Street for the time being. If families need to speak to someone in person there is a duty officer based at George Street.

New referrals will be dealt with by the IAT at Sowton.

Steve West, Child and Adolescent Mental Health Service (CAMHS), Eastern Region

Steve spoke about the Choice and Partnership Approach (CAPA), which takes about 80% of children and young people through the system as fast as possible. He explained how the process works.

Referred to CAMHS



Family, young person and school sent a strengths and difficulties questionnaire (SDQ) to complete to establish the perception of the problem from different perspectives



After the SDQ has been returned the family will be phoned and offered an initial appointment. At the appointment the family will discuss with a clinician what possible treatment is available.



In most instances what is offered will last about 6 weeks. This works for about 80% of those going through the system. The other 20% will require more specialised services.

Steve stressed some of the advantages of the new system.

- There are now wider referral routes into CAMHS and both families and Young People may refer direct.
- The Choice appointment is a general appointment; ‘Why are you here?’ ‘What can we do?’
- Both the Young Person and Parent are making an informed choice about the treatment they want. It is all about partnership.

The system is working well at the moment but is starting to slow down at the specialist end as they currently do not have enough specialists.

Conversation Events.

The conversation events were discussed. The Exeter event for 2nd February is being held at County Hall.

Debbie Wheeler, Parent Partnership Service

Debbie fed back on the interest for the IPS training. About 60 parents are interested in attending the courses. It had been widely advertised so there is a good mix of people and the plan is to start the training in March.

A fourth Parent Partnership worker has been appointed and will cover the North Devon area.

County Forum

Margaret fed back on the news from the recent County Forum

Jeanette Kemlo has been re-appointed County Chair and Cathie Wreford-Holden (Teignbridge) was elected as Vice Chair.

Ian Simmons (East Devon) will sit with Jeanette on the Children’s Trust Board.

Margaret will attend the Parenting Strategy Board as Parent Carers’ Voice representative.

There was a concern that children with special needs are not always well represented on local forums that look at the needs of children in general. It is important that all professionals understand what the issues are for children with special needs. In some instances the attitudes of some professionals need to be challenged.

The County Forum had been asked to look at a draft policy on direct payments. The policy aims to clarify how families can spend the money to ensure it is being used to meet the needs of the family

and the child. Representatives from the County Forum will work with Devon County Council to draw up a policy.

Following on from this there was a discussion in general about the current budget constraints. This led on to a question about the delays in OT assessment and then the further delay in receiving the equipment that the family had been assessed for. Hils offered to ask Chris West to attend a future meeting to discuss the situation.

The County Forum is also looking for evidence for Ofsted about children being asked to stay away from schools during Ofsted inspections. Any parent who is being asked to keep their child at home should contact Nicky or Margaret with the details.

4. Local Issues

It was asked up to what age paediatricians continue to see children. It was thought to be dependant on the condition as different teams have different ages for leaving or transferring to an adult team.

The question was then asked as to what happens to young people where the paediatrician prescribes medication and that young person would perhaps not fit easily into an adult team; the example being given of a young person with an Autistic Spectrum Disorder who is prescribed an anti-psychotic drug.

This raised other questions such as the transfer of young people from the CAMHS service into adult mental health services and the pathway for high functioning ASD young people into adult services. It was agreed to raise some of these questions initially at the CAMHS day planned for 3rd March.

5. Information and Any Other Business

CAMHS Unwrapped – 3rd March, Tiverton.

A day explaining what CAMHS is about and what it can offer. For more information or to book a place contact Nicky.

How can libraries be more accessible to children with special needs? If you have any ideas, such as longer book loans, more DVDs with subtitles, etc, please let Nicky know so we can forward your ideas on.

There being no other business Margaret thanked everyone for attending.

Date of next meeting: **Tuesday 17th March**
Venue **The Cowick Barton, Exeter**

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